

S. HRG. 109-284

# *Senate Hearings*

*Before the Committee on Appropriations*

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Departments of Labor,  
Health and Human Services,  
Education, and Related  
Agencies Appropriations

*Fiscal Year* 2006

109<sup>th</sup> CONGRESS, FIRST SESSION

H.R. 3010

CORPORATION FOR PUBLIC BROADCASTING  
DEPARTMENT OF EDUCATION  
DEPARTMENT OF HEALTH AND HUMAN SERVICES  
DEPARTMENT OF LABOR  
NONDEPARTMENTAL WITNESSES

**Labor-HHS-Education Appropriations, 2006 (H.R. 3010)**

**DEPARTMENTS OF LABOR, HEALTH AND HUMAN  
SERVICES, EDUCATION, AND RELATED AGEN-  
CIES APPROPRIATIONS FOR FISCAL YEAR 2006**

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**HEARINGS**

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED NINTH CONGRESS

FIRST SESSION

ON

**H.R. 3010**

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, 2006, AND  
FOR OTHER PURPOSES

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**Corporation for Public Broadcasting  
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, EDUCATION, AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

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**WEDNESDAY, MARCH 2, 2005**

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

The subcommittee met at 9:30 a.m. in room SD-126, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.  
Present: Senators Specter, Cochran, Harkin, and Kohl.

DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY

**STATEMENT OF HON. MARGARET SPELLINGS, SECRETARY**

**ACCOMPANIED BY:**

**C. TODD JONES, ASSOCIATE DEPUTY SECRETARY FOR BUDGET  
AND STRATEGIC ACCOUNTABILITY  
THOMAS SKELLY, DIRECTOR, BUDGET SERVICE**

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen, the Appropriations Subcommittee on Labor, Health, Human Services, and Education will now proceed. We are joined by the distinguished Secretary of Education, Margaret Spellings, who has had an outstanding academic and professional career, served for 6 years with then-Governor George Bush of Texas, came to the White House 4 years ago and has recently been appointed and confirmed as Secretary of Education.

As I had talked to the Secretary earlier, our Senate schedule is very, very crowded. We have on the floor at the moment the Bankruptcy bill, for which I have duties as chairman of the Judiciary Committee, and the majority leader has scheduled a meeting at 10 o'clock on pending asbestos legislation, which is a matter of real importance to the administration and to the Congress, so I'm going to have to excuse myself a few minutes before 10 to attend that meeting, but my distinguished ranking member, Senator Harkin, has agreed to take my place. He does that with great distinction. He and I have exchanged the gavel seamlessly for longer than either of us is prepared to admit. But we have a true partnership, and when he's here I know it will be in very good hands.

I've already talked to Senator Harkin about waiving our opening statements so we can go right to your testimony, Madame Secretary, and use the time to the maximum advantage to hear from you.

#### SUMMARY STATEMENT OF HON. MARGARET SPELLINGS

Secretary SPELLINGS. Thank you very much, Mr. Chairman. Thank you; good morning, Mr. Chairman, Senator Harkin, I'm thrilled to be here. This is my first appearance before your committee and I know you'll be as kind and gentle on me as you are with other administration officials.

I certainly appreciate the hard work that we have to do together, a lot of tough choices this year, and I pledge to work with you productively to get to a good result.

First, I'd like to introduce my budget team: Tom Skelly, the Budget Service Director, and Todd Jones, Associate Deputy Secretary for Budget and Strategic Accountability. And let me take this opportunity to say a special thanks to Chairman Specter. I, and my entire Department, wish you a full and speedy recovery.

Senator SPECTER. Thank you.

#### REDUCING THE DEFICIT AND IMPROVING RESULTS

Secretary SPELLINGS. I am here to testify on behalf of President Bush's 2006 discretionary budget request for the Department of Education. The President's budget accomplishes several goals; the first is fiscal discipline. In his February 2 State of the Union Address, the President underscored the need to restrain spending in order to sustain our economic growth and prosperity. It is important that total discretionary and non-security spending be held to levels proposed in the 2006 budget. Its savings and reforms will help us achieve the President's goal of cutting the budget deficit in half by 2009, and we urge Congress to support them.

The fiscal year 2006 budget includes more than 150 reductions, reforms, and terminations in non-defense discretionary programs, and of those, a third are under the Department of Education. We are committed to working with Congress to achieve these savings. Given the fiscal realities, we must target our resources towards flexibility and results, and let me tell you a little about those results.

#### HIGH SCHOOL REFORM

First, the budget would expand the promise of the No Child Left Behind Act to our Nation's high schools. No Child Left Behind rests on the common sense principles of accountability for results, data-based decisionmaking, high expectations for all, and empowering change. These principles have proven good for our elementary and middle schools, and they are needed today in our high schools.

Let me share a few facts that I know you probably have heard before: our 15-year-olds perform below average internationally in mathematics, literacy, and problem solving. Just 68 out of every 100 entering ninth-graders will receive their high school diploma on time. Just 27 will enter college and still be enrolled by their sophomore year, when nearly 80 percent of the fastest-growing jobs



require at least that level of preparation. Two-thirds of those who do graduate from high school are not adequately prepared for college, and more than half of all college students take remedial education courses when they go to post-secondary education.

Last weekend, the bipartisan National Governors Association reported that high schools are failing to prepare too many of our students for work and higher education, and Bill Gates told them, “Training the workforce of tomorrow with today’s high schools is like trying to teach kids about today’s computers on a 50-year-old mainframe.” Even the New York Times, just yesterday, and the Washington Post editorial pages have weighed in. The Times said, “American students are falling farther and farther behind their peers in Asia and Europe.” It called for a far more rigorous curriculum across the board, and the Post called on States to “stop blocking testing and standards and find ways to raise them.” Call it what you will—a challenge, a problem, a crisis—it’s imperative that we give our high schools the tools to succeed in the economy in which 80 percent of these jobs require more rigorous levels of education.

#### HIGH SCHOOL INTERVENTION INITIATIVE

The President’s \$1.24 billion High School Intervention Initiative would help give students the academic skills needed to succeed in the 21st century. These reforms would be designed and directed, not by the Federal Government, but by States and school districts themselves. The budget would provide \$250 million to measure student achievement annually, and hold schools accountable for student performance. As we have learned from No Child Left Behind, what gets measured, gets done.

#### READING FIRST STATE GRANTS

We’ve made a serious effort in improving basic literacy in the early grades. We spent more than \$2.7 billion in Reading First grants to States and school districts, training more than 90,000 teachers, and teaching 1.5 million students. Today, reading and math scores are up in all States across the Nation, and urban school districts are leading the way.

#### RAISING READING AND MATH AND TEACHER INCENTIVES

Some high school students struggle with reading and math, too. They would benefit from our Striving Readers program, \$200 million, a \$175 million increase over 2005, and a new secondary education mathematics initiative of \$120 million. A \$500 million Teacher Incentive Fund would reward our best educators, and attract more of them to serve in our most challenging schools.

#### PROVIDING FOR MORE CHALLENGING CURRICULA

As you’ve heard, there is a near-unanimous call for more rigorous high school curricula. The President’s budget would invest \$45 million, an increase of \$42.5 million, to encourage students to take more challenging course work. This includes a boost for the public-private State Scholars program, which strives for a college-ready

curriculum in every high school, and new, enhanced Pell Grants for students completing such rigorous programs.

The budget also provides a 73 percent increase to expand the availability of advanced placement in international baccalaureate programs in high-poverty schools.

#### CONTINUING PRIORITIES

Second, the President's budget continues the solid progress begun under No Child Left Behind. Congress overwhelmingly passed this bipartisan law just 3 years ago, and today, across the country, test scores are rising, schools are improving, and the achievement gap is beginning to close. The budget would increase Title I Grants to Local Educational Agencies, the engine of No Child Left Behind, by \$603 million. This represents a 52 percent increase since the law was signed. The budget also provides a \$508 million increase for the Special Education Grants to States program, 75 percent higher than 5 years ago.

#### COLLEGE AFFORDABILITY

Finally, the President's budget makes college affordability a high priority. It would provide \$19 billion over 10 years in mandatory funds for Pell Grants, resulting from student loan program reforms. This will retire the Pell Grant funding shortfall and help more than 5 million recipients attend college next year alone. The maximum individual Pell Grant would be increased by \$100 for each of the next 5 years, to \$4,550, and grants would be available year-round, so students can learn on their own time-table.

#### PRESIDENTIAL MATH AND SCIENCE SCHOLARS

To encourage more students, especially poor and minority students, to enter the critical fields of math and science, our budget also includes a new Presidential Math/Science Scholars Program, which would award up to \$5,000 each to low-income college students pursuing degrees in those demanding and in-demand fields.

#### COMMUNITY COLLEGE ACCESS GRANTS

Finally, the budget establishes a new \$125 million Community College Access Grants fund to support dual enrollment credit transfers for high school students taking college-level course work. With this budget's passage, student financial assistance will have risen from \$48 billion to \$78 billion during this administration.

In conclusion, let me say that I appreciate and respect the priorities you make and the promises you keep as the people's representatives. What I have just outlined are the President's education priorities; the common thread in all of them is aligning needs with results.

#### PREPARED STATEMENT

We will not agree on everything, it will not always be easy to find common ground in a Nation on wartime footing, and a tight fiscal climate, but I am here to listen to your priorities. The President has made tough choices, we know you will, too. And we want

to work with you to make the very best choices for America's students.

Thank you very much.  
[The statement follows:]

PREPARED STATEMENT OF HON. MARGARET SPELLINGS

Mr. Chairman and Members of the Subcommittee: Thank you for this opportunity to testify on behalf of President Bush's 2006 discretionary request for the Department of Education. I believe we have a strong, focused budget proposal this year, one that reflects the need for both fiscal discipline and continuing support for State and local efforts to carry out No Child Left Behind. Moreover, our budget would significantly strengthen the impact of No Child Left Behind at the high school level, helping to ensure that every student not only graduates from high school, but graduates with the skills to succeed in either the workforce or in postsecondary education.

President Bush is requesting \$56.0 billion in discretionary appropriations for the Department of Education in fiscal year 2006, a decrease of \$529.6 million, or less than 1 percent, from the 2005 level. This request is consistent with the President's overall 2006 budget, and reflects his determination to cut the Federal budget deficit in half over the next 5 years. Even with the proposed reduction, discretionary appropriations for education would be up nearly \$14 billion, or 33 percent, since fiscal year 2001.

REDUCING THE DEFICIT AND IMPROVING RESULTS

In his February 2 State of the Union Address, the President underscored the need to restrain spending in order to sustain our economic prosperity. As part of this restraint, it is important that total discretionary and non-discretionary spending be held to levels proposed in his fiscal year 2006 budget request. The savings and reforms proposed in this request are critical to achieving the President's goal of cutting the budget deficit in half by 2009, and we urge the Congress to support this goal.

Overall, the President's 2006 discretionary request proposes more than 150 reductions, reforms, and terminations in non-defense programs. The Department of Education's budget proposal includes several major reductions and 48 terminations, 33 of which are small, narrow-purpose programs funded at less than \$40 million in 2005. On behalf of the Department, I want the Members of this Subcommittee to know that we are determined to work with the Congress to achieve these savings.

Let me add that our proposed reductions and terminations reflect the long-standing practice of this administration to streamline government, end unnecessary duplication, and redirect scarce taxpayer dollars only to those programs that work. Many of our proposed eliminations were requested by previous administrations as well, on the grounds that they were a low priority and lacked results. In other words, the reductions proposed in our 2006 request reflect not only the obvious need for fiscal discipline, but also our determination to spend taxpayer dollars as effectively as possible. As President Bush has said, "A taxpayer dollar ought to be spent wisely, or not spent at all."

HIGH SCHOOL REFORM

As most of you know, our request for elementary and secondary education focuses on strengthening the impact of No Child Left Behind in our high schools through the \$1.5 billion High School Initiative. Our key proposal in this area is \$1.24 billion for High School Intervention, which would support a wide range of locally determined reforms aimed at ensuring that every student not only graduates from high school, but graduates with the skills to succeed in either college or the workforce. We also are asking for \$250 million for High School Assessments to increase accountability for high school achievement and give principals and teachers new tools and data to guide instruction and meet the specific needs of each student.

Together, these two components of the President's High School Initiative would give States and school district administrators more effective tools for improving high schools than they have under the existing array of uncoordinated, narrow-purpose programs that this initiative would replace.

The need to direct more attention to our high schools is beyond question. Currently just 68 out of every 100 ninth-graders will graduate from high school on time. Moreover, a recent study by the Manhattan Institute showed that two-thirds of students leave high school without the skills to succeed in college. As a result, only

27 of those original 100 ninth-graders make it to their sophomore year of college, and just 18 graduate from college. These figures are even more troubling when you consider that 80 percent of the fastest-growing jobs require at least some postsecondary education.

In addition to High School Intervention and Assessments, we are seeking a \$175 million expansion of the new Striving Readers program, which supports the development and implementation of research-based methods for improving the skills of teenage students who are reading below grade level. Similarly, a new, \$120 million Secondary Education Mathematics Initiative would help raise mathematics achievement, especially for at-risk students, in our high schools. We also want to help strengthen high school curricula by providing a \$22 million increase for the Advanced Placement program, as well as a total increase of \$45 million for the State Scholars programs to encourage more students to complete a rigorous high school curriculum.

And as you consider our High School Initiative, I hope you will keep in mind the startling costs of the alternative: American companies and universities currently spend as much as \$16 billion annually on remedial education to teach employees and students the basic skills they should have mastered in high school.

#### CONTINUING PRIORITIES

The 2006 budget continues to place a strong priority on our three largest programs, which together form the foundation of the Department's efforts to help ensure that students at all levels have the opportunity to obtain a high-quality education. We are asking for a \$603 million increase for the Title I Grants to Local Educational Agencies program, which is the engine driving the President's No Child Left Behind reforms. If enacted, this request would result in a \$4.6 billion or 52 percent increase for Title I since the passage of the NCLB Act.

The budget also provides a \$508 million increase for the reauthorized Special Education Grants to States program, for a total increase of \$4.8 billion, or 75 percent, over the past 5 years.

The third major continuing priority for 2006 is the Pell Grant program. Our budget includes a comprehensive package of proposals to restore Pell Grants to sound financial footing and significantly increase the purchasing power of the Pell Grant. These proposals would provide a combination of discretionary and mandatory funding that would retire the \$4.3 billion Pell Grant shortfall, while raising the Pell Grant maximum award from \$4,050 to \$4,550 over the next 5 years. In 2006 alone, the request would provide a \$1.3 billion increase for Pell Grants, for a total of \$13.7 billion, to raise the maximum award to \$4,150 and provide grants to an estimated 5.5 million low-income postsecondary students.

#### NO CHILD LEFT BEHIND

Title I remains our key priority for successfully implementing No Child Left Behind, but our 2006 request includes a major new proposal to help meet the law's requirement that every classroom be led by a highly qualified teacher. The new Teacher Incentive Fund would provide \$500 million to help stimulate closer alignment of teacher compensation systems with better teaching, higher student achievement, and stronger teaching in high-poverty schools.

Data on teacher qualifications show that high-poverty schools continue to have greater difficulty than low-poverty schools in attracting and retaining highly qualified teachers. For example, a recent study of California schools by The Education Trust-West showed that high-poverty schools tend to have teachers with fewer years of experience who, by definition under current, seniority-based compensation systems, are paid lower salaries than more veteran teachers.

The Teacher Incentive Fund would give States \$450 million in formula grants to reward and retain effective teachers and offer incentives for highly qualified teachers to teach in high-poverty schools. A separate, \$50 million competitive grant program would encourage the development and implementation of performance-based compensation systems to serve as models for districts seeking to more closely link teacher compensation to student achievement.

In addition to Title I and the Teacher Incentive Fund, our 2006 request maintains strong support for No Child Left Behind programs, including almost \$3 billion for Improving Teacher Quality State Grants, \$1.1 billion for Reading First and Early Reading First, and \$412 million for State Assessment Grants.

#### EXPANDING OPTIONS FOR STUDENT AND PARENTS

Finally, our request includes funding to continue the expansion of educational options for students and families. No Child Left Behind is helping to ensure that stu-

dents in low-performing schools have the opportunity to transfer to a better school, or to obtain tutoring or other supplemental educational services from the provider of their choice. And Federal dollars are now financing opportunity scholarships that permit low-income students here in the District of Columbia to attend better-performing private schools.

The 2006 budget would build on these new options by providing \$50 million for a new Choice Incentive Fund that would support State and local efforts to give parents the opportunity to transfer their children to a higher-performing public, private, or charter school. The request also maintains significant support for the charter school movement, with \$219 million for Charter Schools grants and \$37 million for the Credit Enhancement for Charter School Facilities program.

#### CONCLUSION

I believe these highlights of our 2006 request show that we have a strong budget for education, one that makes hard but necessary decisions to put significant resources where they can do the most to help improve the quality of our education system at all levels. I want to conclude with just a few comments on recent charges that our Administration is underfunding education, or that our 2006 proposal is an "anti-education" budget.

First, the numbers just don't add up for our critics. As I noted earlier, under our request, President Bush would increase discretionary spending for the Department by \$14 billion, or 33 percent, since taking office in 2001. Key programs have done even better: Title I would be up \$4.6 billion, or 52 percent; Special Education Grants to States would rise \$4.8 billion, 75 percent; and Pell Grants would be up \$4.5 billion, or 51 percent. And by the way, all of these increases have come at a time of historically low inflation.

Second, with total national spending on elementary and secondary education more than doubling over the past decade, from roughly \$260 billion to well over \$500 billion, it's very hard to make the case that money is where we are falling short in education, especially when all that new money has produced so little in the way of improved student achievement.

Third, like nearly all Federal education spending, No Child Left Behind is intended to leverage "not replace" the much larger share of education funding coming from State and local sources. Even the tremendous increases of the past 4 years have succeeded in lifting the Federal share of elementary and secondary spending by just 1 percentage point, from roughly 7 percent to about 8 percent. Our goal should be to help States and school districts spend smarter on education, not just more, and No Child Left Behind is accomplishing this goal.

Fourth, fully 3 years after the passage of No Child Left Behind, and during its third school year of implementation, I have yet to see a methodologically sound study providing any documentation of the charge that the law is underfunded. Does the law entail additional costs? The answer is yes, and our budgets have reflected those costs, but I have yet to see any evidence that we have significantly increased financial burdens on States or school districts, much less passed on any "unfunded mandate."

Finally, context matters, and the size of the Federal budget deficit matters. To keep our economy strong, and to create new jobs for future graduates, we need to reduce the deficit and encourage more private sector investment in our economy. The Department of Education is doing its part to help achieve this critical goal.

Thank you, and I will be happy to take any questions you may have.

#### INTRODUCTION OF COMMITTEE CHAIRMAN

Senator SPECTER. Thank you very much, Madame Secretary. We've been joined by the distinguished chairman of the full Committee, Senator Cochran. Would you care to make an opening statement?

#### OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Mr. Chairman, I'm happy to join you this morning to welcome the Secretary to our hearings. I'm encouraged by the progress that the administration has made in targeting funds to areas of special need where school districts don't have the resources to do the job they would like to do in helping educate our

elementary and secondary students. I think the traditional programs that have helped in this regard, such as Title I, need to be supported and we hope we can build on the things we've learned in the past about some teacher training programs that have improved morale, like the National Writing Project. I hope that we can get the administration's support for continuing programs of that kind. But, overall I think you have a big task, no more important job in Government than helping to see that we do the right thing for education programs throughout the country. It's the bulwark of our freedom and our economic prospects for the future. Everyone has a right to enjoy a good, quality education, and I think that's the goal of this administration. Strong leadership has been provided in that regard, and I congratulate you for the work you've done in the past, and also the President, for his leadership.

Secretary SPELLINGS. Thank you, Senator.

Senator COCHRAN. Thank you for being here and cooperating with our committee.

Secretary SPELLINGS. Thank you.

#### PROPOSED REDUCTIONS TO FEDERAL EDUCATION BUDGET

Senator SPECTER. Thank you very much, Mr. Chairman. Thank you for an abbreviated statement, Madame Secretary, which gives me time to initiate a round of questioning for which we customarily have 5 minutes; although with only a few of our members present, that will be elongated into a number of rounds.

As I mentioned to you in our conversation earlier, I'm very much concerned about the fact that the budget has a reduction of .9—almost 1 percent—and that is in the face of the inevitable problem of inflation. And we are telling the American people about this budget in the context of tremendous expenses which are going in other directions—very necessary expenses beyond any doubt—in what's happening around the world as we defend freedom with the President's initiative, and he deserves a lot of credit for what is happening around the world, with his leadership. With elections in surprising places, and more elections forthcoming. But, when we return to our constituents, we have some very tough questions to answer about education.

#### FEDERAL SHARE OF EDUCATION FUNDING

Education is a capital asset, and a capital investment. There's no more important expenditure that the government makes, and we all know the Federal share of that is relatively limited, somewhere in the 7 to 8 percent range. And, appropriately—as you have already noted—the initiatives are to come from local school boards, where they are close to the problem in the States, that is our system of federalism, and it is a good system.

#### PROPOSED PROGRAM ELIMINATIONS

I would begin on my request to you, Madame Secretary, as we work through the process—and you've only been in office since January 20—but, this subcommittee is going to need to have the specifics on why you have eliminated 48 programs. Those programs have come into existence as a result of study by the Congress,

which has the fundamental appropriations authority under the Constitution. The President has to sign the bills, but the Congress has the authority under appropriations, and these programs have been suggested by a variety of people—one of them is mentoring seventh grade students which has come out of Philadelphia, and has very, very strong support. And every one of these programs has a sponsor. And when we sit down on our legislative agenda, people are very concerned. So, a beginning point is to give us—with specificity—why those programs have been eliminated.

[The information follows:]

#### PROGRAMS PROPOSED FOR ELIMINATION

The 2006 request continues the practice of the Bush Administration—also consistent with previous administrations over the past 25 years—of proposing to eliminate or consolidate funding for programs that have achieved their original purpose, that duplicate other programs, that may be carried out with flexible State formula grant funds, or that involve activities that are better or more appropriately supported through State, local, or private resources. In addition, the government-wide Program Assessment Rating Tool, or PART, helps focus funding on Department of Education programs that generate positive results for students and that meet strong accountability standards. For 2006, PART findings were used to redirect funds from ineffective programs to more effective activities, as well as to identify reforms to help address program weaknesses.

The following table shows the programs proposed for elimination in the President's 2006 budget request. Termination of these 48 programs frees up almost \$4.3 billion—based on 2005 levels—for reallocation to more effective, higher-priority activities. Following the table is a brief summary of each program and the rationale for its elimination.

[In millions of dollars]

Program terminations	Amount
Alcohol Abuse Reduction .....	32.7
Arts in Education .....	35.6
B.J. Stupak Olympic Scholarships .....	1.0
Byrd Honors Scholarships .....	40.7
Civic Education .....	29.4
Close Up Fellowships .....	1.5
Community Technology Centers .....	5.0
Comprehensive School Reform .....	205.3
Demonstration Projects for Students with Disabilities .....	6.9
Educational Technology State Grants .....	496.0
Elementary and Secondary School Counseling .....	34.7
Even Start .....	225.1
Excellence in Economic Education .....	1.5
Exchanges with Historic Whaling and Trading Partners .....	8.6
Federal Perkins Loans Cancellations .....	66.1
Foreign Language Assistance .....	17.9
Foundations for Learning .....	1.0
Gaining Early Awareness and Readiness for Undergraduate Programs .....	306.5
Interest Subsidy Grants .....	1.5
Javits Gifted and Talented Education .....	11.0
Leveraging Educational Assistance Partnerships .....	65.6
Literacy Programs for Prisoners .....	5.0
Mental Health Integration in Schools .....	5.0
Migrant and Seasonal Farmworkers .....	2.3
National Writing Project .....	20.3
Occupational and Employment Information .....	9.3
Parental Information and Resource Centers .....	41.9
Projects With Industry .....	21.6
Ready to Teach .....	14.3
Recreational Programs .....	2.5
Regional Educational Laboratories .....	66.1
Safe and Drug-Free Schools and Communities State Grants .....	437.4
School Dropout Prevention .....	4.9

[In millions of dollars]

Program terminations	Amount
School Leadership .....	14.9
Smaller Learning Communities .....	94.5
Star Schools .....	20.8
State Grants for Incarcerated Youth Offenders .....	21.8
Supported Employment State Grants .....	37.4
Teacher Quality Enhancement .....	68.3
Tech-Prep Demonstration .....	4.9
Tech-Prep Education State Grants .....	105.8
Thurgood Marshall Legal Educational Opportunity Program .....	3.0
TRIO Talent Search .....	144.9
TRIO Upward Bound .....	312.6
Underground Railroad Program .....	2.2
Vocational Education National Programs .....	11.8
Vocational Education State Grants .....	1,194.3
Women's Educational Equity .....	3.0
Total .....	4,264.4

PROGRAM TERMINATIONS (DESCRIPTIONS)

Alcohol Abuse Reduction .....	<i>Millions</i> \$32.7
<p>Supports programs to reduce alcohol abuse in secondary schools. These programs may be funded through other Safe and Drug-Free Schools and Communities National Programs and State Grants for Innovative Programs.</p>	
Arts in Education .....	35.6
<p>Makes non-competitive awards to VSA arts and the John F. Kennedy Center for the Performing Arts as well as competitive awards for national demonstrations and Federal leadership activities to encourage the integration of the arts into the school curriculum. Eliminating funding for the program is consistent with Administration policy of terminating small categorical programs with limited impact in order to fund higher priorities. Arts education programs may be funded under other authorities.</p>	
B.J. Stupak Olympic Scholarships .....	1.0
<p>Provides financial assistance to athletes who are training at the United States Olympic Education Center or one of the United States Olympic Training centers and who are pursuing a postsecondary education. Athletes can receive grant, work-study, and loan assistance through the Department's postsecondary student aid programs. Rated Results Not Demonstrated by the PART due to lack of performance data and program design deficiencies, including its duplication of other Federal student aid programs.</p>	
Byrd Honors Scholarships .....	40.7
<p>Promotes academic excellence and achievement by awarding merit-based scholarships to high school students, through formula grants to State educational agencies, who have demonstrated outstanding academic achievement and who show promise of continued academic excellence. This program duplicates existing Federal student financial assistance programs, as well as State, local and private efforts that provide merit-based resources for postsecondary education. Rated Results Not Demonstrated by the PART due to lack of performance data and program design deficiencies.</p>	
Civic Education .....	29.4
<p>Provides a single non-competitive award to the Center for Civic Education to conduct We the People, a program to improve the quality of civics and government education. Also makes non-competitive and competitive awards for the Cooperative Education Exchange, a program to improve civic and economic education through exchange programs. Request is consistent with the Administration's policy of terminating small categorical programs that have limited impact, and for which there is little or no evidence of effectiveness, to fund higher priority programs.</p>	
Close Up Fellowships .....	1.5



Non-competitive award to Close Up Foundation supports fellowships to low-income students and teachers participating in Close Up visits to Washington, DC and other activities. Peer organizations provide scholarships to some of their participants without Federal assistance, and the organization’s successful private fundraising eliminates the need for the program.

Community Technology Centers ..... *Millions*  
\$5.0

Supports centers that offer disadvantaged residents of economically distressed areas access to computers and training. Program has limited impact and funding for similar activities is available through other Federal agencies.

Comprehensive School Reform ..... 205.3

This program largely duplicates activities that are readily carried out under the Title I Grants to LEAs program. In the 2000–01 school year, about 30,000 Title I schools (62 percent) were implementing research-based reform models and, beginning with 2002, the NCLB Act made statutory changes to further encourage schools to carry out the types of whole-school reforms supported by the Comprehensive School Reform program. For Comprehensive School Reform (continued): example, comprehensive reform is encouraged as part of school improvement efforts undertaken by Title I schools that do not make adequate yearly progress toward State standards for at least 2 consecutive years. Also, the Act lowered the poverty threshold for Title I schoolwide projects to 40 percent, thus expanding the number of Title I schools that are eligible to use Title I funds to carry out comprehensive school reform.

Demonstration Projects to Ensure Quality Higher Education for Students  
with Disabilities ..... 6.9

Funds technical assistance and professional development activities for faculty and administrators in institutions of higher education in order to improve the quality of education for students with disabilities. This program has achieved its primary goal of funding model demonstration projects. New projects can and do receive funding under FIPSE.

Educational Technology State Grants ..... 496.0

This program provides funding to States and school districts to support the integration of educational technology into classroom instruction, technology deployment, and a host of other activities designed to utilize technology to improve instruction and student learning. Schools today offer a greater level of technology infrastructure than just a few years ago, and there is no longer a significant need for a State formula grant program targeted specifically on (and limited to) the effective integration of technology into schools and classrooms. Districts seeking funds to integrate technology into teaching and learning can use other Federal program funds such as Improving Teacher Quality State Grants and Title I Grants to Local Educational Agencies.

Elementary and Secondary School Counseling ..... 34.7

Elementary school and secondary school counseling may be funded through other larger and more flexible Federal programs, such as ESEA Title V—A State Grants for Innovative Programs.

Even Start ..... 225.1

This program aims to improve educational opportunities for children and their parents in low-income areas by integrating early childhood education, adult education, and parenting education into “family literacy” programs. However, three separate national evaluations of the program reached the same conclusion: children and adults participating in Even Start generally made gains in literacy skills, but these gains were not significantly greater than those of non-participants. Also, the Administration rated the program as Ineffective in the 2004 PART process. Other high priority programs such as Reading First and Early Reading First are better structured to implement proven research and to achieve the President’s literacy goals.

Excellence in Economic Education ..... 1.5

Supports a grant to a single national non-profit educational organization to promote economic and financial literacy for K–12 students. Elimination is consistent with Administration policy of terminating small categorical programs with limited impact in order to fund higher priorities.

	<i>Millions</i>
Exchanges with Historic Whaling and Trading Partners .....	\$8.6
<p>Supports culturally based educational activities, internships, apprenticeship programs and exchanges for Alaska Natives, Native Hawaiians, and children and families of Massachusetts. Elimination is consistent with Administration policy of terminating small categorical programs with limited impact in order to fund higher priorities.</p>	
Federal Perkins Loans Cancellations .....	66.1
<p>Reimburses institutional revolving funds for borrowers whose loan repayments are canceled in exchange for undertaking public service employment, such as teaching in Head Start programs, full-time law enforcement, or nursing. These reimbursements are no longer needed as the Administration is proposing to eliminate the Perkins Loan program, which duplicates other student loan programs and serves a limited number of institutions.</p>	
Foreign Language Assistance .....	17.9
<p>Activities to promote improvement and expansion of foreign language instruction may be supported by larger, more flexible ESEA programs, such as Improving Teacher Quality State Grants and State Grants for Innovative Programs.</p>	
Foundations for Learning .....	1.0
<p>Competitive grants provide services to children and their families to enhance young children's development so that they become ready for school. The request is consistent with the Administration's effort to increase resources for high-priority programs by eliminating small, narrow categorical programs that duplicate other programs, have limited impact, or for which there is little or no evidence of effect. The budget request includes funding for other, larger programs that support early childhood education and development.</p>	
Gaining Early Awareness and Readiness for Undergraduate Programs .....	306.5
<p>Provides grants to States and partnerships to support early college preparation and awareness activities at the State and local levels to ensure low-income elementary and secondary school students are prepared for and pursue postsecondary education. GEAR UP received an Adequate PART rating because it employs a number of strategies that other studies have found to be effective, but no data are available to measure progress toward long-term program goals. The proposed new High School Intervention initiative would provide a more comprehensive approach to improving high school education and increasing student achievement, especially the achievement of those most at-risk of educational failure and dropping out.</p>	
Interest Subsidy Grants .....	1.5
<p>Program finances interest subsidy costs of a portfolio of higher education facilities loans guaranteed under Federal agreements with participating institutions of higher education. Balances from prior year appropriations are sufficient to cover all remaining obligations.</p>	
Javits Gifted and Talented Education .....	11.0
<p>Primarily supports research and demonstration grants, but these grants are not structured to assess program effectiveness and identify successful intervention strategies that could have broad national impact. Only research programs that can be held accountable to rigorous standards warrant further investment.</p>	
Leveraging Educational Assistance Partnerships .....	65.6
<p>Program has accomplished its objective of stimulating all States to establish need-based postsecondary student grant programs, and Federal incentives for such aid are no longer required. State grant levels have expanded greatly over the years, and most States significantly exceed the statutory matching requirements. State matching funds in academic year 1999-2000, for example, totaled nearly \$1 billion or more than \$950 million over the level generated by a dollar-for-dollar match.</p>	
Literacy Programs for Prisoners .....	5.0
<p>Provides competitive grants to State and local correctional agencies and correctional education agencies to support programs that reduce recidivism through the improvement of "life skills." Request is consistent with the Administration's effort to eliminate small programs that have only indirect or limited effect.</p>	

	<i>Millions</i>
Mental Health Integration in Schools .....	\$5.0
<p>Makes competitive grants to increase student access to mental health care by linking school systems with the mental health system. The request is consistent with the Administration’s effort to increase resources for high-priority programs by eliminating small, narrow categorical programs that duplicate other programs, have limited impact, or for which there is little or no evidence of effect.</p>	
Migrant and Seasonal Farmworkers .....	2.3
<p>Supports rehabilitation services to migratory workers with disabilities, but such activities may be funded through the VR State Grants program.</p>	
National Writing Project .....	20.3
<p>Supports a nationwide nonprofit educational organization that promotes K–16 teacher training programs in the effective teaching of writing. States may support such activities through flexible programs like Improving Teacher Quality State Grants. Rated Results Not Demonstrated by the PART review due to lack of reliable performance or evaluation data on the effectiveness of supported interventions.</p>	
Occupational and Employment Information .....	9.3
<p>This career guidance and counseling program has a narrow purpose and no demonstrated results. The PART review of this program rated it Results Not Demonstrated, largely due to a lack of data on program outcomes.</p>	
Parental Information and Resource Centers .....	41.9
<p>Parent education and family involvement activities are required and funded under other ESEA programs, such as Title I Grants to Local Educational Agencies, and are a specifically authorized use of funds under ESEA Title V-A State Grants for Innovative Programs. The PART review of this program rated it Results Not Demonstrated, partly because of its unclear statutory purposes.</p>	
Projects With Industry .....	21.6
<p>PWI projects help individuals with disabilities obtain employment in the competitive labor market. VR State Grants serves the same target populations and may provide the same services. Rated Adequate by the PART process but also determined to be duplicative of the much larger VR State Grants program. In addition, data reliability problems undermine accurate assessment of program performance.</p>	
Ready to Teach .....	14.3
<p>This program supports competitive grants to nonprofit telecommunications entities to carry out programs to improve teaching in core curriculum areas, and to develop, produce, and distribute innovative educational and instructional video programming. State Grants for Innovative Programs and Improving Teacher Quality State Grants provide ample resources for the types of activities supported by this program.</p>	
Recreational Programs .....	2.5
<p>Supports projects that provide recreation and related activities for individuals with disabilities to aid in their employment, mobility, independence, socialization, and community integration. The program has limited impact, and such activities are more appropriately financed by State and local agencies and the private sector.</p>	
Regional Educational Laboratories .....	66.1
<p>Recent reauthorization did not make needed improvement in structure and function of the Regional Educational Laboratories, which have not consistently provided high quality research and development products or evidence-based training and technical assistance.</p>	
Safe and Drug-Free Schools and Communities State Grants .....	437.4
<p>Provides formula grants to States to help create and maintain drug-free, safe, and orderly environments for learning in and around schools. The program has not demonstrated effectiveness and grant funds are spread too thinly to support quality interventions. The Administration proposes to redirect some of the program’s funds to provide an increase for Safe and Drug-Free Schools National Programs, which is better structured to support quality interventions, and to permit grantees and independent evaluators to measure Safe and Drug-Free Schools and Communities State Grants progress, hold projects accountable, and determine which interventions are</p>	

most effective. The Administration’s Performance Assessment Rating Tool (PART) rated this program as Ineffective in 2004.

School Dropout Prevention ..... *Millions*  
\$4.9

Significantly higher funding for dropout prevention and re-entry programs available through Title I Grants to LEAs, Title I Migrant State Grants, and State Grants for Innovative Programs makes this program unnecessary. Also, at the 2006 request level, States are required to reserve approximately \$110 million from their Title I allocation for purposes of helping students stay in school and make the transition to public schools from local corrections facilities and community day programs.

School Leadership ..... 14.9

Program supports recruiting, training, and retaining principals and assistant principals—activities that are specifically authorized under other, much larger programs such as Improving Teacher Quality State Grants and State Grants for Innovative Programs.

Smaller Learning Communities ..... 94.5

A separate program is not needed for the purpose of creating smaller learning communities. The number of fundable applications for grants under the 2004 competitions dropped significantly and the Department lapsed more than \$26.4 million from the fiscal year 2003 program appropriation. One likely reason for the low level of interest in the program is the lack of compelling evidence on the effectiveness of the smaller learning communities strategy in strengthening high school education and raising achievement. The creation or expansion of smaller learning communities in large high schools may be supported by Title I Grants to Local Educational Agencies or State Grants for Innovative Programs—the latter of which specifically authorizes the creation of smaller learning communities. Also, the President’s proposed new High School Initiative will give educators greater flexibility to design and implement approaches for improving the achievement of high-school students.

Star Schools ..... 20.8

Supports distance education projects to improve instruction in a variety of curricular areas. Programs such as State Grants for Innovative Programs and Improving Teacher Quality State grants provide ample resources for these activities.

State Grants for Incarcerated Youth Offenders ..... 21.8

Formula grants to State correctional agencies assist and encourage incarcerated youth to acquire functional literacy skills and life and job skills. Request is consistent with the Administration’s effort to eliminate small programs that have only indirect or limited effect on improving student outcomes.

Supported Employment State Grants ..... 37.4

Program has accomplished its goal of developing collaborative programs with appropriate public and private nonprofit organizations to provide supported employment services for individuals with the most significant disabilities. Supported employment services are also provided by the VR State Grants program.

Teacher Quality Enhancement ..... 68.3

Program provides funds to improve recruitment, preparation, licensure, and support for teachers by providing incentives, encouraging reforms, and leveraging local and State resources to ensure that current and future teachers have the necessary teaching skills and academic content knowledge to teach effectively. All of the activities allowable under the Teacher Quality Enhancement program can be carried out under other existing Federal programs. Rated Results Not Demonstrated by the PART process due to lack of performance data and program design deficiencies.

Tech-Prep Demonstration ..... 4.9

This program to establish secondary technical education programs on community college campuses has narrow and limited impact. The Administration’s proposed \$1.2 billion High School Initiative will give educators greater flexibility to design and implement programs that best meet the needs of their students, including Tech-Prep programs. States could use funds to support vocational education, mentoring and counseling programs, partnerships between high schools and colleges, or other approaches.

	<i>Millions</i>
Tech-Prep Education State Grants .....	\$105.8
<p>A separate State grant program to support State efforts to develop structural links between secondary and postsecondary institutions that integrate academic and vocational education is unnecessary. The Administration’s proposed \$1.2 billion High School Initiative will give educators greater flexibility to design and implement programs that best meet the needs to their students. States could use funds to support vocational education, mentoring and counseling programs, partnerships between high schools and colleges, or other approaches.</p>	
Thurgood Marshall Legal Educational Opportunity Program .....	3.0
<p>Program provides minority, low-income or disadvantaged college students with the information, preparation, and financial assistance needed to gain access to and complete law school study. Disadvantaged individuals can receive assistance through the Department’s student financial assistance programs.</p>	
TRIO Talent Search .....	144.9
<p>Provides grants to colleges to encourage disadvantaged youth to graduate from high school and enroll in a postsecondary education program. The proposed new High School Intervention initiative would provide a more comprehensive approach to improving high school education and increasing student achievement, especially the achievement of those most at-risk of educational failure and dropping out. Talent Search received a Results Not Demonstrated PART rating due to a lack of data on key performance measures and no evaluation findings.</p>	
TRIO Upward Bound .....	312.6
<p>Provides grants to colleges to support intensive academic instruction for disadvantaged high school students and veterans to generate the skills and motivation needed to pursue and complete a postsecondary education. The proposed new High School Intervention initiative would provide a more comprehensive approach to improving high school education and increasing student achievement, especially the achievement of those most at-risk of educational failure and dropping out. Upward Bound received an Ineffective PART rating due to a lack of data on key performance measures and evaluation results that found the program has limited overall impact because services are not sufficiently well targeted to higher-risk students.</p>	
Underground Railroad Program .....	2.2
<p>Provides grants to non-profit educational organizations to establish facilities that house, display, and interpret artifacts relating to the history of the Underground Railroad, as well as to make the interpretive efforts available to institutions of higher education. The program has largely achieved its original purpose.</p>	
Vocational Education National Programs .....	11.8
<p>The program’s activities, which include research, assessment, evaluation, dissemination, and technical assistance, would be addressed as part of the Administration’s proposed High School Initiative for ensuring that secondary students improve their academic achievement and graduation rates.</p>	
Vocational Education State Grants .....	1,194.3
<p>Funds would be redirected to support a new comprehensive strategy for improving the effectiveness of Federal investments at the high school level and for a community college access initiative. The High School Initiative will give educators greater flexibility (coupled with enhanced accountability) to design and implement programs that best meet the needs of their students. States could use funds to support vocational education, mentoring and counseling programs, partnerships between high schools and colleges, or other approaches.</p>	
Women’s Educational Equity .....	3.0
<p>Activities promoting educational equity for girls and women may be supported through larger, more flexible programs like ESEA Title V-A State Grants for Innovative Programs.</p>	

PROPOSED REDUCTIONS TO EDUCATION PROGRAMS

Then there’s almost \$1 billion in program reductions, so we need to know the specifics there, again. There are new initiatives which

we will consider very, very carefully, \$2.325 billion, but those are some of the places where we're going to need to start.  
[The information follows:]

## PROGRAMS PROPOSED FOR REDUCTION IN FISCAL YEAR 2006

## EDUCATION DEPARTMENT DISCRETIONARY BUDGET, DECREASES

[Dollars in thousands]

Program	2005 appropriation	2006 request	2006 request over 2005 appropriation	
			Amount	Percent
<b>ESEA:</b>				
Indian Education National Activities .....	\$5,129	\$4,000	-\$1,129	-22.0
Education for Native Hawaiians .....	34,224	32,624	-1,600	-4.7
Impact Aid Construction .....	48,544	45,544	-3,000	-6.2
Alaska Native Education Equity .....	34,224	31,224	-3,000	-8.8
Advanced Credentialing .....	16,864	8,000	-8,864	-52.6
Physical Education Program .....	73,408	55,000	-18,408	-25.1
State Grants for Innovative Programs .....	198,400	100,000	-98,400	-49.6
<b>Total, ESEA .....</b>	<b>410,793</b>	<b>276,392</b>	<b>-134,401</b>	<b>-32.7</b>
<b>IDEA:</b>				
IDEA Technical Assistance & Dissemination .....	52,396	49,397	-2,999	-5.7
IDEA Technology and Media Services .....	38,816	31,992	-6,824	-17.6
IDEA State Personnel Development .....	50,653	.....	-50,653	-100.0
<b>Total, IDEA .....</b>	<b>141,865</b>	<b>81,389</b>	<b>-60,476</b>	<b>-42.6</b>
<b>Postsecondary:</b>				
National Technical Institute for the Deaf .....	55,344	54,472	-872	-1.6
Strengthening Alaska Native & Native Hawaiian Serving Institutions .....	11,904	6,500	-5,404	-45.4
TRIO Other .....	13,335	3,625	-9,710	-72.8
<b>Total, Postsecondary .....</b>	<b>80,583</b>	<b>64,597</b>	<b>-15,986</b>	<b>-19.8</b>
<b>All Other ED Programs:</b>				
Helen Keller National Center .....	10,581	8,597	-1,984	-18.8
Research & Innovation in Special Education .....	83,104	72,566	-10,538	-12.7
VR Assistive Technology .....	29,760	15,000	-14,760	-49.6
VR Demonstration and Training .....	25,607	6,577	-19,030	-74.3
Adult Basic & Literacy Education State Grants .....	569,672	200,000	-369,672	-64.9
<b>Subtotal, Other ED Programs .....</b>	<b>718,724</b>	<b>302,740</b>	<b>-415,984</b>	<b>-57.9</b>
<b>S&amp;E: Program Administration .....</b>	<b>419,280</b>	<b>418,992</b>	<b>-288</b>	<b>-0.1</b>
<b>Subtotal, S&amp;E .....</b>	<b>419,280</b>	<b>418,992</b>	<b>-288</b>	<b>-0.1</b>
<b>Total, All Other ED .....</b>	<b>1,138,004</b>	<b>721,732</b>	<b>-416,272</b>	<b>-36.6</b>
<b>Total, Decreases .....</b>	<b>1,771,245</b>	<b>1,144,110</b>	<b>-627,135</b>	<b>-35.4</b>

## PROGRAM REDUCTIONS (DESCRIPTION)

## No Child Left Behind (NCLB):

Indian Education National Activities .....	<i>Millions</i> \$4.0
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The request provides \$4.0 million for National Activities, which funds research, evaluation, and data collection designed to fill gaps in our understanding of the educational status and needs of Indians and on identifying educational practices that are effective with Indian students. The program also provides technical assistance

to school districts and other entities receiving Indian Education formula and discretionary grants.

Education for Native Hawaiians .....	<i>Millions</i> \$32.6
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The Education for Native Hawaiians program provides supplemental education services and activities for Native Hawaiians, many of whom perform below national norms on achievement tests of basic skills in reading, science, and math. Grants support a variety of authorized activities. Other Department elementary and secondary education programs, particularly the State formula grant programs, also support improved achievement for Native Hawaiians. The proposed \$1.6 million reduction in funding reflects the elimination of two one-time grants included in the 2005 appropriation.

Impact Aid Construction .....	45.5
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School districts also generally pay for most of their school construction costs using their own resources and rely on property taxes to finance these costs. Districts affected by Federal operations have limited access to those sources of funding. The \$45.5 million proposed for Construction would provide both formula and competitive grants to school districts. Formula grants assist districts with large proportions of military dependent students and students residing on Indian lands. Competitive grants focus on helping LEAs make emergency renovations and modernization upgrades. The request is reduced by \$3 million in funding reflecting a one-time project in fiscal year 2005.

Alaska Native Education Equity .....	31.2
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The Alaska Native Education Equity program provides educational services to meet the special needs of Native Alaskan children. By statute, a portion of funds must be awarded annually to specific entities. The remaining funds support competitive grants for teacher training, student enrichment, and other activities that address the special needs of Alaska Native students in order to enhance their academic performance. Other Department elementary and secondary education programs, particularly the State formula grant programs, also support improved achievement for Alaska Native students. The proposed \$3 million reduction reflects the elimination of two one-time grants included in the 2005 appropriation.

Advanced Credentialing .....	8.0
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This program supports the development of advanced credentials based on the content expertise of master teachers. Funds also support related activities to encourage and support teachers seeking advanced credentials. The 2006 request would support the American Board for the Certification of Teacher Excellence's development of an Initial Certification and a Master Certification to give States and districts more options for improving teacher quality and, most importantly, raising student achievement. The reduced request reflects the Department's decision not to extend its 5-year grant to the National Board for Professional Teaching Standards beyond the additional year of funding directed in the fiscal year 2005 appropriation.

Physical Education Program .....	55.0
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This program provides competitive grants to local educational agencies and community-based organizations to pay the Federal share of the costs of initiating, expanding, and improving physical education programs (including after-school programs) for students in kindergarten through 12th grade, in order to make progress toward meeting State standards for physical education. Funds may be used to provide equipment and other support enabling students to participate in physical education activities and for training and education for teachers and staff. The 2006 request includes funds to pay for continuation costs for physical education grants, as the first year of a 2-year phase out of the program in order to redirect resources to higher-priority activities.

State Grants for Innovative Programs .....	100.0
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This program provides flexible funding to State and local educational agencies for a wide range of authorized activities serving all students. Examples include reducing class size, professional development, funding Title I supplemental educational services, and creating smaller learning communities. The reduced request reflects a decision to redirect funding to higher-priority activities that are better targeted to national needs and have stronger accountability mechanisms.

Individuals with Disabilities Education Act (IDEA):

	<i>Millions</i>
IDEA Technical Assistance and Dissemination .....	\$49.4

This program provides technical assistance and disseminates materials based on knowledge gained through research and practice. The proposed reduction reflects a restructuring of funding for technical assistance. This request is in addition to the separate \$5 million request for a Transition Initiative and \$10 million to be set-aside under the Grants to States program under a newly authorized technical assistance authority to help States meet data collection requirements. These other sources of funding for technical assistance will free up funds under this program for activities to help States, local educational agencies, teachers, parents, and others to implement the Individuals with Disabilities Education Improvement Act of 2004.

IDEA Technology and Media Services .....	32.0
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This program supports research, development, and other activities that promote the use of technologies in providing special education and early intervention services. Funds are also used for media-related activities, such as providing video description and captioning of films and television appropriate for use in classrooms for individuals with visual and hearing impairments and improving accessibility to textbooks for individuals with visual impairments. The proposed reduction reflects the elimination of funding for one-time projects funded in 2005.

IDEA State Personnel Development .....	0
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No funds are requested for the State Personnel Grants program, newly authorized by the Individuals with Disabilities Education Improvement Act of 2004, because the entire fiscal year 2005 appropriation remains available for obligation through September 30, 2006. These funds will be used to support 41 continuation awards and 8 new awards.

Postsecondary:

National Technical Institute for the Deaf .....	54.5
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The request represents a decrease of \$872,000 below the 2005 appropriation reflecting completion of construction projects funded in 2005.

Strengthening Alaska Native & Native Hawaiian Serving Institutions ....	6.5
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The request includes \$6.5 million for Part A, Section 317, Strengthening Alaska Native & Native Hawaiian-serving Institutions to cover the continuation of 12 projects. No funds are requested for new awards. The Administration does not believe a new round of awards is appropriate until we have the opportunity to determine the extent of need and the most effective means of helping to strengthen these institutions. In fiscal year 2005, we are proposing to increase the average new award size to an estimated \$500,000 and invite eligible applicants to propose projects with a specific focus on renovation and improvements to their classrooms, libraries, laboratories, and other instructional facilities.

Federal TRIO Programs, Other .....	3.6
Staff Training .....	2.5
Dissemination Partnership Projects .....	0
Evaluation .....	0
Administration/Peer Review .....	1.1

The reduced request for TRIO activities, overall, for 2006 reflects the decision to shift high-school-related TRIO resources to the proposed High School Intervention initiative, which would provide a more flexible, comprehensive, and accountable approach to addressing the college preparation needs of high school students. The new initiative would help ensure that the types of services currently provided by programs like Upward Bound and Talent Search are part of a broader effort to provide students, especially those most at-risk, with the full range of services they need in order to succeed.

The remaining Federal TRIO Programs would receive \$369.4 million to maintain services for more than 420,000 low-income, first-generation (or disabled) individuals. Among these remaining programs, Staff Training, Dissemination Partnership Grants, Evaluation, and Administrative Expenses would be reduced by a total of \$9.7 million due to the elimination of the Upward Bound and Talent Search programs, which typically comprise more than half of TRIO grants. New Staff Training funds, down \$2.8 million from 2005, would fund 6 new awards, at an average funding level of \$417,000, to provide nearly 2,000 TRIO professionals with the skills necessary to run effective projects. Funding for Dissemination Partnership Grants



would be eliminated because sufficient best practices at the postsecondary level are already available. Evaluation funding would be temporarily reduced by \$525,000 due to the completion of the current round of program studies. Funding for administrative expenses, covering peer review of new award applications and other expenses, including performance measurement and analysis, would decrease by \$2 million.

All Other ED Programs:

	<i>Millions</i>
Helen Keller National Center .....	\$8.6

This program serves individuals who are deaf-blind, their families, and service providers through a national headquarters Center with a residential training and rehabilitation facility and a network of 10 regional offices that provide referral, counseling, and technical assistance. The reduced request does not include the additional \$2.0 million earmarked for the Center in 2005, which is not expected to be fully expended in 2005. At the request level, the Center would provide direct services for approximately 95 adult clients, 12 high school students, and 10 senior citizens at its residential training and rehabilitation program and serve 2,000 individuals, 500 families, and 1,100 agencies through its regional offices.

Research & Innovation in Special Education .....	72.6
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This program supports research to address gaps in scientific knowledge in order to improve special education and early intervention services and results for infants, toddlers, and children with disabilities. The request would support investments in special education research to advance our understanding of early intervention and assessment for young children with disabilities, language and vocabulary development, assessment for accountability, secondary and postsecondary outcomes, and serious behavior disorders. The decrease is equivalent to the amount of funds earmarked by Congress in 2005 for one-time projects. This program, which received a Results Not Demonstrated rating following a PART analysis completed during the 2005 budget process, was recently moved to IES as part of IDEA reauthorization. The new Center for Special Education Research within IES will develop priorities for future research, as well as a plan for carrying out research programs with measurable indicators of progress and results.

Vocational Rehabilitation—Assistive Technology .....	15.0
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The request includes \$15 million for the Alternative Financing Program (AFP), which provides grants to States to establish or expand loan programs that help individuals with disabilities purchase assistive technology devices and services. To date, the AFP has provided or facilitated loans totaling \$15.5 million to 1,515 individuals with disabilities. These loans are enabling individuals to acquire technology they might not otherwise be able to obtain that improves their quality of life and, in many cases, enables them to work or participate in other productive activities. No funding is requested for other programs authorized under the Assistive Technology Act, as recently revised, including the AT State grant program, the Protection and Advocacy (P&A) for Assistive Technology program, and National Activities. While States have received more than 10 years of support for activities under the antecedent program, the Department has been unable to identify and document any significant benefits. The Administration has proposed to discontinue funding for the AT State grant program and instead, as part of the New Freedom Initiative, support the AFP, which holds greater promise of providing tangible benefits to individuals with disabilities. Activities carried out under the AT P&A program can be carried out under the Protection and Advocacy of Individual Rights program.

Vocational Rehabilitation—Demonstration and Training .....	6.6
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Demonstration and Training programs support projects that expand and improve the provision of rehabilitation and other services authorized under the Rehabilitation Act, including related research and evaluation activities. The request would provide a total of \$6.6 million for new activities, including \$2.0 million that would be used to jointly fund the Transition Initiative under the Special Education account. The request would eliminate \$8 million for one-time projects in fiscal year 2005.

Adult Basic and Literacy Education State Grants .....	200.0
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The Administration requests \$200 million for Adult Basic and Literacy Education State Grants, with the expectation that new authorizing legislation will be enacted in 2006. This request is consistent with the Administration's goal of decreasing funding for programs with limited impact or for which there is little or no evidence

of effectiveness. A PART analysis of the program carried out as part of the fiscal year 2004 budget process produced a Results Not Demonstrated rating. The program was found to have a modest impact on adult literacy, skill attainment and job placement, but data quality problems and the lack of a national evaluation made it difficult to assess the program's effectiveness. The request for State Grants includes level funding for the English Language and Civics Education grants, which enable States experiencing high levels of immigration to respond to the specialized educational needs of the immigrant/limited English proficient population.

Salaries and Expenses: Program Administration .....	<i>Millions</i> \$419.0
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The 2006 request includes \$419 million, a slight decrease of \$300,000 from the 2005 level, for the Program Administration account, which funds administrative support for most programs and offices in the Department. The request includes \$254.2 million for the 2,242 FTE, and \$164.8 million for non-pay costs. The non-pay request includes \$4.1 million to continue implementation of the Performance Based Data Management Initiative, which will collect timely data on student achievement and educational outcomes. Other non-pay costs include rent, travel, data collection, evaluations, computer hardware and software support for the staff, and other administrative activities.

#### FOREIGN LANGUAGE ASSISTANCE PROGRAM

Let me begin as to a question—in the minute and a half that I have remaining—with a letter which Senator Cochran and I sent to you earlier this month, which you have responded to, regarding the new grant competition under the Foreign Language Assistance Program. We're concerned that the competition does not reflect congressional intent in appropriating these funds; we intended that they would help schools offer foreign language instruction to their students. Will you comment on that, please?

Secretary SPELLINGS. Senator, I've just recently become familiar with that issue, and I am trying to get to the bottom of all the various local issues that undergird that, but I think one of the things that we at the Department are trying to do is to provide maximum latitude to States and local districts on funding, and yet hold them accountable for results, and I will be glad to look into that issue more—I know that you just received the letter, I think, late last night—so, I want to work with you on these issues, and I'll look forward to talking with the local folks in your communities who have raised their concerns.

Senator SPECTER. As I had announced earlier, I have other commitments, which I'm going to have to leave for, and as I said earlier, Senator Harkin will take over on the hearing if there is no other Republican present. Let me now turn to Senator Harkin for questioning. Senator Harkin, you have the floor.

#### OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN [presiding]. Madame Secretary, again, thank you very much for appearing before the subcommittee, I thank the chairman for being here, too, and in absentia, thank Senator Specter for his great leadership of this subcommittee. I was just thinking, it has been 15 years, really, that we've worked together as chairman and ranking member, back and forth on this subcommittee, and it has been a great partnership. I think this really is one subcommittee that has worked together in a true bipartisan fashion—through Republican and Democratic administrations—through all those years. I've really appreciated that working relationship that we've had, especially on this subcommittee.

## PROPOSED REDUCTION IN TOTAL EDUCATION FUNDING

I just wanted to make a couple of statements about the budget that has come up here. I think we have to take a look at where we're headed, and why we're shifting some of the monies around. I—first of all—think that we need to put some more into the budget for education. The President's budget cuts funding for education for the first time in 10 years—now I'd be glad to listen to any counters to that—and we look at No Child Left Behind, and we discussed this before, you can say, "Well, it's funded." But I'm talking about what expectations were when we passed No Child Left Behind—which I supported at that time—and I think the expectation level was that we would be at a certain level of funding, and we're not there.

Title I, if it were fully funded, would cover about 3 million more children. As for special education, and kudos to this administration for moving ahead on funding—but the fact is, we still are only around 19 percent of what we had promised 30 years ago. And, so I will continue to prod whether it's this administration or any other one, as I did the one before yours, to continue to try to get towards that 40 percent full funding level. So, we're still underfunded, I think, in special education. In Iowa—we had the Governor in yesterday talking to our bipartisan group, Senator Grassley and I and our congressional delegation—he said Iowa would stand to lose about \$14.1 million for career and technical education, \$2.4 million for education technology, \$3.4 million for safe and drug-free schools, \$1 million for family literacy programs, and \$1.1 million for comprehensive school reform. That's the money that Iowa gets now that we wouldn't get under this budget. Again, it comes at an especially bad time, some 11,000 schools across the country have been designated "in need of improvement," meaning they failed to make adequate yearly progress for 2 years in a row, and now they face sanction. That's about twice as many schools as last year. The number will go up sharply next year when AYP requirements even get tougher, this thing keeps getting tougher, year after year.

So with this new budget, it seems like we're again asking for more reforms without really getting the resources; we're asking local school districts to make dramatic academic gains at the same time that we're cutting their funding. So, I don't know how we can expect 11,000 schools that are in need of improvement to hire better teachers, to close the achievement gap at a time when funding is being cut.

I looked at the \$1.5 billion High School Initiative, and then I thought, well, you couple that with the \$2.2 billion in cuts to other education programs—like voc ed and GEAR UP and TRIO and smaller learning communities and things like that—so it seems like we're eliminating \$2.2 billion for high schools, and replacing it with \$1.5 billion for the new High School Initiative, which still represents a cut to our high schools.

The Perkins/Voc Ed Program is also one that bothers me greatly, because you say that this would go to other high school initiatives, but in Iowa, 30 percent of our Perkins money goes to community colleges—so it's not high school—it goes to community colleges. And this has been a great thing in Iowa for economic development

and for getting skills to our high school students going to community colleges.

So, anyway, these are just some of the questions that I have about the budget, and about the thrust of it. Have I seen worse? Yes. Have I seen better? Yes. So, this falls someplace in the middle, at least as I see it. But I'd like to just ask a few questions.

#### NO CHILD LEFT BEHIND REQUIREMENTS

First of all, about No Child Left Behind, Madame Secretary, you've got to be aware—as we all are—that we're hearing from our constituents about No Child Left Behind. A lot of concerns about it, educators, parents, they believe the law is too rigid, it's narrowing the curriculum. I don't know if this is just anecdotal or not, but I keep hearing stories about schools—in order to meet the rigid requirements of hiring better trained teachers, and qualified teachers for curriculums to meet No Child Left Behind—the first person that gets fired is the art teacher, or the music teacher, or the P.E. teacher. They're the ones who are let go. So, curriculums are being narrowed.

The goal of 100 percent proficiency for all sub-groups in all subject areas seems to me to be unrealistic for our schools. We see States like Virginia, talking about pulling out from the law, even if it means giving up hundreds of millions of dollars from the Federal Government. So I was kind of surprised to see that now we want to extend this into high schools. It seems to me we ought to make the system work for grade schools first, before we go to high schools.

Now—I'm going to bring this to a close here—you talked about remedial education. We're spending all this money later on downstream for remedial. If you're doing this in high school, that's kind of remedial. If we get it early on in grade schools, we don't have to remediate it in high school. So, it would seem to me that this high school initiative—I'm not adamantly opposed to it—it just seems to me that this is not the right time to do it. It seems to me, we've got to put those resources more into No Child Left Behind in elementary schools.

#### HIGH SCHOOL INITIATIVE

Last, I must say I wear another hat—I'm on the education authorizing committee—and you are trying to make this change by putting on two sentences on our Appropriations bill. I think that's the wrong approach. This is an authorizing measure. I would think that both Senator Enzi and Senator Kennedy—Chair and ranking member of the HELP Committee, and others of us on the authorizing committee—would want to have something to say about how we extend the No Child Left Behind Act into high school as an authorizing measure, rather than putting it on an appropriations bill.

So, two questions, Madame Secretary. This High School Initiative—should we put that money back into the grade schools, put it into the elementary schools now, rather than trying to extend the law. Second, shouldn't this be done in an authorizing measure?

Secretary SPELLINGS. Thank you, Senator, you've put out some great points that I'm thrilled to be able to respond to.

First, as I said in my opening statement, there is some urgency in high school, no doubt about it. We need to be able to walk and chew gum—as we would say in Texas—and that is attend to, and stay the course, on No Child Left Behind. That’s why we’ve sustained these large growths in reading funds; that’s why we have a \$600 million increase in Title I. But we also need to make sure that we are getting kids out of high school, fully prepared to either be successful in the work place or in college. I think we can, and we must, do both.

Let me speak to the philosophy of this budget, overall, and that is—and this was at play, certainly, in the design and development of No Child Left Behind—and it is that we need to be very clear with States about what our expectations are, and then give them a lot of latitude in results, with respect to resources. That’s why these 45 programs have been proposed for elimination, because the President believes that they do not represent, necessarily, either a critical mass, or have not, in all cases, been an effective use of resources.

So the vision here is to create a new high school program in Title I, be clear with States about what we expect, and if they’re getting great results with vocational education, or TRIO, or GEAR UP, or technology or whatever, there certainly is no impediment to doing that. And I’m confident—having represented local school boards—that when those programs get results for kids, they will. But I think the same people who are talking to you about the need for flexibility in No Child Left Behind, talk to me about how we prescribed a lot of particular, specific programs—with particular grant application processes, deadlines and so forth—and we are too much in their way with respect to managing their dollars. The National Governors Association just this weekend, as I said, met. This was one of the things they have called for. That’s why we believe that the assessment and the measurement and the accountability is so critical, but let’s give them more flexibility with respect to managing resources.

#### USE OF AUTHORIZING AND APPROPRIATIONS PROCESSES

As to the issue of the authorizing versus appropriations matter, certainly that is something that I have spoken with Senator Enzi and Senator Kennedy about—as you are well aware—we have the Perkins reauthorization before us, the Higher Education Act before us; therefore many opportunities to tackle some of those policy matters, rightfully, on the authorizing side as well. So, thank you for that.

Senator HARKIN. So, we could do this in the authorizing committee, rather than doing it in appropriations?

Secretary SPELLINGS. Well, I think the whole issue of high school is something that people are recognizing—within this body and around the country—needs attending to. Certainly resources, obviously, are a part of that equation, but I think there are some things on the policy side with respect to high school, such as what the expectations are, what the timelines are, and various other things that are going to be at issue here as well. This High School Assessment Initiative—though we’ve called for \$250 million immediately to begin to develop those—we recognize it is more com-

plicated. States are going to use end-of-course exams, some States will use exit exams, some States will use Advanced Placement exams, or other standardized assessments as a proxy for their assessment qualifications. It's going to take time. We don't envision this being fully implemented until 2009, 2010 when the first entering class of No Child Left Behind kids would have made it through the pipeline, if you will. So, there are a lot of things that are at play from a policy point of view, in addition to the resources that are needed here, from this committee.

Senator HARKIN. I still think we're going to have to examine this under authorization, rather than just appropriations.

Let me just ask one question more, and then I'll go over to Senator Kohl. When the President says you're going to spend the taxpayers' dollars, it "ought to be spent wisely, or not spent at all." Of course, that raises the question: Whose wisdom? Ours or yours?

#### STUDENT LOAN PROGRAMS

But, there is one thing I want to bring to your attention, and that has to do with the student loan program, about spending money. Quite frankly, I think a lot of your proposals make a lot of sense on the student loan program. You're proposing to use the savings to increase Pell Grants—that's good—so I applaud that, I think you're headed in the right direction. But, I just want to bring something else to your attention. Even if we adopt your recommended changes to the student loan programs, your own budget documents, and I refer here to page 371, specifically, of the budget appendix, show that the cost to taxpayers—of each \$100 lent under the Federal Family Education Loans, the FFEL program—it costs \$8.91 in taxpayer subsidies. That's your own budget. On the other hand, your documents show that each \$100 lent under the Direct Loan Program makes a profit of \$2.06 to the taxpayers. In other words, returning \$2.06 to the Treasury. Well, that means a student with total subsidized loans of \$17,000—which is about the average debt of a student finishing a 4-year college right now, we're just taking averages—under the FFEL Program, that costs the Government, taxpayers, \$1,514, to be exact. The same loans to a student in the Direct Loan Program makes a profit of \$360. So, Madame Secretary, given these facts—and the continuing need to find the monies for increasing Pell Grants, and other student aid for disadvantaged students—shouldn't we be doing everything we can to encourage colleges to join the Direct Loan Program?

Secretary SPELLINGS. Well, certainly, Senator, that's obviously an option before them. I think our proposal has attempted to look at the broad range of financial aid services—how we manage it—from Perkins loans at 5 percent interest rates, to a 3 point something or other average rate in Direct Lending and the FFEL Program, and to look at this in a more efficient, effective way—we've had a transformation, if you will, of the financial services industry, elimination of the middle man in some cases, different relationships between universities and students and the Federal department and banks, and others—and we believe that there are efficiencies and savings to be drawn by looking at those programs broadly. To the tune of about \$30 billion over 10 years, I believe, eliminating that short fall once and for all, and applying those efficiencies, those

savings toward student aid. I think we will, maybe, have discussions about how to turn the various dials across the spectrum of financial aid, and how the loan program balances with resources towards grants—our neediest students—that’s why the President has put a high priority on Pell. But, there’s lots of room to talk about it, as you know, we have a laundry list of various proposals which range from, I think, \$6 billion at the high end, we’ve called for variable interest rates, and a whole laundry list of proposals for your consideration.

Senator HARKIN. Madame Secretary, I appreciate that, I just, again, I look at the table. I was quite amazed when you look at the cost—from the Direct Loans, \$2.06 back to the Treasury, \$8.91 in subsidies out after all of those things you just talked about, which is fine, and good, you still have this problem. You still have money not being wisely spent by the Government. We hear all these stories about these lending institutions flying their student, college directors down for vacations and cruises and all kinds of different things, and they wine them and dine them, but it seems to me with this kind of data that we now have, that your Department ought to be forthright in just saying to colleges, “Look, we want to save the taxpayers’ money. We want to spend the money wisely, get in the Direct Loan Program.”

Secretary SPELLINGS. We certainly, obviously, have supported the Direct Loan Program, and will continue to do that, and as institutions around the country see the merit of that we stand ready to assist them. But again, it’s a place where we’ve sort of had a local control attitude about financing higher education, as we all have together.

Senator HARKIN. I don’t mind local control, this is Federal tax dollars. The States, if they want to waste their money that way let them, but we have our obligation on the Federal level.

Secretary SPELLINGS. Right, I appreciate that.

Senator HARKIN. But, I’m glad to hear what you just said, that’s very important. Thanks, Madame Secretary. Senator Kohl.

Senator KOHL. Thank you very much, Senator Harkin, Secretary Spellings.

#### PROPOSED ELIMINATION OF VOCATIONAL EDUCATION FUNDS

The President’s budget eliminates, as you know, funding for Perkins on the grounds that it is ineffective, and that the money would be better used in the K–12 system. I’ve talked to Brent Smith in Wisconsin who is Chair of the Wisconsin Technical College Board, and he raises an important issue that you ought to consider.

The Chair says that he notes today that the average age of a Wisconsin technical college student is 29. These students have moved beyond the K–12 system, so any diversion of Perkins funding to K–12 would be of no help to them, obviously. And these older students face other obstacles besides a lack of academic preparation. Some are returning to school after years in the work force, some are pursuing highly technical degrees, while others are economically disadvantaged; either single parents, dealing with a disability, or learning English for the first time. That’s why Wisconsin technical colleges use their Perkins money so well to help their stu-

dents meet these unique challenges. They've been successful, as the vast majority graduate, and obtain high-skill, high-wage jobs.

Brent Smith and the Wisconsin Technical College System would like to know, without Perkins, how does the Department expect that technical colleges will serve the current generation of adult Americans—most of whom are well beyond their K–12 years—and who need help right now?

Secretary SPELLINGS. Thank you, Senator, for that question. Let me first say that I am a former vocational education student myself, so I do have appreciation for what they do.

Our budget—with respect to the split between the community college funding that they received from Perkins, and the high school level of funding—we have attempted to accommodate that to make them whole within either the Labor Department budget, or in this budget. So, by our math, the funding for vocational education for high schools, and for community colleges, is about the same. We've called for a community college expansion initiative of \$250 million in the Labor Department budget, \$125 million for a Community College Access Grant to support more articulation between high schools and community colleges, and so forth. So, while it's a different kind of allocation of resources, we do believe those funding levels are approximately the same. As I said—I don't know if you were in the room a minute ago—we believe, the President's notion of how we fund high schools and community colleges is that we ought to be clear with folks about what we expect and then allow them to direct resources as they see fit, to a particular goal, with accountability attached. I'm very confident that—in places like Wisconsin where those vocational education programs are getting demonstrable results for students—that they will be supported by local school boards, and State officials. So long as we know what the data shows. But, I think what we've heard over and over again, even as recently as this last weekend, with the National Governors Association, is that for too many kids, high schools are not working. Particularly for those at the low end of the system, if you will.

Senator KOHL. Are you saying that the Perkins money has not been cut?

Secretary SPELLINGS. I'm saying that we've put the Perkins money in a high school title—

Senator KOHL. I know, but as I point out in my question, it doesn't help the person enrolled in the community college, the vocational college, to get advanced training, it doesn't help that person at all, who needs that training, who's out there today, to allocate more money to high schools. That person, as you know, is obviously way beyond high school.

Secretary SPELLINGS. Right.

Senator KOHL. The Perkins money does serve a very important, useful purpose. It's used well to train these people who are beyond high school, to get back into the work force. So, I'm not sure if I understand your answer.

#### FUNDING FOR COMMUNITY COLLEGES

Secretary SPELLINGS. Let me clarify. And that's why the President has called for additional resources for community colleges—to serve the type of individual you just mentioned through a \$250 mil-



lion plus-up and a partnership grant between local employers, community colleges, and the private sector, as well as an additional \$125 million for community colleges in this Community College Access grants program. So, while they might not be served through the Perkins program, we do believe we've provided resources to community colleges, to allow them to continue to serve the type of student that you've just spoken about.

#### VOCATIONAL EDUCATION FUNDS

Senator KOHL. The Perkins program was \$1.3 billion. Now, you've talked about \$100 or \$200 million. Now, to my way of figuring, that's not a tradeoff.

Secretary SPELLINGS. Under the current Perkins program, as you know, some of the resources are in the K-12 system, and some of the resources are in the postsecondary system, and we have attempted to take the level of resources, approximately, from Perkins, that support high school, and put it in a high school initiative. Likewise, those resources that are serving postsecondary students have been applied to other community college programs to support those type of individuals.

Senator KOHL. I appreciate what you're saying, I think if Brent Smith—who is Chair of the Wisconsin Technical College System—were here, he would be looking at you as quizzically as I am, trying to figure out what it is you're saying that will really help him as the Chair of the Wisconsin Technical College Board, what's going to help him in trying to do his job. I think there is clearly a net minus of money that we're talking about here, of significant proportions. I recognize money is scarce, and we can't do everything we want. But, I think what you're telling me is they won't get the kind of money that they have gotten heretofore. He is saying, as Chair, that they will really, really miss that money, because it is being used very well to help people that are post-high school, educate themselves to get into the work force. That's clearly what he would be saying.

#### PELL GRANTS

Secretary SPELLINGS. I appreciate that point of view. I do want to mention a couple of other things that are on point for the students you are talking about, and that is the enhancement of Pell—more than half of the students that are in community colleges are Pell recipients—and we've also called for allowing that financial aid to be used year round, and for short-term training for individuals like those you've spoken of, to get the necessary skills to re-enter the work force.

#### PELL GRANT ELIGIBILITY AND TAX TABLES

Senator KOHL. All right, well, let me talk about Pell for a minute. Last month most of our delegation from Wisconsin wrote the President about an issue involving Pell Grants.

Specifically, the Department of Education is making immediate changes to the tax tables that determine eligibility for Pell Grants, as you know. As many as 5,500 Wisconsin students—who today get Pell Grants—could completely lose them, and thousands more will

see their Pell Grants reduced. While I agree we need to use accurate tax information to determine eligibility, we need to remember that this will affect students who are in school today, and are counting on Pell Grants to remain in school. It would be unfair to change the rules, I think, in the middle of the game, and I think at the very least, we should all agree not to take money away from students who are, today, relying on the Pell Grants that they are getting. So, will you be able to work with us to see to it that Wisconsin—as well as Pell Grant recipients from other States, will not entirely lose their Pell Grant money, in the middle of their college education?

Secretary SPELLINGS. Let me react to that issue, on the tax tables. This Congress required the Department of Education to update these State tax tables that have not been done since, I believe, the late 1980s, or so, so it's been quite a while, and that's why the impact was more severe than it normally would have been, had we updated them more recently than that.

My understanding is that the average award for those students is about \$400 a year, and many of the folks that would be affected are first-time recipients, so they haven't received the aid yet. So, we do obviously struggle with this issue; we need to have the most accurate information available to fund these programs. But the way we've chosen to approach it in this budget is to increase the Pell award, to align this rigorous course of study to the Pell scholars, to allow for short-term training, to allow for year-round aid and so forth. But, I think we've righted the ship on the updated tax table once and for all, and we need to do it more consistently, and keep it current as we go forward, so that it will minimize the unfortunate effect that it had this time.

Senator KOHL. I do appreciate that, but we apparently have a difference of opinion—and we could probably straighten it out if we looked more carefully at the facts—according to my information, as many as 5,500 in Wisconsin who are getting Pell Grants today could lose them—totally, or in part—as a result of this change. Now, you've said that's not so.

Secretary SPELLINGS. I'm not saying it's not so, I'm saying that my understanding is that the average award is quite small, and some number—I'm not sure that those people will have lost aid—I'll just have to look at Wisconsin's particular situation.

Senator KOHL. Yes.

Secretary SPELLINGS. I'd be delighted to do that.

Senator KOHL. Would you do that?

Secretary SPELLINGS. Sure.

Senator KOHL. I would greatly appreciate it.

Secretary SPELLINGS. Sure.

Senator KOHL. I thank you so much. Thank you, Senator Harkin.  
[The information follows:]

#### IMPACT ON WISCONSIN PELL GRANT RECIPIENTS OF REVISED TAX TABLES

Under the revised tax tables, 1,486 students—or 2 percent—of the 72,252 Wisconsin students projected to receive Pell Grants under the previous tables would not receive grants in academic year 2005–2006. Projected Pell Grant awards in Wisconsin would be reduced by \$4.1 million under the revised tax tables. Based on national trends, the average amount lost per student is \$131; awards to the neediest

students, who qualify for the maximum Pell Grant, would be unaffected by the revised tables.

PROGRAM REDUCTIONS AND DEPARTMENTAL STAFFING

Senator HARKIN. Thanks, Senator Kohl. I just have three or four more questions, Madame Secretary.

The budget proposes to eliminate 48 education programs, and create 12 new ones, for a cut of 36 programs. Well, that's a lot of programs that your Department will no longer have to administer. And yet, the reduction in work is not reflected in the number of employees at the Department of Education.

For example, under the President's budget, the Office of Vocational and Adult Education would practically disappear. Seven of the 10 existing programs would be eliminated, for a funding cut of almost 90 percent. From \$2 billion to \$216 million. And yet, the number of full-time employees for this office would drop by just 3 percent. From 121 to 117. I guess, my question is, why do you need practically the same number of employees to do a tiny fraction of the work? Why isn't that also reflected in the budget?

Secretary SPELLINGS. Well, Senator, that's something certainly that we would take a look at. I do think that we would envision having folks with that kind of capability provide technical assistance on the high school side, so while it's not a one-to-one correlation, we certainly would look at the staffing levels that are appropriate to support the new world order.

I do want to mention one thing, and that is, of the 48 programs that we've called for elimination of, about 15 of them are \$5 million or less. And I think we would agree that it's hard to have a program with a national scope for a small amount of money. The remainder of them are about \$40 million or less, so they are typically fairly small programs of a few million dollars, and 15 of the programs are \$5 million or less.

SUMMARY STATEMENT OF HON. THOMAS SKELLY

Mr. SKELLY. Senator, I would just add, on the vocational education programs, many of those get funding that becomes available only in July. The 2005 Appropriations bill that you already passed this year, would provide funding beginning in July, and indeed in October 2005. We still need the staff in that office to obligate that money and make sure that it's well spent, under the existing law.

The reason we had such a small reduction in employees in the 2006 budget, was that most of the work will still go on under the 2005 appropriation. We'll only see the savings from elimination of funding for those programs in 2007 and 2008.

Senator HARKIN. You're saying you have to last for 1 full year that we have the program, when it's a 90 percent cut and we're going to keep on 117 people to administer that, it doesn't sound right.

Mr. SKELLY. Again, it's going to take time to phase out all of the work. Part of the work of these employees is not just obligating the money each year, it's looking at what happens with the grants that were awarded in prior years, it's closing out those grants; there will be some work involved if Congress were to accept the proposal to eliminate the programs and just working all of that out. So, even-

tually there will be a drop in the staff, as these programs are eliminated. It just won't happen starting October 1, 2005 when this fiscal year begins. There will be a lot of work, still, for a good part of fiscal year 2006.

Senator HARKIN. Well, that's a pretty good answer. But it seems to me that there's going to be a period of time where you're going to have a lot of employees, looking back and assessing a program that's no longer in existence. If it's no longer in existence, why assess it? Why have employees looking back, assessing how a program worked, if you no longer have the darn thing?

Secretary SPELLINGS. Senator, that's certainly something that we would work with you on about what the right levels of staffing that are needed to support—

Senator HARKIN. Again, that's why we look at the budgets and we say, "Well, you can do all this, we've got to see some drop in employees, also. Unless this is not a serious proposal." If it's a serious proposal, it ought to be done also with a cut in the employees also.

#### ELIMINATION OF SMALL PROGRAMS

Now, can I just respond—just a second—to what you said about, a lot of these small programs are \$5 million, or less. I've often said the genius of our American educational system is that we have local control, where you have well springs of ideas and innovation and that type of thing, you don't have a top-down structure where everybody marches to the same tune, that's sort of been the genius of our American educational system—so that experimentation has gone on. But, there has been some experimentation from the Federal side, too. And some of these small programs are just that; they are to test things out. A Senator, a Congressman, or a group gets together and says, "This may be a good approach, let's try it out and see what happens." Then you see if it works, TRIO program being one, of course that's more than \$5 million, obviously, it's a big program, but TRIO program is cut by almost a half. Yet, Trio program goes back—if I'm not mistaken—maybe 1969, 1968, something like that. I first became familiar with that as a Congressman in a rural area of Iowa back in the 1970's. I'd never heard of the TRIO program before. And, so through all these years, I think that it has proven its worth, but it started out as a small kind of a program to test some theories. That you could take kids from families where neither parent had ever gone to college, expose them to college situations, do some summer school training with them, and they would be more apt to pursue a higher education, and that has been proven, we've got data to prove that, going back to 1970. So, when you're cutting some of these small programs—a lot of them I don't even know myself, I mean, they're in there, but—it gets back to this wisdom thing, whose wisdom? Sometimes we put those in there to test things out, it's like the Writing Project that Senator Cochran has been pushing for years. I think that it is a legitimate function for us to try to test these things out and see how they work, and see if they do, and so when some of these are cut, you cut them and you do away with them before we've even seen whether they'll work or not—maybe some will, maybe some won't—it is a testing ground.

Secretary SPELLINGS. A fair point, and I think our question is, then, what's the demarcation between—when have you stopped testing a program, and when have you had a particular kind of model that's set forth for local communities—and I think, as I said again, the President's notion here is, let's be clear about what we expect, let's support measuring that achievement, and using that data to support improvements in the system, but then let's give local school districts the opportunity to double their TRIO Program, or whatever.

#### TRIO PROGRAMS

Senator HARKIN. Madame Secretary, local communities are not going to double TRIO Programs, because—I don't know, how many students are in TRIO now, 300,000 or 400,000, something like that, nationwide—so you go around the Nation, and there's just a few here, and a few there and a few here, and these are the poorest kids, usually from the poorest families, and you get two or three in a local district and, they have no power, they have no say-so. So, the local jurisdiction, the local school district—being pressed hard as they are right now for money, trying to raise funds for schools, being burdened with higher property taxes all the time—this is not going to be a thing that they're going to want to do, because it's so few. When we look at it from a national view—we say there's 300,000 or 400,000 students out there that need this kind of assistance, that we've had the data to show that these kids are more successful in going on to higher education. So, I really don't think it's right to say that local jurisdictions will pick this up, it would just be so small they won't. That's why we started the program, that's why we've kept it up for 35 years.

Secretary SPELLINGS. But we have, obviously, a lot of kids who are in those sorts of positions and giving resources to school districts to design programs as they see fit—TRIO, GEAR UP, vocational education, technology-based programs, and so forth—those that are getting results for them and their kids is a better way to run the railroad, in the President's view.

#### PUBLICIZING THE NO CHILD LEFT BEHIND ACT

Senator HARKIN. Well, I guess I disagree with him on that.

Let me ask you on just, a couple, three other things. This has to do with this Armstrong Williams case. Department of Education funds were used to pay political commentator Armstrong Williams to tout the No Child Left Behind Act. Mr. Williams did so without disclosing that he was being paid with taxpayer's dollars. I was glad to see the President made it clear that such an arrangement was unacceptable. So, what have you done since becoming Secretary to make sure this does not happen again, Madame Secretary? Have you made any attempt to recoup the funds paid to Mr. Williams from Ketchum, the PR company that hired him as a subcontractor?

Secretary SPELLINGS. The first part is, we have commissioned an Inspector General's investigation, which is underway. I expect that report very shortly, he's working hard to get to the bottom of all the facts—what we got, what we paid for, what we didn't get, what the expectations were, and so forth—and so I'm awaiting that infor-

mation before I determine a course of action, obviously. Likewise, the Government Accountability Office is conducting two investigations, one of which was on an initial analysis that apparently the Department did on media outlets and so forth, and that's been responded to. Then there's another one that's ongoing, and our General Counsel in the Department is cooperating fully with that, but, we're still in the fact-finding mode. The President has been clear about this, and I have. I don't think it's acceptable for folks who represent themselves as journalists to be paid for punditry and it won't happen again.

Senator HARKIN. The President made it very clear, and I applaud him for that, I just wondered where you are, and you told me you were waiting for the IG's investigation to come in.

#### OUTREACH AND COMMUNICATION ON FEDERAL PROGRAMS

Madame Secretary, I understand that your Department has a number of contracts with public relations and other similar firms. How much do you plan to spend on these types of contracts in fiscal year 2006? I don't find this anywhere in the budget.

I understand you might not have that information with you, and if you could submit an answer for the record, I'd appreciate that.

Secretary SPELLINGS. I'd be glad to do that. I will say that many of the programs—in fact, some of the ones we've talked about today, or this morning—do call for communications efforts and outreach to parents, the higher ed community, and so on. So, I do think it's important that we not throw the baby out with the bath water, particularly with a new law like this where there are options for parents, there are needs for teachers to be educated, and other educators about what the law provides, and so forth. So, the short answer to your question is, I don't know how much money we'll spend on communications. I certainly will find out what we're looking at.

Senator HARKIN. Someplace buried in there, there's some budget allocation in your Department for that, and we just don't have it and we'd like to take a look at that.

Secretary SPELLINGS. We'll look into it.  
[The information follows:]

#### CONTRACTS WITH PUBLIC RELATIONS FIRMS, ADVERTISING AGENCIES, AND THE MEDIA IN FISCAL YEAR 2006

It is premature to identify at this time what will be the Department of Education's acquisition needs several months in the future, when fiscal year 2006 appropriations will be available for obligation. In considering future contracts, be assured that the Department will very carefully take into account the recommendations of the Inspector General and other reviews of the Department's past contracts to ensure compliance with all applicable laws.

#### GRANTS FOR ENHANCED ASSESSMENT INSTRUMENTS

Senator HARKIN. When we spoke some time ago, I told you—and at a previous hearing, I think on the Authorizing side, Madame Secretary—I said I was going to be like a laser beam on kids with disabilities, and so I'm back to that now with this next question.

It's about the Grants for Enhanced Assessment Instruments program, which is intended to help States improve the quality of their tests. About \$12 million will be available for this program in this

fiscal year, 2005. In the Senate report, we urged the Department, when awarding grants, to give special attention to the needs of students with disabilities, and students with limited English proficiency. As you know, Madame Secretary, many schools have a difficult time—and we spoke about this—assessing the performance of these two groups. Often these students may have learned what they are supposed to have learned, but they can't demonstrate it because they aren't given the appropriate assessment.

So, our report language asked the Department to put a high priority on grant applications that aim to improve the quality of the State tests for these two groups of students. Unfortunately, the Department seems to be ignoring this language. In your budget justification, it says that \$12 million will focus on the use of technology in designing State tests. There's nothing about students with disabilities, or students with limited English proficiency. So, I would appreciate it if you could take our Senate request into account when you award these grants. Perhaps there's a way to combine the Department's priorities with the Senate's priorities. Again, this is money wisely spent, there's wisdom, perhaps, on both sides here.

For example, technology might be a good way to provide a special accommodation for students with disability. So, if you're going to do the technology, make it applicable to students with disabilities, so I hope you take another look at our report language, and at least update me on how you're going to do that for next year.

Secretary SPELLINGS. I absolutely will, and let me mention a couple of things. You and I did speak about this, and I convened—on the policy side—a group of experts to help us develop technical assistance, and listen to the educators and the advocacy community about where we are with special ed in the implementation of this law. I said—and I know you agree—that without No Child Left Behind I don't think we would be having this conversation, and I'm glad we are.

Senator HARKIN. I applaud that, and that's one of the reasons I supported that, because I said, "Finally, we're going to get the kids with disabilities, and we're not going to leave them behind, either." So, that's why I'm focusing on this.

Secretary SPELLINGS. Schools are starting to attend to them. But, we've got a long way to go with respect to technical assistance on assessment and on curriculum, and I've asked the organization that you recommended to me to participate on this panel of experts, and this is certainly an area of interest that they have identified. I do pledge to take this into consideration as we award these grants, I think that's the kind of application we're going to see from States. And I do think there's a harmony between the technology application and the needs of these kids.

Senator HARKIN. But, when you put out those requests, again, how they're worded gives the States some idea of what they should put in their grant requests, and if there's nothing in there about better assessment for kids with disabilities, "and please when you put in your grant request, we will look favorably upon that kind of thing," you know that, of course.

Secretary SPELLINGS. Right. But as I travel around the country, talking to educators, this is a hot issue. This is something they're

struggling with, and this is the kind of application I expect to get, frankly.

Senator HARKIN. I'm glad you said that, I just hope that that word goes out there to the community out there, too.

[The information follows:]

#### GRANTS FOR ENHANCED ASSESSMENTS

The Department will give competitive priority to applications for fiscal year 2005 and fiscal year 2006 funds under the Enhanced Assessment Instruments Grants program that propose projects addressing the use of accommodations or alternate assessments to improve the quality of assessments for limited English proficient students and students with disabilities. The notice inviting applications for fiscal year 2005 funds under the program, tentatively scheduled for publication in late spring of 2005, will announce the priority.

#### U.S. CONSTITUTION INITIATIVE

Senator HARKIN. One last question, I'm asking this question on behalf of Senator Byrd, who could not be here. The fiscal year 2005 Consolidated Appropriations Act last December, included language proposed by Senator Byrd that designates September 17 of each year as Constitution Day. The language also required that Federal employees be provided with training and educational materials concerning the U.S. Constitution—both at the time of their orientation as new employees, and on September 17 of each year.

In addition, the new law requires that all educational institutions receiving Federal funds hold an educational program on the Constitution on September 17. The law does not prescribe the exact content of the program, and it does not mandate any particular curriculum. There's no congressional intent to dictate to any educational institutions—public or private—exactly what must be said or done in the program provided by the institutions on this subject. The law simply requires that educational institutions hold a program on the Constitution, on Constitution Day, September 17.

I've been told by Senator Byrd that the Office of Personnel Management is working with the Department of Education on a Constitution initiative, which OPM plans to announce in several months to fulfill the requirements of this new law. Madame Secretary, can you confirm for Senator Byrd that the Department of Education will forward to this subcommittee, by April 1, 2005, its plan and/or guidelines for implementing the law's requirement that certain educational institutions hold a program on the Constitution on September 17.

Secretary SPELLINGS. I certainly will look into that, Senator, I'm not completely familiar with all the particulars that you mentioned, but I will certainly look into it and get back to you and Senator Byrd.

Senator HARKIN. I appreciate that. If you could get back to us, and see if you could do that by April 1, we're already into March. I didn't know if that date was in the law or not.

Secretary SPELLINGS. The 17th is a Saturday, I was just informed, so this year, September 17, Constitution Day is a Saturday, and that particular day kids will not be in school. So I think they're trying to work through issues like that, and run that to ground.



Senator HARKIN. That's one of the things that's supposed to be worked out in the guidelines. Obviously sometimes it will fall on a Saturday or Sunday, so you'll do it on a Friday or Monday, or something like that, I suppose.

Secretary SPELLINGS. Right, right.

Senator HARKIN. I think Senator Byrd just wants to know what your plans are for this.

Secretary SPELLINGS. Right, absolutely, and I will get back to him on that. We do have a working group working on this matter; obviously OPM is on the case also, so I'll report back.

#### CLOSING REMARKS

Senator HARKIN. Madame Secretary, that's all the questions I have, I don't have any other questions from any other Senators, if there's anything else that you'd like to leave with us here, I'd be glad to make sure we have it in the record, if there's anything else.

Secretary SPELLINGS. I've submitted a statement for the record, Senator. Thank you very much for your hospitality, and I appreciate it.

Senator HARKIN. Thank you, Madame Secretary, for being here and being forthright with your answers to the questions, and I look forward to this further submission to the record of those things that we asked about.

Secretary SPELLINGS. Will do, absolutely.

#### STATEMENT OF SENATOR MARY L. LANDRIEU

Senator HARKIN. We have received the prepared statement of Senator Mary L. Landrieu which will be placed in the record.

[The statement follows:]

#### PREPARED STATEMENT OF SENATOR MARY L. LANDRIEU

Thank you very much, Secretary Spellings for giving us your time today. We appreciate your visit to Capitol Hill to help explain some of the budget decisions that were made by the Administration. Also, let me offer you my congratulations and best wishes as you begin your new position as Secretary of the Department of Education.

There is no greater investment we can make in our future than in the education of our children. President John F. Kennedy once said, "Our progress as a nation can be no swifter than our progress in education. The human mind is our fundamental resource." He was right; if we are to succeed, we must make education the forefront of our agenda. We must work to raise academic achievement in our public schools by putting the priority on performance instead of process, delivering results instead of developing rules, and on actively encouraging bold reform instead of passively tolerating failure.

The passage of No Child Left Behind (NCLB) Act in 2001 reaffirmed Congress' commitment to be a more equal partner, instead of a major impediment, to real education reforms. However, the Administration's budget for fiscal year 2006 has not lived up to this promise and as a result they continue to leave children behind. This year, the Bush budget will create a budget shortfall of almost \$9 billion for Title I funding under NCLB. As you know, Madam Secretary, Title I funding makes it possible for all children, regardless of economic background, to have access to a high quality education. In Louisiana, this shortfall will translate to over \$212 million in funding not getting to local educational agencies in Louisiana and leaving behind 66,656 Title I students in the state.

Investing in our children is critical to the well-being of our country. While investments in education without accountability are a waste of tax-payer dollars, accountability without strategic investments in education is a waste of time. If the promise of No Child Left Behind is to be truly fulfilled, we must not only continue the reforms begun under NCLB, we must fully invest in them. Requiring states to meet

new, higher standards is a move in the right direction, but we must provide states with the resources they need to meet these new standards. Every year since the passage of NCLB, the budget shortfall for education spending offered by this Administration has increased. Making sweeping reforms, while robbing states of the resources they need to implement the reforms, is the way that states become left behind in education. The promise to "Leave No Child Behind" is an empty one unless we are willing to make the critical investments necessary to support our nation's children.

What is almost more disturbing than the Administration's lack of interest in fulfilling the promise it made to American students 4 years ago, is the fact that the Administration continues to make new empty promises. This year, the President has proposed a new high school initiative as part of the education budget. He has proposed that \$1.24 billion be spent on the High School Intervention program. I have no objection to the idea behind this program, and wholeheartedly agree with the President that we must work to improve the education standards in our high schools. I do, however, take issue with fact that this new promise is being made when the old promises have yet to be fulfilled.

Empty promises are not only being made in elementary and secondary schools, Madam Secretary. The President's budget includes \$33 million for Enhanced Pell Grants. This increase in Pell Grant funding is exciting, as we should be increasing opportunities for all students to attend a college or university. However, as the adage goes, you cannot steal from Peter to pay Paul. While there is an increase in Pell Grant funding, there have been significant reductions made to college preparatory programs, such as TRIO. In Louisiana, there are currently fifty-nine TRIO programs, and over 17,700 students are currently participating in them. The merits of TRIO have been widely proven. Students who participate in the Upward Bound TRIO program are four times more likely to earn an undergraduate degree than students from similar backgrounds that do not participate in TRIO. In a state like Louisiana, where poverty continues to serve as a barrier to higher education, it is of the utmost importance that we provide all possible services to our students to encourage their pursuit of a college degree. Yet again, while the President highlights his commitment to higher education by increasing the Pell Grant funding, he fails to mention that that increase is coming at the expense of other higher education programs.

There's a story that I remember hearing when I was a little girl about a church in the suburbs of New Orleans. The church was small and its membership was not particularly high. There was a leaky roof on the church, and for anyone who has been to south Louisiana, you know that during hurricane season, the last thing you want is a leaky roof. The church had started raising money to fix the roof, when the preacher got the idea that in order to attract new members, they should buy a new organ. The organ they had was old and, according to the preacher, didn't do justice to the Sunday hymns. The preacher rallied the congregation around the new organ, and everyone forgot about the leaky roof. A year later, the congregation had raised enough money, and one Sunday afternoon, they all moved the organ in. Now it does not take a meteorologist to tell you, it rains almost everyday during the summer in Louisiana, and sure enough, it rained in that little town, and the church roof leaked, and when the congregation arrived Sunday morning, the new organ was wet and broken.

Madam Secretary, I would suggest that perhaps under your leadership, the Department of Education can finish out what it started before the rain comes and what improvements we've made get lost. Under NCLB we have identified the schools in need of improvements, now let's get about the business of improving them. We have identified the teachers who are under qualified, let's get about the business of getting them qualified. We have promised parents choices, let's get about the business of providing them.

Thank you, Madam Secretary.

#### ADDITIONAL COMMITTEE QUESTIONS

Senator HARKIN. 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

## NEW BUDGET RESOURCES

*Question.* The Administration's fiscal year 2006 budget proposes to extend No Child Left Behind to the high school level, by requiring States to test high school students in two additional grades. Studies have documented shortcomings in the preparedness of all high school graduates for work or college. However, funds proposed in the budget to support the high school reform initiative are generated through the elimination of GEAR UP, certain TRIO activities, and the vocational and technical education program. The Administration's goal of reforming high schools is important and laudable. However, eliminating popular and effective programs will make it more difficult to generate support for the Administration's reform proposal. Isn't the goal of helping States and local school districts prepare high school students for the 21st Century workforce and college worthy of new resources, even within a tight budget?

*Answer.* As I mentioned in my opening statement, the first goal of the President's 2006 request is fiscal discipline in terms of total discretionary and non-security spending. Doing our share in achieving that goal means we do not have new resources, overall, in our 2006 budget, and that means we had to make some tough decisions. And we tried to make those decisions not on the basis of popularity or politics, but based on the results produced by the investment of taxpayer dollars.

When we looked at the challenge of reforming our high schools and doing a better job of preparing our students for college and the workforce, we saw little evidence of a meaningful contribution by several current programs. Since we believe our High School Initiative holds greater promise of bringing about real change in the performance of our high schools, it made sense to re-direct funding from other, less-effective activities to the new program. Also, there is considerable flexibility in our High School Intervention proposal, and districts and schools that believe that college preparation and vocational activities are the most appropriate way to meet the needs of their high school students would be free to use funding under the new program to pursue such strategies.

## HIGH SCHOOL ASSESSMENTS

*Question.* The budget proposes \$250 million to pay for the costs of additional assessments proposed in the Administration's High School Reform initiative. According to GAO's report, Title I: Characteristics of Tests Will Influence Expenses; Information Sharing May Help States Realize Efficiencies (GAO-03-361, May 8, 2003) showed that costs for developing and administering tests could vary greatly. What is the basis for the request of \$250 million to pay for these additional assessments?

*Answer.* While test development and administration costs can vary widely, ESEA as reauthorized by NCLB already requires States to assess students in reading and mathematics at least once in the high school grades. The President's proposal would require testing high school students in those subjects in only two additional grades.

Under ESEA Section 1111(b)(3)(D) Congress authorized a total of \$2.34 billion over 6 years to assist States in developing the additional assessments required under NCLB. The additional requirement entailed implementation of assessments in reading and mathematics in each grade from 3rd grade to 8th grade (instead of once in each grade span of 3rd through 5th grade and 6th through 8th grade) plus implementation of science assessments once in each grade span of 3rd through 5th grade and 6th through 8th grade and once in high school. The NCLB requirements add up to 11 more assessments than were required prior to enactment of the Act.

The High School Assessments proposal, which calls for assessing students in reading and mathematics at least three times during high school, would require States to implement two new high school assessments in two subjects, for a total of four new assessments. The proposed funding level of \$250 million a year over several years will provide ample resources to implement the additional assessments. If, for instance, the Congress provides 4 years of funding for the high school assessments, that would equate to \$250 million per assessment (that is, \$1 billion divided by four assessments). This is slightly higher than the amount States received for the MCLB-required tests (\$2.34 billion divided by 11 assessments).

## COST OF ASSESSMENTS

*Question.* How much of the estimated cost of the new assessment requirements would this request meet?

*Answer.* While test development and administration costs can vary widely, the President anticipates that \$250 million a year from fiscal year 2006 through fiscal

year 2009 will cover a significant portion if not all the costs of developing the new assessments.

#### ACCOUNTABILITY UNDER HIGH SCHOOL INTERVENTION INITIATIVE

*Question.* The America Diploma Project recommended that States should not rely exclusively on large-scale assessments, because they “cannot measure everything that high school graduates need to know and be able to do.” How was this recommendation for States considered in the request for assessments specifically or more generally in the Administration’s High School Reform initiative?

*Answer.* While the American Diploma Project (ADP) did state that “graduation exams cannot measure everything that matters”, it recommended that States “measure what matters and make it count.” Consistent with the ADP recommendation, accountability under the High School Intervention proposal would be based on a range of student outcomes that include assessment scores as only one element of high school accountability. Other elements could include graduation rates, course completion, and enrollment in postsecondary education. The High School Intervention proposal would require States to establish clear, measurable goals and show significant improvements in student outcomes. The role of the expanded assessments would be to produce uniform, objective data for measuring student achievement and holding schools accountable for academic improvement of all high school students.

#### ADVANCED PLACEMENT

*Question.* The fiscal year 2006 budget includes \$51.5 million for the Advanced Placement program, an increase of \$21.7 million over the fiscal year 2005 level. This program helps States and school districts expose students, especially low-income and minority students, to more challenging coursework. Studies have found that a key predictor of success in college is exposure to high school coursework of academic intensity and quality, which is why I supported an increase of \$6.2 million or 11.6 percent for this program in fiscal year 2005. What is the biggest challenge school districts must overcome to expose all of their students to challenging courses that prepare students for work or college, in particular those districts that educate large numbers of low-income students and how will these funds and others in the fiscal year 2006 request help address those challenges?

*Answer.* School districts, especially those that educate large numbers of low-income students, face several challenges in creating a pipeline that prepares students for Advanced Placement (AP) and International Baccalaureate (IB) coursework and exams. First, districts need to realign their curriculum so that students are taking challenging coursework in elementary and middle school that prepares them for AP and IB-level courses in high school. Second, districts need to identify and recruit under-represented students, such as low-income and minority students, to enroll in the challenging courses. Third, districts need to provide professional development for teachers, to help them gain the content knowledge and pedagogical skills to instruct students in AP and IB courses. Finally, districts often need to find and implement creative solutions to increase capacity for AP and IB coursework in schools with low-income students, such as on-line coursework and partnerships with institutions of higher education. The funds in the fiscal year 2006 request would allow the Department to award grants to State educational agencies (SEA), local educational agencies (LEA), and national nonprofit educational entities to deal with each of these issues.

#### IMPACT OF THE ADVANCED PLACEMENT PROGRAM

*Question.* This year, the Department must submit a report on the impact of the Advanced Placement program. Do you have anything to share at this moment about the impact of the program?

*Answer.* The Department will submit a report to Congress on the impact of its Advanced Placement program later this spring. The report will show that, nationwide, the number of students participating in AP and IB is increasing. From 2000 to 2004, the percentage of all high school students who took an AP exam rose from 15.9 percent to 20.9 percent. Also, the percentage of all high school students who scored 3 or above on an AP exam rose from 10.2 percent to 13.2 percent.

As overall participation has risen, participation by minority and low-income students has increased as well, but the access gap continues to persist. For example, students attending smaller schools and higher-poverty schools have less access to AP and IB. Also, black, Native American, and economically disadvantaged students participate in AP courses and exams at a lower rate than the national average.

## READING BY THIRD GRADE—READING FIRST PROGRAM

*Question.* President Bush committed to providing \$5 billion over a 5-year period for the Reading First program, which helps students read at least on grade level by the end of third grade. If Congress approves the \$1.042 billion included in the fiscal year 2006 budget request, this 5-year funding goal will be achieved. Is progress being made toward achieving the President's goal of all students reading on grade level by the end of third grade?

*Answer.* Reading First is the largest and most focused early reading initiative this country has ever undertaken. Although it is in its early stages of implementation, its impact is being felt across the country. Reading First provides an opportunity for every State to implement reading programs based on scientifically based reading research. Effective early reading instruction can prevent the difficulties that too many of our students, especially disadvantaged students, now face. Through Reading First, States have an arsenal of proven instructional methods, professional development, and proven interventions to increase the proportion of students who read on grade level by the end of the third grade.

While State-level performance data will not be available until the summer of 2005, there are already very encouraging signs from around the country. For example, less than a quarter of students in first grade at Lowell Elementary School in Mesa, Arizona met the school's benchmark on a national reading assessment in 2003. The students, tested again in 2004 while in second grade, fared considerably better, with almost half meeting the benchmark. School officials, teachers, and parents credit the Reading First program as being an instrumental force behind this improvement. Schools around the country report similar outcomes as students in some of our Nation's neediest schools receive the intensive instruction necessary to help close the achievement gap in reading.

## CORE COMPONENTS OF READING INSTRUCTION

*Question.* How have these funds been used to implement scientifically-based reading instruction?

*Answer.* In order to receive a Reading First subgrant, a local educational agency (LEA) must demonstrate that its core reading curriculum reflects the five essential components of reading instruction, as identified by the April 2000 *Report of the National Reading Panel*. These components are phonemic awareness, phonics, vocabulary development, fluency, and comprehension. Reading First also provides professional development to more than 90,000 K-3 teachers, ensuring that all teachers, including special education teachers, have the skills they need to teach reading and monitor student progress effectively in Reading First classrooms. In addition, the progress of students in Reading First classrooms is closely monitored through valid and reliable assessment instruments so that immediate intervention can prevent students from falling behind.

## ARTS IN EDUCATION

*Question.* The budget proposes to eliminate the Arts in Education program, which was funded at \$35.6 million in fiscal year 2005. In a recent study by the Council for Basic Education, a nonprofit organization that advocates for liberal arts subjects, 25 percent of principals reported decreases in the time their schools devote to the arts and 33 percent expect decreases in the next 2 years. These changes have impacted poor minority students the hardest as 36 percent of principals in schools with large percentages of minority students reported reduced instructional time for the arts, while 42 percent anticipate future decreases. According to the report *Champions of Change*, students who participate in the arts outperform those who don't on virtually every measure. In addition, researchers have found that "sustained learning" in music and theater correlate to greater success in math and reading, and students from lower socioeconomic backgrounds see the greatest benefits. Isn't it important to maintain a Federal commitment to fund arts education, given different student learning styles and interests and the proven benefits of instruction in the arts?

*Answer.* The arts play a significant role in education both for their intrinsic value and because of the ways that they can enhance general academic achievement and improve students' social and emotional development. No Child Left Behind includes arts as a core academic subject and holds arts teachers to the same high standards as it does those who teach English, math, science, and history.

There are a variety of opportunities for districts and schools to include the arts in instruction. Districts seeking to implement arts education activities can use the funds they receive through the Improving Teacher Quality State Grants program to

carry out professional development activities that improve the knowledge of teacher and principals in core academic subjects, including the arts. Additionally, districts may use their funds under the State Grants for Innovative programs to support programs in the arts. Lastly, the arts can also be an important part of learning and enrichment in programs supported by the 21st Century Community Centers program funds by involving cultural partners in the community, such as arts centers, symphonies, and theaters. The Administration's 2006 budget request would continue strong support for all of those programs.

#### EDUCATIONAL TECHNOLOGY

*Question.* According to the Education Commission of the States Report to the Nation on the Implementation of No Child Left Behind, "Many states do not have in place the technology infrastructure needed to collect, disaggregate and report data at the school, district and state levels. NCLB doesn't require the development of statewide data systems but, without them, states will have difficulty meeting a number of the law's requirements." Further, the Department's National Education Technology Plan identified Improving Teacher Training as a recommendation and also stated that, "Teachers have more resources available through technology than ever before, but some have not received sufficient training in the effective use of technology to enhance learning." Given these recent findings and recommendations, why does the budget propose eliminating the Education Technology State Grant program, the only remaining Federal source of funds dedicated to addressing these issues?

#### EDUCATIONAL TECHNOLOGY

*Answer.* The fiscal year 2006 budget request supports the Administration's policy of eliminating categorical programs that have a narrow or limited effect in order to increase support for high-priority programs. Educational technology needs can be addressed by using other sources of Federal funds. For example, districts may use their funds under the Improving Teacher Quality State Grants program to implement professional development programs that train teachers and principals to integrate technology into curricula and instruction in order to improve teaching, learning, and technology literacy.

While developing and operating statewide student data systems are allowable activities with Education Technology State Grant funds, there is little evidence that States use these funds for that purpose. This elimination of the program should not affect States' activities in this area. In order to address the States' need to develop effective longitudinal data systems, the Department has requested continued funding for the Statewide Data Systems program. Continuation of this program will allow States and local educational agencies to use assessment and other data to identify struggling students and track their progress while complying with the requirements of No Child Left Behind.

*Question.* In Pennsylvania, \$22 million of the \$23 million spent specifically on educational technology is generated by the Education Technology State Grant Program and an independent evaluation conducted by Metiri Group and Penn State University found that many of Pennsylvania LEAs are experiencing significant improvements in teacher skill level and student performance because of the funds available through this program. How will Pennsylvania continue to make the kind of progress identified by the evaluation without these resources, especially given the reduction in or elimination of other sources of Federal funds that may be transferred for use under this program?

*Answer.* The Administration recognizes that Pennsylvania, like many States across the country, is facing a difficult budget situation. However, the flexibility provisions in No Child Left Behind allow districts to make use of their Federal assistance by permitting them to more efficiently allocate resources to address their particular needs. Pennsylvania districts will thus continue to be able to use Federal assistance for technology purposes.

#### LEVERAGING EDUCATIONAL ASSISTANCE PARTNERSHIPS

*Question.* The Leveraging Educational Assistance Partnerships program has generated significant State need-based aid through matching funds that totals nearly \$1 billion. Why does the fiscal year 2006 budget propose to eliminate the \$65.6 million in funding for the Leveraging Educational Assistance Partnerships program despite the fact that it is the only Federal program designed to expand the amount of need-based student aid provided by States?

*Answer.* We believe the best way to foster college access and completion is to concentrate resources on Pell Grants, the largest and most need-based Federal grant

program. There is no reason to continue to use scarce resources on LEAP, since Federal assistance is no longer needed to encourage States to provide need-based grant and work-study assistance.

#### STATE PROGRAMS OF UNDER-GRADUATE NEED-BASED STUDENT GRANTS

*Question.* While it is true that funds exceed the matching requirement, don't you believe there should be a Federal role in supporting continued and expanded State need-based aid programs that help all students access and complete college?

*Answer.* When the program was first authorized as the State Student Incentive Grant program in 1972, 28 States had undergraduate need-based grant programs. Now all but two States have need-based student grant programs. The continued existence of the LEAP program has not encouraged the two remaining States to institute State grant programs.

#### STUDENT AID ADMINISTRATION

*Question.* What are the specific administrative challenges associated with the current funding structure and how would a single discretionary appropriation address those challenges?

*Answer.* Funding identical student aid administrative activities from multiple sources creates substantial additional complexity with no additional value for managers or oversight organizations such as Congress, GAO, or Department auditors. A single funding source would result in a process that is both significantly simpler and substantially more transparent.

#### ADJUNCT TEACHERS AND HIGHLY QUALIFIED TEACHERS

*Question.* The budget proposes \$40 million for a new program, the Adjunct Teacher Corps. This program would provide grants to place non-certified teaching professionals in the classroom and allow them to teach on a full or part-time basis. How does this new program, which proposes allowing unlicensed or uncertified teachers, fit with Congress' and the Administration's emphasis on highly qualified teachers in every classroom as envisioned under the No Child Left Behind Act?

*Answer.* The \$40 million request in the 2006 budget for a proposed Adjunct Teacher Corps initiative would provide competitive grants to partnerships of school districts and appropriate public or private institutions to create opportunities for professionals to teach secondary-school courses in the core academic subjects, particularly in mathematics and science.

Grants would be used to: (1) identify, as adjunct teachers, well-qualified individuals outside of the K-12 educational system, including outstanding individuals at the height of their careers in business, government, foundations, and colleges, and (2) facilitate arrangements for them to function in this capacity, for example, by teaching one or more courses at a school site on a part-time basis, teaching full-time in secondary schools while on leave from their jobs, or teaching courses that would be available online or through other distance learning arrangements. In some cases, this initiative would provide opportunities for individuals to substitute teach in hard-to-fill positions.

The intent of the Adjunct Teacher Corps initiative is not to bring more highly qualified teachers into the classroom on a permanent basis, but rather to integrate their knowledge and experience into classroom learning. Although potential participants would typically not be certified or licensed to teach in secondary schools, they often have a wealth of knowledge, skills, and professional experiences and would be able to provide real-world applications for some of the abstract concepts taught in classrooms. Adjunct teachers who are not employees of a school district would not be covered by the NCLB "highly qualified teacher" requirement. On a temporary basis, these teachers would give school districts opportunities to strengthen instruction in secondary schools in the core academic subjects, especially mathematics and science.

#### EVEN START AND FAMILY LITERACY

*Question.* The budget request proposes to eliminate the \$225 million Even Start program. This program successfully supports family literacy programs, which are comprised of adult education, parent education, parent-child activities and early childhood education activities. This concept has shown positive results and was strengthened by the reauthorization of the program under No Child Left Behind. The Administration has pointed to national evaluations conducted of the program as it existed prior to the reauthorization as evidence that it is ineffective. Madam

Secretary, why are you proposing to eliminate this program based on evaluations that do not reflect the outcomes being achieved currently?

Answer. Although the *No Child Left Behind Act of 2001* strengthened some components of Even Start, these changes did not alter the structure or design of the program. Although some local projects may be successful, the overall effectiveness of Even Start remains very questionable. The 2000 Literacy Involves Families Together (LIFT) Act, which authorized Even Start prior to the No Child Left Behind Act, included language encouraging local projects to hire more qualified staff, to use instructional programs that are based on scientifically based research, and to increase the focus on evaluation. However, the changes made through LIFT and later NCLB did not alter the basic elements of the program, and a new evaluation would most likely yield the same results as the first three.

While the premise underlying the Even Start program is attractive, the extent to which family literacy programs can enhance parent literacy and parenting skills is still unknown. The Administration believes that we should redirect the resources now available for Even Start to programs such as Reading First and Early Reading First that are based on a sound, scientifically based approach and are better focused on achieving their goals of improving the literacy skills of young learners.

#### ADULT EDUCATION

*Question.* Currently, nearly half of the adults in Pennsylvania have limited literacy skills. Among individuals who are receiving welfare, are incarcerated, or the long term unemployed, 70 percent have limited skills. Based on the overall reduction proposed in the fiscal year 2006 budget, Pennsylvania programs would lose \$14 million, or 75 percent, of Federal funds for adult education and literacy programs. The fiscal year 2006 performance plan for the Department of Education sets performance targets for the percentage of adults with a high school completion goal who earn a diploma or its equivalent at 46 percent in fiscal year 2005 and 47 percent in fiscal year 2006. How does the Department intend to help States make progress toward the Department's performance goals with 65 percent less funding overall?

Answer. As with K-12 education, adult education is funded primarily through State and local resources, and Federal funds are meant to supplement, not supplant, local efforts to provide educational services to high school dropouts, immigrants, and low-literacy adults. According to data collected by the Department, the Federal Government contributed approximately 26 percent of total adult education program funding in 2003. The budget request also recognizes the importance of addressing the English-language needs of our Nation's immigrant population and therefore includes level funding for the English Literacy and Civics Education (EL/Civics) component of the program, which will support States in addressing the educational needs of their limited English proficient (LEP) populations. Pennsylvania is expected to receive approximately \$1.4 million for EL/Civics grants in 2006.

The Department will continue to provide States and local providers with technical assistance, research and implementation support, and curricular guidance for adult education programs. Through these activities, the Department will enhance the effectiveness of local adult education programs and thus help them to successfully attain the performance goals set by the Department.

#### MATH AND SCIENCE PARTNERSHIPS PROGRAM

*Question.* The fiscal year 2006 budget proposes to reduce funding to States for math and science partnerships in order to provide a set-aside of \$120 million for direct grants to school districts for math programs for secondary students. States are currently using their funds to run competitions that in some cases give a priority to applicants that seek to improve math achievement of middle and high school students. If States are designing their competitions with a priority to address mathematics achievement of secondary students, why should Congress reduce funds for States that best know how to address the educational needs of their school systems?

Answer. For fiscal year 2006, the Administration is requesting \$269 million for the Mathematics and Science Partnerships program, a \$90.4 million increase over the 2005 appropriation. Of the total amount, \$120 million would be used for direct grants to LEAs to accelerate the mathematics achievement of secondary-school students and \$149 million would be awarded to States by formula. The amount provided through formula grants would be a reduction of \$29.6 million from the 2005 level.

American students' poor performance on national and international mathematics assessments, such as the National Assessment of Educational Progress and the 2003 Program for International Student Assessment, provides a compelling rationale for



an intensive, targeted initiative to strengthen the mathematics skills of our middle- and high-school students, especially low-achieving students. The direct competitive grants requested in the budget would focus on ensuring that States and school districts provide professional development that is strongly grounded in research and that helps mathematics teachers become highly qualified. The Administration believes that it is critical to target funds directly to high-quality secondary-school mathematics projects, thus justifying the decrease in formula grants, which would not, as the program is structured, generate the type of intensive focus in secondary-school mathematics achievement that is clearly needed. The remaining funds for the formula grants would allow partnerships to conduct other important activities to improve student achievement, including activities that focus on science and elementary-school mathematics.

*Question.* Why would a direct grant program out of Washington, D.C. be more effective at improving mathematics achievement than a State-based approach that is consistent with the authorization for this program?

*Answer.* The competitive grants would support projects that have significant potential to accelerate the mathematics learning of all secondary students, but especially low-achieving students. This initiative would focus on ensuring that States and LEAs implement professional development projects for mathematics teachers that are strongly grounded in research and that help teachers to improve their instruction in mathematics.

The Administration believes that it is critical to fund efforts specifically to accelerate mathematics learning at the secondary level by helping secondary students master challenging curricula and by increasing the learning of students who have fallen behind in mathematics. Research indicates that many students who drop out of school lack basic skills in mathematics, and our Nation needs to support these students so that they can catch up to their peers and stay in school.

#### CIVIC EDUCATION

*Question.* Funding for the Education for Democracy Act—supporting both domestic and international civic education programs—was eliminated in your budget and that program has successfully helped American students understand and appreciate our fundamental values and principles. This funding also supports a school violence prevention program that has had results in rural and urban settings throughout the country. The international exchange program has been very successful in helping emerging democracies establish an education for democracy program in their schools, so students would begin to understand basic concepts such as the rule of law, the protection of minority rights, and respect for diverse religions and races. The democracy curriculum created from the international exchange program is the only curriculum used in schools throughout Bosnia by all three ethnic groups, the Serbs, the Bosnians, and the Croats. This unique international program is having similar success in more than 60 countries including Russia, Indonesia, and nine countries in the Middle East. Madam Secretary, can you comment on why a program that is consistent with the Administration's desire to advance the ideals of democracy was eliminated from your budget this year?

*Answer.* The request for this program is consistent with the Administration's intent to increase resources for higher priority programs by eliminating small categorical programs that have limited impact, and for which there is little or no reliable evidence of effectiveness. Less than 5 percent of funds (approximately \$1.5 million in fiscal year 2005) available through the Civic Education program support activities specifically related to school violence prevention. The Administration believes that a more effective approach to addressing school violence is to invest in Safe Schools/Healthy Students grants—which would receive \$88.5 million under the 2006 request—to create safe, disciplined, and drug-free learning environments.

Likewise, only a tiny fraction of funds designated for the Cooperative Education Exchange support summer workshops and other activities related to democracy in Bosnia. But, since the Dayton Accords of 1995, the U.S. Department of State and U.S. Agency for International Development have played a key role in promoting democracy in Bosnia and Herzegovina, providing hundreds of millions in support and critical expertise in everything from revitalizing the infrastructure to promoting democratic reforms of education and the media. Further, through the cooperative efforts of American and European Union governments, in 2003 a common curriculum was adopted by all education ministers in Bosnia and Herzegovina. It may have once been true that the Civic Education Project Citizen curriculum was "the only curriculum used in schools throughout Bosnia by all three ethnic groups;" however, it is our understanding that the adoption of a common curriculum in 2003 marked the end of rigid ethnic and religious separation in schools, and that Serbs, Bosnians,

and Croat students now routinely pursue shared courses of study in mixed schools and classrooms.

While the Civic Education program supports some worthwhile activities, there are no reliable measures of the overall effectiveness of interventions supported using program funds. Studies and evaluations conducted by the Center for Civic Education provide limited information on program performance, but none are sufficiently rigorous to yield reliable information on the overall effectiveness or impact(s) of the various interventions supported through this program. Additionally, because one statutorily designated entity receives approximately 75 percent of all Civic Education funds during any single fiscal year, the program's contribution to the Department's overall mission is marginal.

The Administration does not believe additional funding is necessary for the implementation of activities currently supported through this program. The Center for Civic Education is an established non-profit organization with a broad network of program participants, alumni, volunteers, and financial supporters at the local, State, and national levels. The Center also has a long history of success raising additional support through such vehicles as selling program-related curricular materials, trainings, and workshops, partnering with non-profit groups on core activities, lobbying, and seeking support from foundations.

#### SPECIAL EDUCATION TEACHER SHORTAGE

*Question.* The shortage of certified special education teachers is reaching very high levels and the issue needs to be addressed in order to ensure that all students are challenged in school and receive the same high level of education. Several statistics illustrate the point: half of new special education teachers leave the classroom within 3 years; 98 percent of school districts report shortages of special education teachers; in 2002 our nation produced only 213 doctorates in special education; and one out of three faculty openings in special education go unfilled—diminishing the capacity of universities to train special education teachers. What does the fiscal year 2006 budget propose to address this critical shortage?

*Answer.* Recent studies suggest that the on-going special education teacher shortage is affected by a number of factors, including special education teacher turnover rates, changes in the number of children with disabilities served under IDEA and Section 504, teacher training program enrollments and graduation rates, and the extent to which teacher training programs actually prepare teachers for the challenges they will face in the classroom. The fiscal year 2006 budget addresses the problem through multiple IDEA programs, including Grants to States, for which \$11.1 billion is requested, and Personnel Preparation, for which \$90.6 million is requested. SEAs and LEAs have the authority under IDEA to use Grants to States funds for a wide variety of personnel-related activities, including supporting personnel training and professional development and implementing plans to meet personnel shortages. Approximately 90 percent of Personnel Preparation program funds support grants to IHEs for the purpose of improving program curricula and making training and professional development scholarships. Such awards are targeted to improve both the quality and quantity of training for special education teachers and related services personnel. Individuals receiving scholarship assistance through projects funded under program are required to fulfill a 2-year service obligation or repay all or part of the costs of such assistance. This program also currently funds several projects that promote teacher retention through mentoring activities. Repayment obligations and mentoring programs are designed to aid in the retention of beginning special educators, a group that studies have shown to be particularly prone to attrition.

It is worth mentioning that, for many years, one of the primary goals of Federal programs that support special education training has been to alleviate shortages by increasing the supply of special education teachers. However, except in certain isolated areas such as awards to train leadership personnel and personnel serving children with low-incidence disabilities, there is little evidence that these investments have resulted in measurable increases to the overall supply of special education teachers and related services personnel. For this reason, the fiscal year 2006 budget addresses the special education teacher shortage primarily by concentrating scholarship grant support in those areas where States and other investors have limited capacity and incentive to invest (e.g., supporting programs that prepare teachers of children with low-incidence disabilities and leadership personnel).

#### HIGHLY QUALIFIED SPECIAL EDUCATORS

*Question.* What is your plan to ensure that all students benefit from having a highly qualified teacher in their classroom?

Answer. The No Child Left Behind Act of 2001 (NCLB) emphasizes teacher quality as one of the primary factors contributing to improved student achievement. Consistent with this emphasis, and to better equip States for the critical task of ensuring that all teachers of core academic subjects are highly qualified, the Department has dedicated significant resources to such activities as providing on-going technical assistance and developing guidance that clearly articulates how the highly qualified teacher provisions affect all teachers and related personnel, including special educators. As part of an extensive outreach effort on the highly qualified teacher provisions, the Department recently sent a cadre of experts called the Teacher Assistance Corps to each State to clarify the highly qualified requirements, provide technical assistance, and capture promising implementation strategies. Many of these practices are available now through the [www.teacherquality.us](http://www.teacherquality.us) Web site, and more will be added as the Department continues to visit States as part of its highly qualified teacher monitoring. Any State that requests additional technical assistance on the highly qualified teacher requirements as they apply to special education teachers will receive such help. Through the Teacher-to-Teacher initiative, the Department also supports teacher roundtables, regional workshops, a national Research-to-Practice Summit, and electronic teacher video training modules. The Teacher-to-Teacher Web site, at [www.paec.org/teacher2teacher](http://www.paec.org/teacher2teacher), offers on-demand professional development in the latest research-based practices.

Because the recently reauthorized IDEA incorporates the ESEA definition and standards relating to highly qualified teachers with only slight modifications, the Department plans to continue its current focus on working with SEAs and LEAs towards the goal of ensuring that all students benefit from having a highly qualified teacher in their classroom. In addition to such on-going activities, consistent with this focus on highly qualified teachers, in announcing recent competitions for new Personnel Preparation competitive awards the Secretary emphasizes that the Department is interested in funding training programs that prepare highly qualified special educators. By emphasizing these requirements in new awards to grantees training special education personnel, the Department expects to gain critical insights into the most effective and efficient ways of ensuring that program curricula and professional development requirements are aligned with and support the highly qualified teacher requirements.

#### STATE SCHOLARS CAPACITY BUILDING

*Question.* The budget proposes \$12 million in fiscal year 2006 for State Scholars Capacity building. Congress has not provided funds specifically for this purpose previously, but the Department has supported State Scholars Partnerships through funding available under Vocational Education National Programs. With the additional funds requested in fiscal year 2006, subgrants would be made to support State Scholars Partnerships in 26 States. Research has demonstrated that students who complete a rigorous course of study during high school are better prepared to be successful in college and the workforce. Specifically, what are the findings from any evaluation that has been conducted on State Scholar projects?

Answer. Since 1992, the Scholars Initiative has been piloted in local communities within several U.S. states, including Arkansas, Oklahoma, Tennessee, and Texas. We are seeing some good early results in the States and communities that have launched Scholars initiatives. Enrollment in Algebra I and Geometry at Little Rock high schools, for example, rose 6 and 8 percent, respectively, in the district's first year of participation in Arkansas Scholars. However, only one State, Texas, has implemented the State Scholars Initiative statewide for a long enough period for us to begin to examine long-term outcomes. The percentage of Texas high school students who completed the Scholars' recommended course of study rose from 15 percent in 1999 to 63 percent in 2003 (Texas Education Agency, Academic Excellence Indicator System, 2003). We find this highly encouraging, although we cannot attribute these outcomes solely to Texas State Scholars initiative. While students and parents found the recommendations of the Texas Business and Education Coalition to be compelling, and students then increased their enrollment in challenging academic courses, State policy-makers also began to recognize the importance of providing all students with a rigorous academic education. Accordingly, they phased out lower-level graduation requirements in favor of graduation requirements that aligned with the Scholars academic core.

#### PUBLIC SCHOOL CHOICE REQUIREMENT OF THE NO CHILD LEFT BEHIND ACT

*Question.* Reports by The Government Accountability Office, Education Commission of the States and others have documented the challenges school districts face in meeting the public school choice requirement of No Child Left Behind. In re-

sponse to a December 2004 report on the implementation of the No Child Left Behind Act, the Department identified Parental Information and Resource Centers and grants funded under the Fund for the Improvement of Education as sources of outreach and information to parents on a national level about the school choice option. The response stated further that, "We know that our efforts have led to parents learning about, and taking advantage of, their opportunity to transfer students. Much remains to be done, however." What is the Department doing currently and proposing in the fiscal year 2006 budget to help States and school districts effectively implement this provision of the law?

PARENTAL INFORMATION AND RESOURCE CENTERS

Answer. On the budget side, the need to support local efforts to implement the public school choice requirements of No Child Left Behind has been a key rationale for the consistently large increases President Bush has requested for Title I Grants to Local Educational Agencies. With Title I funding up \$4 billion, or 45 percent, over the past 5 years, we believe school districts have sufficient resources to carry out public school choice. And of course we are asking for \$600 million more in 2006.

The bigger challenge has been providing effective technical assistance and guidance to States and school districts. We have published detailed guidance on the public school choice provisions and distributed that guidance widely to key groups, including through presentations and workshops on public school choice at the National Title I Directors Conference, as well as conferences of the Black Alliance for Educational Options, National Alliance of Black School Educators, and National Association of Federal Program Administrators. We plan to continue these efforts at many other conferences during the coming year.

In addition, we have published several "Innovations in Education" guides related to public school choice, including "Creating Strong District School Choice Programs," "Creating Successful Magnet School Programs," and "Successful Charter Schools." The Department has disseminated and presented on these guides widely, and our web site contains information on No Child Left Behind choice options in a variety of formats.

We are currently developing an Interactive Toolkit on Choice that will include tools, templates, and models used by school districts that are successfully implementing public school choice. We also are planning a two-day Train-the-Trainers Conference on Public School Choice intended to expand the number of experts available nationwide to provide technical assistance to districts on public school choice.

NCLB choice options continue to be a key focus of State and local monitoring visits, where we pay special attention to outreach efforts by districts to make parents aware of public school choice. Finally, determining and disseminating the best practices for informing parents about choice options will be a key goal for our new technical assistance centers.

PARENTAL INFORMATION AND RESOURCE CENTERS

*Question.* Why does the Department propose to terminate funding for the Parental Information and Resource Centers program, just months after identifying them as a resource that has helped parents take advantage of their right to transfer their child to a higher performing public school?

Answer. While the Parental Information and Resource Centers (PIRCs) make a limited contribution to informing parents about choice options under the No Child Left Behind Act, the overall structure of the centers limits their effectiveness. For example, one problem with the PIRCs that has been highlighted by the Administration's Performance Assessment Rating Tool is the multiple purposes served by the program, which prevent the kind of focused, tailored delivery of services that can have a meaningful impact in achieving program goals.

We believe the parental involvement and outreach goals of No Child Left Behind are more effectively met through the existing requirements under Part A of Title I for the some 15,000 participating Title I districts and schools, which include not only parental involvement activities but school improvement-related reporting and outreach specifically intended to help parents take advantage of NCLB choice options. The Department continues to work with States and districts to improve the effectiveness of these Part A-funded activities, through both ongoing technical assistance and on-site monitoring visits. The PIRCs activities largely duplicate such efforts, as well as those of the comprehensive technical assistance centers currently under competition, at a time when we must make tough decisions about the best way to invest scarce resources in the most effective manner possible.

## PELL GRANTS

*Question.* The Administration proposed to add \$5.6 billion to the Pell Grants program in fiscal year 2006, \$867 million of which is discretionary and the remaining \$4.7 billion is mandatory spending proposed in the reauthorization of the Higher Education Act. The Administration has proposed a very important investment. What will be the impact of the proposal on the typical students receiving a Pell Grant?

*Answer.* The maximum Pell Grant would increase by \$100 in fiscal year 2006 and by \$500 over the next 5 years. The Administration's budget invests \$19 billion in new funding over the next 10 years to increase grants to low-income students, helping them finance their postsecondary education.

*Question.* How will you pursue this important investment if the Higher Education Act is not reauthorized this year?

*Answer.* The Department's comprehensive student aid proposals would best be implemented through the reauthorization of the Higher Education Act; we will work closely with Congress on these important changes.

## LOANS FOR SHORT-TERM TRAINING

*Question.* The fiscal year 2006 budget includes \$10 million for a new loan program to help dislocated, unemployed, or older workers upgrade their skills. These individuals are not eligible for Federal student loans. This program will be jointly administered with the Department of Labor and could help more than 350,000 individuals acquire the skills they need for work. Madam Secretary, I applaud the Department for this important new initiative, since these individuals are not eligible for Federal student loans and many need help to upgrade their skills. If this new program is approved, how quickly could this new program be implemented?

*Answer.* If this new program is approved, the Department expects to make loans in fiscal year 2006.

*Question.* How will your Department coordinate with the Department of Labor on this program?

*Answer.* The two departments will soon be submitting details on this program specifying each agency's roles and responsibilities. The proposal envisions the Departments of Labor and Education as operating partners, each bringing their particular expertise to the process of expanding training opportunities for American workers.

## TEACHER INCENTIVE FUND AND TEACHER TRAINING

*Question.* The budget request proposes to create a new \$500 million Teacher Incentive Fund, which would change the way teachers are paid and allow schools to use funds to recruit teachers to high-need schools. The existing \$2.9 billion Teacher Quality State Grant program allows school districts to use funds for both of these activities. The Administration should be commended for the proposed increase in funding to support our nation's educators. Why have you proposed to create a new \$500 million program that is the same as an existing program?

*Answer.* The Administration is requesting \$500 million for the Teacher Incentive Fund initiative to allow States and school districts to develop and implement innovative ways to provide financial incentives for teachers who raise student achievement and close the achievement gap in some of our Nation's highest-need schools, to attract highly qualified teachers to those schools, and to redesign teacher compensation systems in order to align pay with performance. This is a different mission from that of the Improving Teacher Quality State Grants program, which focuses mostly on enabling teachers to become "highly qualified."

Under No Child Left Behind, all States are working to ensure that, by the end of the 2005-2006 school year, all classes of the core academic subjects are taught by highly qualified teachers. Funds are available under several formula grant programs, including Improving Teacher Quality State Grants, for professional development and other expenses needed to enable States and school districts to achieve that objective. But the Teacher Incentive Fund will take the national commitment to ensuring a continued high-quality teaching force one important step further by providing significant, dedicated Federal support for rewarding teachers for strong performance, encouraging highly qualified teachers to enter classrooms with concentrations of low-income students, and developing and implementing performance-based teacher compensation systems.

## TEACHER INCENTIVE FUND

*Question.* Can you explain why States and school districts need another source of Federal funds for recruiting teachers and reforming teacher pay systems?

Answer. Although States and school districts are authorized to use Title II Improving Teacher Quality State Grants funds to recruit teachers to high-need schools and to reform teacher pay systems, the Department has found that they seldom use Title II funds for those purposes. For example, a Department survey of districts' use of Title II funds in the 2002–2003 school year indicates that most of the funds were being used for professional development (25 percent) and for teacher salaries to reduce class size (58 percent), and the study also found that, of the remaining allowable activities, no single activity accounted for more than 3 percent of all reported Title II school district funds. In addition, recent monitoring visits to States and school districts suggest that States and school districts continue to spend most of their Title II funds on professional development. Based on these findings, it appears that States and school districts are not using their Title II funds to recruit teachers to high-need schools and to reform teacher pay systems, particularly given other competing needs for Title II funds to improve teacher quality.

Because the Administration believes that it is important for States and school districts to continue to conduct their existing Title II activities at current levels to improve teacher quality, the Administration is proposing additional funds, through the Teacher Incentive Fund, for efforts dedicated to rewarding effective teachers, offering incentives for highly qualified teachers to teach in high-need schools, and designing and implementing performance-based compensation systems that change the way school districts pay teachers. The \$500 million requested for the Teacher Incentive Fund will permit many more school districts to implement these types of reforms and provide a major incentive for needed changes in teacher compensation systems nationally.

*Question.* Why not add the \$500 million to the existing program?

Answer. The Administration believes that, by dedicating \$500 million specifically for teacher incentive efforts, many more States and school districts will develop and implement much-needed reforms in the way teachers are compensated in order to further improve teacher quality. Under the existing program, States are much less likely to implement these reforms.

#### NO CHILD LEFT BEHIND AND FLEXIBILITY

*Question.* While I support the No Child Left Behind Act, I believe there needs to be more state flexibility in the implementation of the Act, because each state has the knowledge of the particular challenges facing its education system, including accounting for students with learning, emotional and English language difficulties. Madam Secretary, you stated in your January 6, 2005 nomination hearing before the Senate Health, Education, Labor and Pensions Committee that, “We must stay true to the sound principles of leaving no child behind. But we in the administration must engage with those closest to children to embed these principles in a sensible and workable way.” Will you provide needed flexibility to Pennsylvania and other States?

Answer. I remain committed to my January 6 statement, Mr. Chairman. We are willing to carefully consider requests from States and school districts for additional flexibility in implementing No Child Left Behind, and we will work very hard to try and provide that flexibility. However, we must remain true to the law's core principles. Just to give you a couple of examples, I believe it would be very difficult—impossible really—to eliminate key requirements like annual testing or the use of subgroup accountability to determine adequate yearly progress.

On the other hand, I think you have already seen that we are willing to work with States in areas like the assessment of special education and limited English proficient students, and in ensuring that all teachers are highly qualified. I have met with experts in these areas and am working with senior Department officials to clarify our policies. So in answer to your question, we will provide flexibility wherever we can do so consistent with the law.

#### COLLEGE ENROLLMENT GAP—FEDERAL TRIO AND GEAR UP PROGRAMS

*Question.* Last year, I asked Secretary Paige what initiatives the fiscal year 2005 President's Budget supports to reverse the increasing college enrollment gap between low- and high-income students. As part of that response, Secretary Paige wrote that, “The Administration also supports strong academic preparation for post-secondary education and training through the Federal TRIO and GEAR UP programs. The Administration is proposing in fiscal year 2005 to spend \$1.13 billion for these two programs.” Why are TRIO's Talent Search and Upward Bound programs and GEAR UP now proposed for elimination?

Answer. The Administration has not requested funding for Upward Bound, Talent Search, and GEAR UP in the fiscal year 2006 budget because we believe our pro-

posed \$1.2 billion High School Intervention initiative would do a better job of improving high school education and increasing student achievement. Today, just 68 out of 100 9th graders will receive their diplomas on time. Moreover, only 51 percent of African-American students and 52 percent of Hispanic students will graduate from high school, and less than a third of students will leave high school ready to attend 4-year colleges. We believe a targeted and comprehensive approach is necessary to overcome these challenges.

#### HIGH SCHOOL INTERVENTION INITIATIVE

The new High School Intervention initiative would require each State to develop a plan for improving high school education and increasing student achievement, especially the achievement of low-income students and students who attend schools that fail to make adequate yearly progress. States would be held accountable for improving the academic performance of at-risk students, narrowing achievement gaps, and reducing dropout rates, but States would have flexibility to provide the full range of services students need to ensure they are academically prepared for the transition to postsecondary education and the workforce. The initiative also would deepen the national knowledge base on what works in improving high schools and high school student achievement by supporting scientifically based research on specific interventions that have promise for improving outcomes.

We believe this High School Intervention initiative would be more effective than our current, disjointed approach that has not served all students well. Replacing Upward Bound, Talent Search, and GEAR UP with a more targeted and comprehensive initiative would help us reach our strategic goals of improving the performance of all high school students and increasing access to postsecondary education. However, in the interest of minimizing the disruption of services to students, funding for the High School Intervention initiative would support existing TRIO and GEAR UP projects that would be eligible for continuation funding in fiscal year 2006.

#### UPWARD BOUND, TALENT SEARCH AND GEAR UP PROGRAM ASSESSMENTS

*Question.* What specific evidence leads you to a different conclusion about the importance of these funded activities?

*Answer.* While we agree that the activities supported by Upward Bound, Talent Search, and GEAR UP are important, the Administration's assessments of these programs have not found evidence that the programs are effective overall in helping disadvantaged students enroll in college. Moreover, we believe the new High School Intervention initiative would incorporate the best elements of these programs to achieve better results.

Evaluation findings demonstrate that Upward Bound projects serve low-income students who have unusually high educational expectations and who would enroll in college regardless of their participation in the program. The high college enrollment rate for these Upward Bound students (65 percent) hides the reality that only 34 percent of the neediest students served by Upward Bound enroll in college. Although the program could have a significant impact if it served more students who truly need help, we do not have evidence to show that our efforts to target more of the neediest students have been successful.

Similarly, we do not have evidence to demonstrate that GEAR UP and Talent Search increase college enrollment rates, even though both programs appear to have some positive effects. Data for GEAR UP and Talent Search show that both programs are meeting their short-term performance goals, evaluation findings for GEAR UP suggest that it has positive effects on middle school course-taking behavior and student and parent knowledge of postsecondary education.

#### HIGH SCHOOL INTERVENTION INITIATIVE

The new High School Intervention initiative would provide a more coordinated approach at the State level to ensure that the types of services currently provided under programs like GEAR UP, Talent Search, and Upward Bound are part of a broader effort to provide students with the full range of services they need in order to succeed. The initiative's emphasis on supporting scientifically based research would help ensure that resources are focused on those activities that are shown to have the most positive effects.

## QUESTIONS SUBMITTED BY SENATOR MIKE DEWINE

## SAFE DRUG-FREE SCHOOL COMMUNITIES

*Question.* The recommendation in the President's fiscal year 2006 budget request to "zero out" the State Grants portion of the Safe and Drug-Free Schools and Communities program will leave most of America's schools and K-12 students with absolutely no substance abuse prevention and intervention services. With drug use finally on the decline, isn't this the wrong time to get rid of the prevention program that provides America's school aged youth with drug prevention programming?

*Answer.* The Administration proposes to terminate funding for Safe and Drug-Free Schools and Communities (SDFSC) State Grants because of the program's inability to demonstrate effectiveness and the fact that funds are spread too thinly to support quality interventions. For example, SDFSC State Grants provides about 60 percent of local educational agencies (LEAs) with allocations of less than \$10,000, amounts typically too small to mount comprehensive and effective drug prevention and school safety programs.

By comparison, under SDFSC National Programs the Department has greater flexibility to provide large enough awards to support quality interventions. In addition, the National Programs authority is structured to permit grantees and independent evaluators to measure progress, hold projects accountable, and determine which outcomes are most effective. We are requesting \$317.3 million for SDFSC National Programs, an \$82.7 million or 35 percent, increase over 2005.

## SAFE DRUG-FREE SCHOOL COMMUNITIES—UNIFORM MANAGEMENT INFORMATION AND REPORTING SYSTEM

*Question.* To date, the Department has failed to implement the requirements in H.R. 1 (No Child Left Behind Act) for a Uniform Management Information and Reporting System (UMIRS) under the State Grants portion of the Safe and Drug-Free Schools and Communities program. This system was intended to collect uniform data and outcome measures for drug use and violence across all States. The poor PART score this program received is largely due to the failure of the Department to collect this required information and is one of the reasons being given for the zeroing out of the program. What do you intend to do to comply with the requirements of H.R. 1 as far as implementation of the UMIRS?

*Answer.* We have issued non-regulatory guidance to States concerning implementation of the Uniform Management Information Reporting System (UMIRS) requirements contained in Section 4113 of the Elementary and Secondary Education Act (ESEA) as reauthorized by the No Child Left Behind Act of 2001 (NCLB). Consistent with NCLB's emphasis on flexibility and discussions with House and Senate staff during reauthorization, the guidance reiterates the data elements that must be included in the UMIRS, as well as the kinds of data sources that must be included as part of the system. It also addresses the issue of which entity within a State is responsible for implementation of the UMIRS, and covers questions about funding for the system, and periodicity of data collection.

We should also clarify that lack of progress on implementation of UMIRS was not a major factor in the ineffective PART rating received by the program. Safe and Drug-Free Schools and Communities State Grants received this rating because the program is not well designed to accomplish its objectives and because it cannot demonstrate results, among other factors. UMIRS was not really an issue.

## TITLE IV INFORMATION COLLECTION AND REPORTING REQUIREMENTS

*Question.* The Department of Education has neglected to implement any of the data collection and reporting requirement reforms that Congress specifically included in Title IV of H.R. 1, including the Uniform Management Information and Reporting System and a minimum data set, to be reported on by all States to the Secretary. States and local education agencies (LEA's) across the Nation have exercised due diligence and are working to document what they think is required by Title IV, but have had to do this without any guidance at all from the Department. How and when do you intend to rectify this situation, especially given that this failure on the Department's part is one of the main reasons this program has not been able to "demonstrate results" and is slated for elimination?

*Answer.* We have requested information from States concerning implementation of the Safe and Drug-Free Schools and Communities Act State Grants programs as part of the Department's Consolidated Report for NCLB Programs. As you know, ESEA Section 9303 authorizes the creation of the consolidated report and mandates that the report collect information on the performance of the States under "covered



programs.” The consolidated report replaces pre-NCLB individual, program-specific reports.

The first consolidated report covering the SDFSCA State Grants program was due to the Department in June 2004. The Department requested information from the States about the performance measures and targets they established for the SDFSCA State Grants program. In this initial report, covering school year 2002–2003, States provided baseline information for the performance measures that they established for the program. In the next consolidated report, scheduled to be submitted to the Department in April 2005, States will report data for their targets for the 2003–2004 school year.

In addition to information about performance measures and progress toward achieving targets, the Department also asked States to provide information about the number of out-of-school suspensions and expulsions by school type (elementary, middle/junior high, or high school) for alcohol or drug-related offenses, or for fighting or weapons possession.

#### INFORMATION COLLECTION AND REPORTING REQUIREMENTS

We are very sensitive to the issue of creating burden related to information collection and reporting, and have worked hard to select the smallest possible data set that will permit us to assess the extent to which States are meeting their established targets to prevent youth drug use and violence. We believe that our focus on progress toward identified targets and suspension and expulsion data is consistent with that goal. While this information cannot provide scientific evidence about the effectiveness of the SDFSCA State Grants Program (only research studies that include experimental designs are capable of demonstrating the effectiveness of an intervention), it does provide an important tool for States to use in assessing their progress in addressing youth drug use and violence.

Our experience in administering the SDFSCA State Grants program and other NCLB provisions, including the Unsafe School Choice Option (USCO) requirements, indicates that States need to focus additional attention and resources on improving the quality and consistency of data they collect concerning youth drug use and violence, and to take steps to improve the way in which such data are used to manage youth drug and violence prevention initiatives. Accordingly, in fiscal year 2004, we held a competition for Data Management Improvement Grants to help States develop, enhance, or expand the capacity of States and LEAs (and other State agencies and community-based entities that receive SDFSC State grant funds) to collect, analyze, and use data to improve the management, and report the outcomes, of drug and violence prevention programs. We awarded 11 such grants in fiscal year 2004 and estimate making an additional 7 awards in fiscal year 2005. Among other things, these grants will assist recipients of SDFSC State grant funds to use data to assess needs, establish performance measures, select appropriate interventions, and monitor progress toward established performance measures.

As a complement to these grants, we have awarded a contract to help support the development of a model data set that includes, at a minimum, the UMIRS elements. This technical assistance effort will build on the work done by the Department of Health and Human Services Office of Substance Abuse Prevention, as well the activities of other Federal agencies that either collect youth drug use and violence data or use that data in policymaking, including the Centers for Disease Control and Prevention, the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, the Office of Juvenile Justice and Delinquency Prevention, and the Office of National Drug Control Policy. We will be working with these Federal agencies and all of the States to develop a model data set that can be adopted by States. The initiative also includes technical assistance services for the States, as well as activities designed to identify and disseminate best practices in this area. We believe that this approach provides the appropriate balance between State flexibility and leadership in this area.

#### TEACHER INCENTIVE FUND—STATE GRANTS AND COMPETITIVE GRANTS

*Question.* In the President’s Budget there is a proposal for a \$500 million new Teacher Incentive Fund. It would encourage States to adopt and implement performance-based compensation systems for teachers. Could you describe your idea for this program a bit more; specifically, how do you see States determining who deserves “merit” pay?

*Answer.* The Teacher Incentive Fund would provide formula grants to State educational agencies (SEAs) to reward effective teachers and to offer incentives for highly qualified teachers to teach in high-need schools. In addition, the Department would make competitive grants to SEAs, local educational agencies (LEAs), and non-

profit organizations to design and implement performance-based compensation systems that change the way school districts pay teachers. The Department would use \$450 million for the formula grants and \$50 million for the competitive grants.

Under the formula component of the initiative, the Department would provide grants to SEAs by a formula. States would use these funds to give monetary awards to: (1) teachers who raise student achievement or make significant progress in closing the achievement gap among groups of students; and (2) highly qualified teachers who agree to teach in high-need schools.

SEAs would develop their own strategies for identifying the teachers who have done the best job at raising achievement or narrowing achievement gaps, or both, and, thus, qualify for a monetary award. A State might give awards directly to individual teachers, or reward all of the teachers in a high-performing school, or both. An SEA could also choose not to offer monetary awards directly to teachers and, instead, make competitive grants to LEAs to provide monetary awards to teachers who are raising student achievement or closing the achievement gap. An SEA would specify in its application to the Department the procedures and criteria it would employ.

States would have similar flexibility in designing programs to attract highly qualified teachers to schools that face the greatest challenges in meeting the objectives of No Child Left Behind and then rewarding those who take positions in those schools. A State might use funds at the State level to create a statewide system providing rewards, or higher salary, to those teachers. The Department's expectation, however, is that SEAs would use most of the money for competitive grants to LEAs that have the best strategies for using the funds to recruit qualified teachers to high-need schools. The States would describe in their applications the procedures and criteria they would use to implement the program, including the State's definition of a "high-need school" (generally a school with a high poverty rate and poor performance on State assessments). All public school teachers who receive a monetary award under this activity would be required to meet the "highly qualified teacher" requirements under the Elementary and Secondary Education Act, and the Department would also encourage States to include additional criteria to ensure that salary increments go to teachers who have demonstrated a high level of performance.

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#### QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

##### ADEQUACY OF NCLB FUNDING—STUDIES SUPPORTING

*Question.* The Administration has repeatedly claimed that there is more than enough money available to States to fully implement the requirements of the No Child Left Behind Act. However, many reports and studies—including those done by the National Conference of State Legislatures, the Ohio Department of Education, and the New Hampshire Association of School Administrators—have found that Federal funding is falling significantly short of the costs of implementing NCLB and providing the remediation efforts to improve student achievement. Can you please provide us with specific studies and analyses you have used to justify your confidence that the funding provided is fully sufficient for States and school districts to meet all the provisions of NCLB?

*Answer.* No Child Left Behind was met with charges of underfunding almost from the moment it was signed by President Bush, despite the fact that it was accompanied by a \$4.6 billion increase in funding in its first year alone. Many of the early so-called studies of the costs of the new law have been little more than summaries of authorized funding levels, while others were based on assumptions that applied to only one or two States, ignoring that fact that implementation costs vary greatly according to how far along a given State was in its own standards-based reform efforts. Some studies also ignored the fact that many of the requirements of No Child Left Behind—such as annual assessment, determining adequate yearly progress, and school improvement—were not new at all, but expansions or enhancements of the previous law.

What is most striking to me, however, is that 3 years into No Child Left Behind, I have yet to see a comprehensive, convincing study or report documenting the real costs of the law, even for a single State or school district. For example, the National Conference of State Legislatures Task Force on No Child Left Behind recognized that (1) "the federal government has dramatically increased funding to K–12 education since passage of No Child Left Behind;" (2) that while "estimates vary widely," Federal funding "covers the costs" of administrative compliance with NCLB; and (3) a key step to meeting NCLB proficiency goals involves reallocating current re-

sources, and not just increasing the Federal contribution, which is dwarfed by State and local spending on education.

Interestingly, even after a thorough review of existing cost studies, the Task Force did not attempt to provide an authoritative estimate of its own. Rather, it concluded that because each State's experience with NCLB is unique, "Cost estimates must be made on a state-by-state basis."

On the basis of what we know now, I think it is reasonable to conclude that cost is not, at least not yet, a major obstacle to implementing No Child Left Behind. It may well be that in the future States and school districts will be able to provide more reliable and persuasive data on the costs of moving their students toward NCLB proficiency goals. But we have yet to see such data and, in their absence, I believe demands for more money are more of a political than an educational or analytical exercise.

#### HIGH SCHOOL ASSESSMENTS

*Question.* Your proposal to expand NCLB reading and math tests in high schools raises the question of what consequences would be imposed on schools based on those test results. Currently, under NCLB, federally mandated sanctions for failure to make AYP apply only to schools that receive Title I funds. Since less than 10 percent of high schools get Title I funds, are you proposing to expand the scope of Federal consequences for failure to make AYP to all high schools, regardless of whether they get Title I funding?

*Answer.* No, we are not proposing to expand the current school improvement requirements to non-Title I high schools. As is the case under current law, only high schools receiving Title I funds would be subject to improvement requirements, including the provision of public school choice and supplemental educational services, if they do not make adequate yearly progress.

The expanded assessments would provide a uniform, objective mechanism for measuring student achievement and for holding high schools accountable under the President's High School Intervention initiative. They would also offer information about individual student progress and help educators make informed decisions for helping students advance through high school.

#### ASSISTIVE TECHNOLOGY STATE GRANT PROGRAM

*Question.* Last October, President Bush signed Public Law 108-364, the Assistive Technology Act. I was the lead co-sponsor in the Senate. This legislation supports services that ensure that people with disabilities will have access to the assistive technology they need—technology that makes independent living possible in many cases. This legislation was one of few bipartisan successes we had last year, being unanimously endorsed by Republicans and Democrats alike in both the House and the Senate. Yet less than 5 months after the President signed the new law, his budget zeroes it out. The reason given in the budget is that "the Department has been unable to identify and document any significant benefits." It is my understanding that the Department has collected data from every State funded under this law, yet not once in 15 years issued the statutorily required report to Congress that would document the impact of these programs. It seems to me like you are punishing people with disabilities who get services from these programs because the Department has failed to do its job. How would you respond?

*Answer.* The President signed the reauthorization of the AT Act because its goal is consistent with the goals of the New Freedom Initiative, that is, to promote the full participation of people with disabilities in all areas of society by expanding education and employment opportunities, promoting increased access into daily community life, and increasing access to assistive and universally designed technologies. The kinds of activities authorized by the bill, particularly the Alternative Financing Program (AFP), have the potential of enabling individuals with disabilities to have more control over their lives and greater participation in schools, work environments, and communities, through increased access to assistive technology. State interest in the AFP is very high; during the last competition we awarded \$35.8 million, but received requests for \$42.3 million. In fiscal year 2005, the Department received just over \$4 million for the AFP and our fiscal year 2006 budget request includes \$15 million.

The design of the AT State grant program, however, is not ideal because it mandates four specific activities that States must carry out. States are unable to focus their efforts on those activities most needed to increase consumer access to, and ownership of, assistive technology within their State. Further, the new State formula grant program permits States to spend up to 40 percent on activities that have not been shown to have direct benefits to individuals with disabilities. Therefore,

we targeted our 2006 request to funding for the AFP rather than the new AT State grant program.

The Department recently sent the required annual report to Congress for the AT State grant program. This report, dated February 2005, provides a compilation of data for fiscal years 2001, 2002, and 2003 that States provided to NIDRR using a web-based data collection instrument. Among other things, the report contains data required by the AT Act on such activities as improving interagency coordination relating to assistive technology, streamlining access to funding for assistive technology, and producing beneficial outcomes for users of assistive technology. In fiscal year 2001, the first year in which States reported data using this web-based system, NIDRR received data from 51 of the 56 grantees, but all 56 States reported for fiscal years 2002 and 2003. This report is also available at <http://www.ed.gov/about/offices/list/osers>.

#### EVIDENCE ON THE EFFECTIVENESS OF THE REGIONAL LABS

*Question.* The enactment of two pieces of legislation, the No Child Left Behind Act (NCLB) and the Education Sciences Reform Act, have brought scientifically based research, development, dissemination, and technical assistance to the forefront of K-12 education. Yet for the last 3 years, President Bush has eliminated funding for the important research conducted by regional education laboratories in his budget request. The Administration has indicated in justification documents that the labs "have not consistently provided high quality research and development products or evidence-based training and technical assistance." Can you cite specific evaluations studies that support this justification?

*Answer.* Our budget request is based on the fact that we do not have comprehensive, rigorous evaluations of the products and services developed by the regional educational laboratories to warrant further investment beyond the more than \$1.5 billion in Federal funds the program has received since 1966. The most recent Federal evaluation of the program was conducted in 1998 by Decision Information Resources, Inc. Panels of peer reviewers assessed the performance of each laboratory in meeting the duties outlined in their contract, and provided information to guide program improvement for the remainder of the contract period. Although it provided useful feedback on the strengths and weaknesses of each laboratory, the findings could not be generalized across laboratories and did not provide an assessment of the performance of the program as a whole.

In June 1993, Maris Vinovskis, an outside analyst brought in by Diane Ravitch, then Assistant Secretary for Education Research and Improvement, examined the quality of research and development at 5 regional educational laboratories, 4 of which are part of the 10 current regional education laboratories. Dr. Vinovskis, currently a professor at the Department of History and Institute for Social Research at the University of Michigan, focused on many of the issues of concern to education research generally. He found that much of the applied research conducted by the laboratories was based solely upon case studies, limiting the applicability of the findings to school settings generally. Although Dr. Vinovskis praised some of the work conducted by the laboratories, particularly that of the Far West Lab, now WestED, he questioned both the underlying methodology and the practical implications of many of the other laboratory products for classroom use.

Since its creation in 2002, the Institute of Education Sciences has addressed the issues Dr. Vinovskis raised over a decade ago by significantly expanding its support of applied research that uses rigorous scientifically based methods to find solutions to the problems faced by educators and policymakers. As we stated in our budget request, achieving the Department's strategic goal of transforming education into an evidence based field will require not only more and better research but also new and better ways to use research-based knowledge and translate research to practice. To reach this goal, the Administration is improving the way we foster knowledge utilization by establishing the What Works Clearinghouse, revamping the Education Resources Information Center, and significantly expanding the capacity of the Comprehensive Centers to provide technical assistance that helps schools apply research findings in classrooms. We believe these investments are more tailored to the needs of States, districts, and schools than the regional educational laboratories.

#### COMPREHENSIVE CENTERS

*Question.* I am pleased that the Department has requested funds for new comprehensive centers, which will work with States and districts in helping schools implement No Child Left Behind. A new Request for Proposals for the Comprehensive Centers will be released this summer. The statute calls for a center in each of the 10 designated regions and at least 10 additional centers to be structured on a vari-

ety of criteria. Can you tell us what your plans are for structuring the second ten centers; will they be based on population or topic, or a combination thereof?

Answer. The statute calls for a total of not less than 20 new Comprehensive Centers, while requiring that the Department establish at least one center in each of the 10 geographic regions served by the regional educational laboratories. The locations of the other centers will be determined through the competition, which will take into consideration elements identified in the law, including the number of school-aged children, the proportion of disadvantaged students in the various regions, the increased cost burdens of service delivery in sparsely populated areas, and the number of schools identified for improvement under Title I.

The centers other than the required 10 will likely be a combination of additional regional centers in high-need jurisdictions and a few “content” centers with responsibilities across States and across Centers in major priority areas related to NCLB implementation. The Department has not yet made final decisions on this issue.

#### REGIONAL ADVISORY COMMITTEE ASSESSMENTS

*Question.* Specifically, how will the needs assessments conducted by the Regional Advisory Committee process factor into your plans for these new Centers?

Answer. In designing the competition for awards to the new Comprehensive Centers, the Department is required to consider the findings of 10 Regional Advisory Committees (RACs), convened to assess regional needs for technical assistance to support high-quality implementation of No Child Left Behind. The Department established the RACs in November 2004 and expects to receive written reports from each committee by the end of March 2005.

The Department will consider the RAC assessments in drafting the request for proposals establishing priorities for the new centers, which the Department expects to publish in May. Also, the written reports from the RAC needs assessments will be available on the Department’s web page so that applicants can use them to as a resource in designing their proposals for new Comprehensive Centers.

#### ADULT EDUCATION STATE GRANTS

*Question.* The President’s proposed budget calls for large cuts in the Adult Basic and Literacy Education program because it did not demonstrate results under the Program Assessment Rating Tool (PART). The Department says the program shows modest impacts on adult literacy and skill attainment but data quality problems and the lack of a national evaluation made it difficult to assess the program’s effectiveness. How does that assessment justify a 75 percent cut in funding?

Answer. We have requested a reduction in the Adult Education program due to severe budget constraints that the Federal Government now faces and in order to direct funds to a new initiative to strengthen high schools. In addition, the PART review of the program shows that the program does not demonstrate strong program performance outcomes. Currently, the program has failed for three consecutive years to reach performance targets measuring skill attainment of both Adult Basic Education and English as a Second Language students.

#### ADULT EDUCATION RESEARCH

*Question.* Wouldn’t it instead point first toward gathering better data and calling for a national evaluation through WIA reauthorization?

Answer. Due to the diversity in age, skill level, learning disability status, and level of English proficiency of the adult education student body, a national evaluation would be extremely cost-intensive and would not likely produce results that could be generalized across States or localities. Adult Education providers also vary considerably and include community-based organizations, local educational agencies, correctional facilities, community colleges, and other entities. However, the Department actively conducts research targeting specific areas of instruction, curriculum, data collection, and program characteristics. For instance, we use Adult Education national leadership funding to address such issues as explicit literacy instruction for adult English as a Second Language participants and the use of technology to support adult education programs.

#### ENHANCED ASSESSMENT INSTRUMENTS GRANTS

*Question.* Madame Secretary, as we discussed at the hearing, the Senate included report language urging the Department, when awarding enhanced assessments grants, to give special attention to the needs of students with disabilities and students with limited English proficiency. Do you plan to specify this priority in the request for proposals for this grant application?

Answer. Yes. We have revised the notice inviting applications to give competitive priority to projects that will address the use of accommodations or alternate assessments in assessing limited English proficient students and students with disabilities.

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QUESTIONS SUBMITTED BY SENATOR DANIEL K. INOUE

NATIVE HAWAIIAN EDUCATION

*Question.* On the subject of Native Hawaiian Education, there were reports that the Native Hawaiian Education Council was not getting information from the Department of Education. Is your department now working with the Native Hawaiian Education Council and providing them with information?

Answer. The Department has been working to improve communications with the Council. Department officials met with a number of Council members on February 15, 2005 to discuss ways to improve communication between the Council and the Department. The meeting also addressed ways to improve the Council's effectiveness and its technical assistance activities. We will continue to communicate with the Council and assist its members in fulfilling their duties.

CHARTER SCHOOLS

*Question.* Charter schools are an important addition to Hawaii's education system. How do you feel about charter schools, and are there additional funding opportunities for charter schools?

Answer. Charter schools are an important reform, and a key element of the Administration's efforts to expand school choice for students and parents. This is reflected in the strong support for charter school programs contained in the 2006 budget request. This request would support planning, development, and initial implementation activities for approximately 1,200 charter schools, as well as enhanced dissemination activities by schools with a demonstrated history of success. Further, a portion of the funds are available to States for subgrants to assist charter schools with their facilities financing. This program component, the Charter Schools Per-Pupil Facilities Aid program, complements an additional source of funding for charter schools, the Credit Enhancement for Charter School Facilities, which provides assistance to help charter schools meet their facility needs. Additionally, many charter schools are eligible for Federal funds under both discretionary and formula grant programs, such as the Teaching American History and Rural Education Achievement programs.

PERKINS VOCATIONAL EDUCATION AND PERKINS LOAN PROGRAMS

*Question.* In the President's budget he plans to cut Perkins vocational education and loan programs. Is there some alternative proposal for these programs?

Answer. The President's fiscal year 2006 budget does not request funding for Vocational Education programs because those programs have not demonstrated effectiveness and in order to direct funds to a new initiative to strengthen high schools. The President believes that a targeted initiative will be more effective than current programs in meeting the major need for reform and improvement of American high school education. The new program would give States and districts more flexibility in designing and implementing services and activities to improve high school education and raise achievement, particularly the achievement of students most at risk of failure. States and school districts would be able to use funds for vocational education, tech-prep programs, and other purposes, depending on State and local needs and priorities. The Department would use part of the money to conduct carefully designed research in order to identify the most effective strategies for raising high school achievement and eliminating achievement gaps.

The President's budget requests \$1.24 billion for the new high school intervention program and \$250 million to ensure that students are assessed in reading/language arts and mathematics at least three times during high school. The 2006 budget also includes more than \$400 million for related programs to strengthen high school achievement, including \$200 million to expand the use of research-based interventions for secondary school students who read below grade level and thus are at greater risk for dropping out of school, \$120 million to accelerate the mathematics achievement of secondary school students through research-based professional development for math teachers, \$52 million to increase the availability of Advanced Placement and International Baccalaureate programs in high-poverty schools, \$12 million to encourage students to take more rigorous courses through the State

Scholars program, and \$33 million in enhanced Pell Grants for State Scholars as they pursue higher education.

The budget request also includes a \$125 million Community College Access grants initiative, which would support expansion of “dual-enrollment” programs under which high school students take postsecondary courses and receive both secondary and postsecondary credit. It would also help ensure that students completing such courses can continue and succeed in 4-year colleges and universities.

#### FUTURE OF VOCATIONAL EDUCATION

*Question.* In your opinion what is the future for vocational education?

*Answer.* Vocational education is predominantly funded with State and local dollars and will continue without a Federal categorical aid program. Secondary vocational education will thrive if the field responds promptly and aggressively to demands from the business community and postsecondary education that it provide students with a more rigorous academic education, particularly in mathematics and science. All of our youth, regardless of their post-graduation plans, need a rigorous academic foundation. As the American Diploma Project documented in its research, “[s]uccessful preparation for both postsecondary education and employment requires learning the same rigorous English and mathematics content and skills. No longer do students planning to go to work after high school need a different and less rigorous curriculum than those planning to go to college.” If the field fails to respond to this new imperative, policy-makers, business leaders, postsecondary educators, and parents and students will increasingly question the value and relevance of secondary vocational education.

*Question.* Will it become part of the President’s Higher Education Act?

*Answer.* Eligible recipients of grants, loans, and college work-study assistance under HEA student aid programs have long been eligible to use that assistance to pursue vocational degrees and certificates. The President’s proposals for HEA reauthorization would allow that type of assistance to continue.

#### QUESTIONS SUBMITTED BY SENATOR HERB KOHL

##### FUNDING FOR NO CHILD LEFT BEHIND

*Question.* I supported No Child Left Behind because it guaranteed that flexibility and accountability would come with more Federal funding to make it work. Instead, funding levels have fallen billions short of what was authorized. These cuts cause real hardship. To make ends meet, schools are being forced to cut staff and important programs like summer school, class size reduction, arts and foreign languages.

Last year, Secretary Paige suggested that funding has no connection to student achievement. He seemed to believe that schools receive plenty of money to meet these requirements—even though superintendents, school boards, state legislatures and teachers consistently say otherwise. If we want this law to work—a goal which most of us share—don’t you think it’s time that the Administration become more responsive to these funding concerns; isn’t it time to provide the funding that was authorized?

*Answer.* As I stated earlier in response to a question from Senator Harkin, I believe there is little evidence for the claim that lack of funding is the central obstacle to effective implementation of No Child Left Behind. With national spending on elementary and secondary education roughly doubling over the past decade, from about \$260 billion to more than \$500 billion, it’s hard to make the case that we’re not spending enough on education. I realize that circumstances vary from State to State and district to district, and that many areas are dealing with tight budgets, but from a national perspective, as I said, I don’t think funding is the primary problem.

On the issue of authorization levels, the Members of this Subcommittee know as well as I do that these are just targets—wish-lists, really—established by the authorizing committees when they pass new legislation. They rarely are accompanied by any careful analysis of what it actually costs to make a program work as intended, and the situation is the same with No Child Left Behind. And in the absence of any reliable data on the actual or prospective costs of No Child Left Behind, merely pointing to authorization levels is not a very persuasive argument for higher funding levels, particularly at a time of fiscal constraint at the Federal level.

The Administration, just like the Appropriations Committees, has had to make hard-nosed judgments about how much we can afford for NCLB and other programs in light of tight fiscal constraints. Last year, for example, the Administration asked for substantially more funding for both Title I and IDEA—the two programs most

frequently identified by critics as being underfunded—than the appropriators provided in their final 2005 appropriations act.

#### SPECIAL EDUCATION FULL FUNDING

*Question.* Many of us here have worked hard every year to increase funding for Special Education. Year after year, school districts in Wisconsin tell me that this is one of their top concerns. They think it's wrong that the Federal Government continues to ignore its commitment to pay 40 percent of the costs as authorized in the original IDEA law. Just last December, the President signed the IDEA Reauthorization into law with an authorized funding level of \$12.4 billion for 2005. Just days later, he signed the Omnibus Appropriations bill which only provided \$10.6 billion. This year, the President's budget only proposes \$11.1 billion for fiscal year 2006—still \$3.5 billion short of what is authorized for 2006. This trend begs the question: does the Administration plan to fully fund IDEA and do you have a plan to get there?

*Answer.* The Administration is committed to assisting States and school districts with meeting the costs of special education. This President has requested record-level increases for special education since he entered office.

The 2006 President's budget request for \$11.1 billion includes an increase of \$508 million over the 2005 level. It would maintain the Federal contribution at its highest level—19 percent of the national average per pupil expenditure. If enacted, the request would result in an increase of \$4.8 billion or 75 percent since 2001.

The President has opposed mandatory full funding for special education because of the importance of taking into account competing budget priorities during the formulation of the budget each year. In the current fiscal environment, there are limited resources for Federal discretionary programs not related to national defense or homeland security. In this environment, the 4.8 percent increase requested for the Special Education Grants to States program is significant.

#### E-RATE

*Question.* E-rate is a vital program that provides classrooms with the technology they need to enhance teaching and learning. E-rate grants give students more opportunities to develop the skills they need to compete in the 21st Century. This past year, Wisconsin received over \$24 million from this program. However, as you know, e-rate grants were in jeopardy last year because of new rulings related to the Antideficiency Act. Congress was able to fix the problem last year and e-rate grants have resumed. But that was just a one-year fix and we need to pass legislation to fix it permanently in order to fully cover all pending applications for E-rate. I look forward to working with my colleagues in the Senate to meet this goal. Can we count on your support for the E-rate program?

*Answer.* I understand that the Administration has not yet taken a policy position on legislative initiatives regarding the E-rate. That said, the financial management responsibilities required by the Antideficiency Act are designed to protect taxpayers and beneficiaries of U.S. Government programs by ensuring that spending agreements do not exceed available resources. The PART review by OMB and recent reports from GAO have identified fiscal and managerial problems with the program. The FCC has taken some steps to address these problems, including collaborating with our Department on more accurate measurement of E-rate effectiveness.

#### READING FIRST GRANTS

*Question.* I supported No Child Left Behind because I believed in the combination of more funding, more flexibility, and more accountability for results. However, many believe that the flexibility piece has not lived up to its promise and that certain No Child Left Behind regulations are overly proscriptive. One example that has been brought to my attention is the Reading First grant program. Last October, the Madison School District decided to pass on an additional \$2 million in Reading First grants because new Federal guidelines would have required a substantial change in a curriculum that had already been successful with 80 percent of students. Can you explain why schools with successful programs are being forced to change in order to qualify for Federal funds?

*Answer.* One of the advantages of the Reading First program is that local education agencies (LEAs) retain considerable flexibility in the selection of a reading program. Schools are permitted to implement the core reading curriculum of their choosing, so long as it addresses the five critical factors, identified by the 2000 *Report of the National Reading Panel*, upon which the Reading First program is based: phonemic awareness, phonics, vocabulary, fluency, and comprehension. Although the reading program used by Madison Metropolitan Public Schools (MMPS) proved



successful with many of its students, the Wisconsin Superintendent of Public Instruction awarded a Reading First subgrant due to a gap of 2 to 4 years in reading levels between third graders in five elementary schools.

A Federal review of the MMSD curriculum, undertaken as a part of Reading First monitoring for the 2004–2005 school year, revealed that the MMSD program failed to address all of the required elements of a scientifically based reading program. The district worked with technical assistance providers to address these gaps through the addition of supplementary materials, lesson plans, and exercises but ultimately decided to continue its own reading curriculum.

*Question.* Why were new Federal guidelines issued?

*Answer.* The Department issued non-regulatory guidance for the Reading First program in April 2002. States and local educational agencies have used this guidance as a resource to guide successful implementation of Reading First. We have not issued any additional guidance since that time.

#### QUESTIONS SUBMITTED BY SENATOR PATTY MURRAY

##### D.C. VOUCHER PROGRAM

*Question.* Secretary Spellings you are more than aware of the tight budget this country is facing. Education is facing a cut for the first time in decade. The President has proposed elimination of 48 programs including some very popular programs. I understand that the determination for which programs were eliminated comes from the evaluations of the Program Assessment Rating Tool (PART) administered by OMB. And that evaluation includes which programs are ineffective so that funds can be redirected to effective programs. As an appropriator, I agree that the government should only be funding programs that are effective and serving their intended purpose.

However the President has continued to fund in his budget a program that is not serving its intended purpose—the D.C. voucher program. As I understand it, only about 75 students out of roughly 1,350 students receiving vouchers come from schools labeled in need of improvement—the highest priority of students in the original legislation. That is less than 6 percent of the participating students. Further, over 200 students receiving vouchers were already attending private schools. According to the Washington Post, this number includes a student who is an 8th grader at Sidwell-Friends who had been attending the school since 5th grade. Clearly those students are just being subsidized by taxpayers, not being provided increased “choice” as proponents would argue.

In such tight budget times, how can you justify continuing a program that is clearly not serving the intended population?

*Answer.* On the contrary, I believe that the program is serving the students who Congress intended it to serve and that, as the program matures, it will be even more successful in providing educational opportunities to low-income students attending schools identified for improvement.

All of the students receiving scholarships this year met the statutory eligibility requirements; they are from families with incomes of less than 185 percent of the poverty level, or roughly \$35,000 for a family of four [correct?]. Raising a family on that income is certainly not an easy task. While some of these families were already paying private school tuition, you can imagine the kinds of sacrifices they were making to provide their children with that opportunity. While we believed it was appropriate to limit the number of scholarships going to students already attending private schools, and we did so, we also did not feel that it would be fair to penalize families who had been making such a sacrifice.

The Department also faithfully implemented the requirement to give priority to students enrolled in D.C. public schools identified for improvement under No Child Left Behind. However, only 15 schools were in NCLB “needs improvement” status last year, and seven of the schools, enrolling the great majority of those students, were high schools. D.C. private high schools had only a small number of slots they could make available to scholarship recipients during the first year of the program, in part because Congress was very late in passing the fiscal year 2004 appropriations act and, thus, the program was slow in getting underway. (Most D.C. private high schools accept applications and make enrollment decisions in the fall and early winter. Because of the late Congressional appropriations process and then the time needed to select an organization to administer the program and then select scholarship recipients, the program could not link recipients with schools until late spring.

Further, the great majority of students who applied for scholarships were in elementary and middle schools, in part because there are just more students in those

grades and in part because upper-grade high school students who are nearing the end of their high school careers are typically less interested in changing schools. For these reasons, the number of students receiving scholarships who came from schools in need of improvement was, I think, understandable given the circumstances.

I am very confident that the number of students from those schools who participate in the program will rise very significantly during the next school year. For one thing, a total of 68 D.C. schools have now been identified for improvement, including many elementary schools. Secondly, our grantee, the Washington Scholarship Fund, has more time this year to recruit students from those schools and to recruit private schools to accept those students.

Further, of the 15 schools identified for improvement last year, seven were high schools. High-school students are less likely than elementary- and middle-school students to want to change schools. In addition, because of the late passage of the appropriations bills and the need to select competitively a grantee to administer the program, it was not until March 2004 that the Washington Scholarship Foundation (WSF) was selected to operate the program and begin to solicit applications from parents on behalf of students. This is well past the time when many of the area's private high schools require students to apply for the following school year. As a result, few private high schools had places remaining for D.C. Choice participants.

I feel confident that, with more time for the WSF to publicize the program and to assist parents in completing applications and more schools (particularly elementary schools) identified for improvement, the program will be even more successful in providing low-income parents of students who attend low-performing schools with expanded options for their children's education.

#### D.C. VOUCHER PROGRAM EVALUATION

*Question.* What evaluations has OMB done on the D.C. voucher programs and can you make that information available?

*Answer.* The D.C. Choice initiative has not been reviewed using the PART instrument. The program is in its first year of operation so it is too early to determine its effectiveness or undergo a PART review. However, the Department has moved ahead with the required evaluation of the program.

*Question.* Part of the law also says that you must do evaluations of the students receiving the vouchers as compared to students in D.C. public schools and compared to students who applied for and did not receive vouchers. What is the status of the evaluations required in the original statute?

*Answer.* The evaluation of the D.C. Opportunity Scholarship Program has been underway since spring 2004, when the Department's Institute of Education Sciences awarded a contract to a team of researchers from Westat, Georgetown University, and Chesapeake Associates. The evaluators collected information on program applicants in spring 2004, conducted lotteries to fairly allocate scholarships and placements at the grade levels and schools where there were more applicants than space available, and drafted a report examining the extent and characteristics of student and school participants in the program's first year. In the next few months the evaluators will be collecting data on academic achievement, on other student outcomes, and on parent satisfaction for the first group of applicants. The evaluators will, at the same time, be collecting applicant information, conducting lotteries, and beginning a descriptive analysis of the spring 2005 applicants.

*Question.* When can Congress expect to see the results of the analysis?

*Answer.* The evaluators are finalizing their first year report and it should be available to Congress this spring. While the focus of the evaluation is on examining the effectiveness of the D.C. Opportunity Scholarship Program, no impact information is available at this point because the initial group of program participants—those who applied in spring 2004 to receive scholarships for the 2004–2005 school year—have only recently matriculated at their new schools. Instead, this report examines the extent of student and school interest in the program and the characteristics of those participating. The report provides an important foundation for the later examination of program impacts.

#### HIGH SCHOOL INTERVENTION/PREPAREDNESS

*Question.* Secretary Spellings, as you and I have discussed before, I have always seen the Department of Education as a resource for schools, other education agencies, parents, and students. However, in the administration of this program, I understand that the Department sent an email to the Washington Scholarship Fund asking them to alter one of their Frequently Asked Questions on whether or not a school affiliated with the voucher program can still apply its own admissions standards. The following email was sent to WSF from the Department: “the House Ed

Committee has been reluctant to put this answer in writing. Many members (of Congress) are unaware that the schools can pick the students . . . I am not sure how to fix the answer but if this document is made public, it may damage their vote count." Clearly the Department was concerned that the reality that vouchers provide choices to schools not students and their families would become better known.

How does providing incomplete information to families on the program increase a parent's "choice" about where their child can attend school?

Answer. After Congress enacted the D.C. School Choice Incentive program, the Department moved quickly and aggressively to provide parents with complete information on the choices that would be available to eligible students. We did nothing to prevent parents of eligible students from receiving that information.

The e-mail message included in the recent People for the American Way report fails entirely to present a full or balanced picture on the actions taken by the Department and its grantee, the Washington Scholarship Fund (WSF), during this period. The e-mail concerns the language WSF would include in an informational package mailed to private schools about participation in the program. Although the Department and WSF discussed different options for explaining policies regarding schools' admissions criteria, the package that WSF mailed to the schools asks the question, "Can a school apply its own admissions criteria?" answers "Yes," and then explains how a school may test eligible students to determine whether they are admissible and, if so, how they should be placed in grades or classes within the school. The Department made no attempt to prevent this information from reaching both the schools and the parents.

#### EFFECTS OF PROPOSED HIGH SCHOOL INITIATIVE

*Question.* Secretary Spellings, you and I have previously discussed our mutual interest in improving our Nation's high schools and I hope we can continue that conversation. As you know, I have my own bill on high school reform called the Pathways For All Students to Succeed Act that I will be reintroducing this Congress. My bill focuses on reading and writing skills, academic counseling including creating graduation plans with students and their families, accurate calculations and data collection on high school graduation rates, and funding to turn around low performing schools using best practices.

The President's budget eliminates the Perkins program, GEAR UP, and part of the TRIO program and effectively creates a block grant and would require more testing at the high school level. You and the President have said that the idea would be to allow States to determine how to spend that block grant—if they determine career and technical education to be most needed to fund that, if it's GEAR UP, fund that. The problem with that theory is that all of these programs are needed along with new ways and investment to improve our high schools.

Considering that the President is proposing a high school block grant to States, how does he think that will improve problems in high schools such as high dropout rates amongst poor and minority students or a lack of academic preparedness for postsecondary education?

Answer. It sounds like your bill would support a number of potentially useful strategies to improving the performance of our secondary schools, and I believe that States and school districts would be able to support many of them under the President's High School Intervention proposal. Where I would have to disagree is with your assertion that "all of these programs are needed," including the grab bag of currently authorized programs, to improve our high schools. The problem with categorical programs like Perkins, TRIO, and GEAR UP is that they only support specific educational strategies, and thus if those strategies don't meet the needs of your school or district, those programs can't help you. Under the President's more flexible proposal, districts and schools choose the best strategy for meeting the educational needs of their students, and the High School Intervention initiative helps pay for it. This broader flexibility would be accompanied by much stronger accountability for results than is found in the current programs. We think that's a better way to get the results we need in our high schools.

#### DISADVANTAGED HIGH SCHOOL STUDENTS

*Question.* One of my constituents, Bill Gates, spoke to the National Governor's Association High School Summit. As you know, the Gates Foundation is doing critical work with our Nation's high schools. He talked about our Nation's high schools as a question of morals and values and I couldn't agree more. The Federal role in education has traditionally been to ensure that disadvantaged students are receiving an equal education but it is exactly those students, poor and minority students, who

are dropping out at the highest rates. What is the Department of Education doing at the high school level to target improving education for those students?

Answer. The President's High School Initiative, including \$1.24 billion for High School Intervention and \$250 million for High School Assessments, is specifically targeted at the students you describe, particularly those students most at risk of dropping out, who tend to be poor and minority. In particular, the combination of individual education plans based on 8th-grade assessment data and more regular assessment throughout high school would help principals and teachers focus on the students with the greatest need for assistance.

In addition, our 2006 budget includes proposals like the expansion of the Striving Readers program, which target students who are falling behind and at risk of dropping out.

#### HIGH SCHOOL INTERVENTION PROGRAM AND STRIVING READERS

*Question.* As the public conversation about education focuses on high school reform, it's important to recognize that improving the literacy skills of our Nation's youth is the key to really improving the success of our high schools in preparing students for the 21st century. If our Nation's high school students do not have adequate literacy skills, they will not be able to graduate prepared for college and the workplace no matter what other supports and programs are put in place. Such interventions need to take place in 9th grade before students drop out or become disengaged in their academic future. The President has requested \$200 million to expand the Striving Readers program to support interventions to improve the skills of struggling adolescent readers.

How does the Administration plan to engage the education policy and literacy communities in this initiative to ensure that this money is spent efficiently on high-quality interventions that not only help struggling adolescent readers, but complement and support real high school reform?

Answer. Department staff have met with several organizations to solicit their suggestions on implementing the Striving Readers program. For example, staff met with representatives of the National Association of School of School Boards of Education and the Alliance for Excellent Education, which published the recent Reading Next report on adolescent literacy. In addition, the Department has received input from developers of adolescent literacy programs. The Department plans future outreach efforts in planning and promoting the Striving Readers program.

#### HIGH SCHOOL INTERVENTION

*Question.* Only one-in-three 18 year olds is even minimally prepared for college and the picture is bleaker for poor and minority students. High school students—especially those most at risk of dropping out of school—need sound advice, strong support and an advocate to ensure they are getting all the support and services they need to take rigorous courses and have a plan in place for graduation and life after high school. Every student must have a clear graduation plan that assesses their needs and identifies coursework, additional learning opportunities and other supports to make their goals a reality. The President's budget includes \$1.24 billion for a High School Intervention which would require districts to "ensure that targeted high schools develop and implement individual performance plans for entering students based on 8th-grade assessment data." My bill, the PASS Act contains a similar proposal.

Would this plan be a mandatory activity for recipients, and would the money be required to be used not just for identifying needs, but providing supports and interventions?

Answer. Under the Administration's High School Intervention proposal, each grantee would be responsible for developing and implementing individual performance plans for entering students. Schools would use those plans to select interventions and strategies with the greatest potential for improving the achievement of their students. In addition to developing those plans, districts would use the funds to implement specific interventions designed to strengthen instruction and improve the academic achievement of students, particularly those students at the greatest risk of failing to meet challenging State academic standards and dropping out of high school. The High School Intervention proposal would provide districts with the flexibility to use their funds to meet their specific needs without having to apply for several discrete grants.

#### SPECIAL ALLOWANCE ON LOANS FUNDED FROM TAX-EXEMPT SECURITIES

*Question.* In its fiscal year 2005 budget, the Administration proposed eliminating a 9.5 percent guarantee on all new student loans. But in this year's budget, the Ad-

ministration simply says it proposes to make the Taxpayer—Teacher Protection Act's provisions permanent. But the Taxpayer—Teacher Protection Act still leaves a \$100 million a year 9.5 percent loan loophole. That remaining loophole allows the holders of 9.5 percent loans to “recycle” loan payments from students and the Government back into new loans that some lenders claim are also entitled to a 9.5 percent rate of return.

Do you support shutting down completely and permanently the 9.5 percent loan loophole once and for all so that “no new loans have a 9.5 percent guaranteed rate of return?”

Answer. The Taxpayer-Teacher Protection Act prohibits lenders from using refunding and transferring to increase student loan volume receiving the 9.5 percent guaranteed yield, but allows lenders to continue to recycle repayments of existing 9.5 percent loans into new 9.5 percent loans. Those new restrictions are in effect through December 2005; the Administration's proposal would make them permanent.

In adopting the Taxpayer-Teacher Act, Congress and the Administration balanced the needs of current bondholders for a stable and predictable revenue stream against the need to minimize unnecessary subsidy payments. Existing bonds, used for recycling, are maturing and will be retired in the near future.

*Question.* Washington State has seen many brave men and women deployed to serve in the conflicts in Afghanistan and Iraq over the last 3 years. Unfortunately too many have returned as amputees, necessitating a difficult and uncertain recovery process. I was very disheartened to learn that the Department of Education, through the Rehabilitation Services Administration (RSA), has decided not to support training grants for students in prosthetics or orthotics. There are a very limited number of prosthetics and orthotists across the country who can build the artificial limbs and braces that our returning war veterans will need to return to a productive lifestyle. Less Government support to these students will mean fewer practitioners and more difficulty for our newly injured veterans to secure the quality devices they so desperately need and deserve.

Given the significant and growing needs of our returning veterans for these prosthetic or orthotic devices, why did the RSA discontinue these critically needed training grants?

#### REHABILITATION SERVICES ADMINISTRATION'S TRAINING PROGRAM

Answer. The purpose of the Rehabilitation Services Administration's (RSA) Training program is to ensure that skilled personnel are available to serve the rehabilitation needs of individuals with disabilities assisted through the vocational rehabilitation (VR), supported employment, and independent living programs. The Training program provides grants for Long-Term Training, In-Service Training, Continuing Education, Experimental and Innovative Training, Short-Term Training, and Training of Interpreter for individuals who are Deaf and Individuals who are Deaf-Blind.

In fiscal year 2005, the Training program received an appropriation of \$38.8 million, of which \$18.6 million (48 percent) will be directed toward the Long-Term Training (LTT) program. Under the LTT program, grants (averaging \$100,000 annually for 5 years) are competitively awarded to institutions of higher education. Seventy-five percent of these grant funds must be used for direct scholarship support. RSA may support as many as 31 academic fields under the LTT program but, as required by the authorizing statute, directs funding toward the personnel fields with the greatest training needs and/or personnel shortages. As the cost of tuition has increased over time, the impact of the support provided has been reduced. Specifically, over the past 12 years college tuition has more than tripled while level funding (and rescissions since 2003) for the Training program have required RSA to reduce the number of LTT fields supported.

Our primary partners for delivery of rehabilitation services to people with disabilities are the State VR agencies. They are faced with an incredible staffing shortage. A study in progress, being conducted by the American Institutes of Research, has reported that it is likely that the supply of graduates of rehabilitation counseling programs may meet less than half of the number needed to replace retiring counselors in State VR agencies.

To help develop a larger recruiting pool, RSA has focused the LTT program on counselor programs. In 1998, RSA funded LTT program grants in 17 areas. In 2005, it will fund 11, and may fund fewer in the future. RSA is very aware of the need for Prosthetists and Orthotists and many other rehabilitation professionals. However, given the Training program's level of resources, the reduced buying power of its scholarship dollars, and the tremendous demand for counselors in State VR

agencies, RSA will continue to focus the LTT program on personnel fields that directly link to the provision of VR counseling.

*Question.* Will the Department of Education reinstitute these training grants to support those students studying to be the next generation of providers of artificial limbs and braces?

*Answer.* As discussed earlier, the tremendous shortage of VR counselors that the State agencies face make changes in the number of fields supported under the LTT program not feasible. RSA must continue to target the grants under the LTT program to the largest professional field—VR counselors.

VOCATIONAL/TECHNICAL EDUCATION—POSTSECONDARY STUDENTS ATTAINMENT AND COMPLETION TARGETS

*Question.* According to Sec. 113(b)(3)(A)(i) of Perkins, the State eligible agency, with input from eligible recipients, shall establish the level of performance for each of the core indicators, and the State eligible agency may express the level in “a percentage or numerical form, so as to be objective, quantifiable, and measurable . . .”

The Washington State eligible agency, with the support of the State community and technical college system, has expressed the State’s targets for the core indicators for postsecondary student attainment and completion as numerical targets (e.g., the number of students completing postsecondary career and technical education). The State has chosen to express the targets numerically because the State’s goal is to increase the number of trained workers in order to meet employer demand. The Office of Vocational and Adult Education has rejected the choice of the State, and refused to accept any target not expressed as a percentage.

Why has the Department of Education ignored the discretion that Congress clearly granted State eligible agencies when Washington State is fully and demonstrably committed to improving the performance of its vocational and technical education programs and to meeting the skill needs of State employers?

*Answer.* As you indicate, eligible agencies are free under the law to express their performance levels in a percentage or numerical form. Regardless of how eligible agencies choose to express their performance levels, however, the Department has asked each eligible agency, in guidance that we issued after providing an opportunity for public comment, to define both a numerator (number of individuals achieving an outcome) and a denominator (number of individuals seeking to achieve an outcome) in submitting their proposed performance levels to us for review.

We cannot fulfill the requirements of the Perkins statute without this information. Section 113(b)(3)(A)(i)(II) of Perkins mandates that each proposed performance level “require the State to continually make progress toward improving the performance of vocational and technical education students.” We cannot determine whether a State has satisfied this requirement if an eligible agency only provides numbers or percentages. Though the number of individuals who achieve an outcome may increase from year to year, this may not indicate that the performance of vocational and technical education students has improved. It may instead be the result of an increase in population. Similarly, an increase in the percentage of individuals achieving an outcome may or may not reflect improvement in the performance of vocational and technical education students; changing the definitions of the numerator and denominator could also cause it.

In reaching agreement with eligible agencies on their performance levels, the Department also is required by the Perkins Act to consider “how the levels of performance involved compare with the State adjusted levels of performance established for other States taking into account factors including the characteristics of participants when the participants entered the program and the services or instruction to be provided.” (See section 113(b)(3)(A)(vi) of the Act). It would be inequitable for the Department to consider only the number of individuals achieving an outcome in making comparisons across States and determining appropriate performance levels. Given the significant differences in the sizes of their populations, Rhode Island, Washington State, and California, for example, should not be expected to reach performance levels that require same numbers of individuals to achieve certain outcomes.

For these reasons, we have given each eligible agency the flexibility to express its performance levels however it chooses, but asked all agencies to define both a numerator and a denominator in their submission of proposed performance levels. We cannot implement the law the Congress has enacted without this information.

Washington is the only State that has expressed periodic misgivings about providing all of the information that we have sought from States to evaluate their proposed performance levels consistent with the law’s requirements. However, the Washington State eligible agency, the Washington State Workforce Training and

Education Coordinating Board, has acknowledged recently that it is inappropriate and misleading to measure performance, either at the secondary or postsecondary level, simply on the basis of the number of students who achieve an outcome. In February 2005, the Washington State Workforce Training and Education Coordinating Board issued a report on behalf of itself and agencies in Florida, Michigan, Montana, Oregon, and Texas that made recommendations to States on how best to measure performance in education and training programs. Integrated Performance Information for Workforce Development: A Blueprint for States recommends that States express performance levels as percentages, with clearly defined numerators and denominators.

#### IMMIGRANT LITERACY

*Question.* According to the Aspen Institute, immigrants supplied half of our workforce growth in the 1990s and will account for all of our net workforce growth over the next 20 years. More immigrants arrived in the 1990s—13 million—than in any other decade in U.S. history. Demographers and employers are warning Members of Congress about a severe worker shortage in the United States in the next decade. They have told me we must increase our investments in these newly arriving workers with literacy training and other support services. If we do not, we run the very real risk of losing our worldwide economic competitiveness.

The President's proposed budget cuts to Adult Basic and English Literacy, coupled with his efforts to reduce funding for workforce programs, do just the opposite.

What steps is the Department of Education taking to provide the kinds of resources needed to ensure that the employers and the new immigrant workers in Washington State will have ready access to a literate and well-trained workforce?

*Answer.* The Department agrees that the health and success of our workforce require emphasis on English language education, particularly in those areas most affected by increased immigration. The Department continues to address actively the language and education needs of immigrant students, at the elementary and secondary levels as well as at the adult level. The request includes level funding at \$68.6 million for English Literacy and Civics Education (EL/Civics) grants, which serve a vital purpose in States with large numbers of non-English-speaking immigrants. According to the Educational Testing Service study, "A Human Capital Concern: The Literacy Proficiency of U.S. Immigrants," the average literacy level of immigrants is far below that of U.S. adults. The report also found that immigrants with higher literacy proficiencies have improved labor market outcomes and were less likely to be poor and in need of Government support. This population comprises approximately 40 percent of those served by Adult Education State grants, including EL/Civics grants. Unlike regular Adult Education State grants, which rely upon decennial U.S. Census data, EL/Civics grants utilize a formula based on a combination of 10-year Census averages and recent population data and are, therefore, more responsive to fluctuations in immigration patterns.

According to a 2005 report by the National Clearinghouse for English Language Acquisition, 54 percent of LEP students in the United States are foreign born. ESEA Title III, Part A authorizes Language Acquisition State grants to serve limited English proficient (LEP) and immigrant students at the elementary and secondary level. The President's fiscal year 2006 budget request for Title III includes \$627 million for that program. In fiscal year 2004, Washington State's allocation under Language Acquisition State Grants was \$9,607,031, and preliminary estimates for 2005 and 2006 indicate that the State will receive increases in both years (assuming enactment of the President's budget request for 2006). This program is similarly responsive to fluctuations in immigrant populations and requires States to reserve at least 15 percent of their funding each year to increase grants to districts that have experienced a significant increase in the percentage or number of recent immigrant students over the preceding 2 years. Through both the EL/Civics program and the Title III program, Washington and other States have numerous options for addressing the literacy needs of LEP adults and youth.

#### TEACHER QUALITY ENHANCEMENT PROGRAM

*Question.* Funding for Title II of the Higher Education Act—Teacher Quality—is the only dedicated source of Federal support to reform and strengthen teacher preparation available to higher education institutions. Grants awarded under this program enable partnerships between Schools of Education, Arts and Sciences Departments at colleges and universities and local schools to work together to achieve the requirement that all students be taught by highly qualified teachers, as mandated by the No Child Left Behind Act.

Given the well-documented shortages of highly qualified teachers in certain disciplines and in rural and hard to serve urban communities, why has the Administration eliminated all funding for Title II of HEA in their fiscal year 2006 budget proposal to the Congress?

Answer. The Administration understands that the quality of the teacher is one of the most significant determinants of student learning and, as such, the Department of Education's budget supports major efforts to meet the President's goal of placing a qualified teacher in every classroom in America in order to ensure that no child is left behind. Spending on programs that are designed to improve teacher quality was more than \$3 billion in fiscal year 2005 and the Administration's budget request increases this amount to more than \$3.6 billion in fiscal year 2006. Included in this request is \$500 million for a major new initiative designed to improve teacher quality. The Teacher Incentive Fund would reward teachers whose students make the most achievement gains, provide incentives for teachers to teach in the most challenging schools, and encourage States and LEAs to adopt performance-based pay plans. These measures will do even more to ensure that effective teachers are available to teach our children. Even with proposed program eliminations, spending on teacher quality would increase substantially in fiscal year 2006 under the Administration's budget request.

In reviewing the portfolio of programs within the Department dedicated to achieving the goal of improving teacher quality, the Administration concluded that providing additional funds to the Teacher Quality Enhancement program would not be the most effective use of funds. State and local entities may already use funds they receive under a number of other Department programs, including the Improving Teacher Quality State Grants program and the Transition to Teaching program, to carry out the kinds of activities supported through the Teacher Quality Enhancement program.

#### IMPROVING TEACHER QUALITY STATE GRANTS

For example, the Improving Teacher Quality State Grants program focuses on preparing, training, and recruiting high-quality teachers. Under that program States may use funds to reform teacher and principal certification and licensing requirements, support alternative routes to State certification, support teacher and principal recruitment and retention initiatives, and initiate innovative strategies to improve teacher quality.

Additionally, under that program States are required to award subgrants on a competitive basis to partnerships that are structured similarly to the partnerships mandated under the Teacher Quality Enhancement program and consisting of at least one institution of higher education, one high-need local educational agency, and one other entity. Partnerships may receive funds to support new teacher and principal recruitment and retention initiatives as well as to support a broad range of innovative initiatives to improve teacher quality, including signing bonuses and other financial incentives, teacher and principal mentoring, reforming tenure systems, merit pay, teacher testing, and pay differentiation initiatives.

#### TRANSITION TO TEACHING PROGRAM

The Transition to Teaching program is also intended to help mitigate the shortage of qualified licensed or certified teachers in many of our Nation's schools by, among other things, encouraging the development and expansion of alternative routes to certification. The program provides funds to States, local educational authorities, and partnerships to support efforts to recruit, train, and place high-quality teachers in high need schools and school districts.

#### TEACHER QUALITY ENHANCEMENT PROGRAM

In light of the serious programmatic deficiencies identified through the PART process when the Teacher Quality Enhancement program was assessed in 2003, the Administration has concluded that the resources previously used to support this program should be shifted to higher-priority programs and initiatives that have greater potential to be effective in improving teacher quality. The Administration's budget request for programs in the Department designed to improve the quality of teachers demonstrates its commitment to ensuring that all American students have access to the highest quality teachers.

#### ELEMENTARY AND SECONDARY SCHOOL COUNSELING PROGRAM

*Question.* As part of the *No Child Left Behind Act*, Congress expanded the Elementary and Secondary School Counseling Program (ESSCP) to include secondary



school activities. However, due to the program's statutory funding trigger, secondary schools will not benefit unless total funding exceeds \$40 million, with the base amount reserved for elementary schools. Providing \$75 million for the ESSCP will trigger the statutory requirement to support secondary school counselors, while maintaining funding for elementary school counselors.

The Elementary and Secondary School Counseling Program is intended to provide schools with the necessary resources so that school counselors, school psychologists, school social workers, child and adolescent psychiatrists, and other qualified psychologists can work together to establish a comprehensive counseling program to improve academic achievement, provide career/education planning and facilitate personal/social development.

Why did you decide to no longer fund the Elementary and Secondary School Counseling Program? It seems contradictory to one of the strongest messages from the President's fiscal year 2006 budget proposal, i.e., the need for high school reform.

Answer. The budget request to eliminate funding for the Elementary and Secondary School Counseling program is part of an overall budget strategy to discontinue programs that duplicate other programs that may be carried out with flexible State formula grant funds, or that involve activities that are better or more appropriately supported through State, local, or private resources. Specifically, the 2006 budget proposes termination of 48 programs in order to free up almost \$4.3 billion (based on 2005 levels) for reallocation to higher-priority activities within the Department, including high school reform. Under the Administration's \$1.24 billion High School Intervention initiative, school districts will be able to include student counseling services as part of comprehensive strategies they adopt to raise high school achievement and eliminate gaps in achievement among subgroups of students.

The 2006 President's budget request also reflects the Nation's priorities to improve our homeland defenses, strengthen the armed forces, and promote economic opportunity. In order to ensure sustained economic prosperity, the President believes that it is imperative that spending be restrained and that the Nation's budget deficit be cut in half by 2009. The 2006 request would put us on track toward achieving that goal.

#### SCHOOL COUNSELING SERVICES

*Question.* Why would you eliminate the one program that supports the school personnel in secondary schools (as well as elementary schools) who promote academic achievement, career planning and personal/social development which is so desperately needed by high school students?

Answer. School counseling has, for many decades, been supported almost entirely with State and local funds. The very small amount of money appropriated for the Elementary and Secondary School Counseling program is unlikely to have more than a minimal impact on the availability of counseling services nationally. As stated in the answer to the previous question, under the Administration's \$1.24 billion High School Intervention initiative, school districts may include student counseling services as part of comprehensive strategies they adopt to raise high school achievement and eliminate gaps in achievement among subgroups of students.

In addition, if school districts choose to do so, they may support counseling programs with the funds they receive under the State Grants for Innovative Programs authority, which allows them to implement programs that best meet their needs. Furthermore, the Elementary and Secondary Education Act (ESEA) provides school districts with additional flexibility to meet their own priorities by consolidating a sizable portion of their Federal funds from their allocations under certain State formula grant programs and using those funds under any other of these authorized programs. A school district that seeks to implement a school counseling program in some or all of its schools may use funds from those programs to do so.

#### QUESTIONS SUBMITTED BY SENATOR MARY L. LANDRIEU

##### EDUCATION PROGRAMS PROPOSED FOR BUDGET CUTS

*Question.* Can you please provide justification beyond that given in the Department of Education fiscal year 2006 Budget Summary for the cuts made to the following programs:

##### *Educational Technology State Grants*

Answer. Schools and districts have made great gains in educational technology in recent years. In 2003, 93 percent of schools reported that they had access to the

Internet in instructional rooms; just 2 years prior, only 77 percent of schools offered this access. While many schools continue to have technology-related needs, particularly in training teachers to integrate technology into instruction, those needs can be met with resources available through other Federal programs. For example, activities to support technology-based professional development as well as school-based reform efforts that include technology are allowable under the State Grants for Innovative Programs and the Improving Teacher Quality State Grants program. Also, under the State and Local Transferability Act, most LEAs may transfer up to 50 percent of their formula allocation under certain State formula grant programs to their allocations under any of the other authorized programs or to Part A of Title I. Therefore, an LEA that wants to implement technology programs may do so under the authorities granted through the individual programs or may transfer funds from, or to, its State Grants for Innovative Programs or Improving Teacher Quality State Grants allocation, without having to go through a separate grant application process.

#### *Arts in Education*

Answer. The request to eliminate funding for the Arts in Education program supports the Administration's policy of increasing resources for high-priority programs by eliminating categorical programs that have narrow or limited effect. These categorical programs siphon off Federal resources that could be used by State and local educational agencies to improve the academic performance of all students. However, activities in the arts are allowable under larger State formula programs such as those mentioned above; by exercising the transferability authority, districts may choose to continue successful arts programs to fit the unique need of their students.

#### *Safe and Drug-Free Schools and Communities State Grants*

Answer. The Administration proposes to terminate funding for Safe and Drug-Free Schools and Communities (SDFSC) State Grants because of the program's inability to demonstrate effectiveness and the fact that funds are spread too thinly to support quality interventions. For example, SDFSC State Grants provides about 60 percent of local educational agencies (LEAs) with allocations of less than \$10,000, amounts typically too small to mount comprehensive and effective drug prevention and school safety programs.

By comparison, under SDFSC National Programs the Department has greater flexibility to provide large enough awards to support quality interventions. In addition, the National Programs authority is structured to permit grantees and independent evaluators to measure progress, hold projects accountable, and determine which outcomes are most effective. We are requesting \$317.3 million for SDFSC National Programs, an \$82.7 million, or 35 percent, increase over 2005.

#### *Alcohol Abuse Reduction program*

Answer. No funding is requested for the Alcohol Abuse Reduction program, because it is duplicative of other Elementary and Secondary Education Act (ESEA) programs. Local educational agencies (LEAs) that receive Safe Schools/Healthy Students grants or the proposed research-based grant assistance under SDFSC National Programs may use those funds to support similar activities. LEAs may also use their ESEA Title V (State Grants for Innovative Programs) funds as well as funds they may transfer to ESEA Title V from their ESEA Title II Improving Teacher Quality State Grants program) allocation, to support alcohol abuse prevention.

#### *Elementary and Secondary School Counseling*

Answer. The budget request to eliminate funding for the Elementary and Secondary School Counseling program is part of an overall budget strategy to discontinue programs that duplicate other programs that may be carried out with flexible State formula grant funds, or that involve activities that are better or more appropriately supported through State, local, or private resources. Specifically, the 2006 budget proposes termination of 48 programs in order to free up almost \$4.3 billion (based on 2005 levels) for reallocation to higher-priority activities within the Department.

The 2006 President's budget request also reflects the Nation's priorities to improve our homeland defenses, strengthen the armed forces, and promote economic opportunity. In order to ensure sustained economic prosperity, the President believes that it is imperative that spending be restrained and that the Nation's budget deficit be cut in half by 2009. The 2006 request would put us on track toward achieving that goal.

School counseling has, for many decades, been supported almost entirely with State and local funds. The very small amount of money appropriated for the Ele-

mentary and Secondary School Counseling program is unlikely to have more than a minimal impact on the availability of counseling services nationally. Under the Administration's \$1.24 billion High School Intervention initiative, school districts may include student counseling services as part of comprehensive strategies they adopt to raise high school achievement and eliminate gaps in achievement among subgroups of students.

In addition, if school districts choose to do so, they may support counseling programs with the funds they receive under the State Grants for Innovative Programs authority, which allows them to implement programs that best meet their needs. Furthermore, the Elementary and Secondary Education Act (ESEA) provides school districts with additional flexibility to meet their own priorities by consolidating a sizable portion of their Federal funds from their allocations under certain State formula grant programs and using those funds under any other of these authorized programs. A school district that seeks to implement a school counseling program in some or all of its schools may use funds from those programs to do so.

#### *Carl Perkins Vocational and Technical Education*

Answer. The President's fiscal year 2006 budget does not request funding for Vocational Education because of severe budget constraints that the Federal Government now faces and to eliminate programs that have shown little evidence of effectiveness in order to fund a new initiative to strengthen high schools. Despite decades of Federal investment, the Vocational Education program has produced little evidence of improved academic outcomes for students. The most recent National Assessment of Vocational Education found no evidence that high school vocational courses contribute to academic achievement or postsecondary enrollment, and the "Program Assessment Rating Tool" (PART) review rated the program as ineffective. On the most recent NAEP assessments, less than 10 percent of vocational students scored at or above proficiency in mathematics (2000) and only 29 percent scored at or above proficiency in reading (1998).

A 2002 Public Agenda survey showed that 73 percent of employers rate the writing skills of recent high school graduates as fair or poor, while 63 percent express dissatisfaction with graduates' math skills. All high school students need a solid academic preparation, whether they plan to enter the world of work immediately after graduation or pursue postsecondary education. The High School Intervention program proposed in the budget to replace Vocational Education would give States and districts more flexibility to improve high school education and raise achievement, particularly the achievement of students most at risk of failure. States and school districts would be able to use funds for vocational education, tech-prep programs, and other purposes, depending on State and local needs and priorities. The Administration believes that a targeted initiative will be more effective than current programs in meeting the major need for reform and improvement of American high school education.

The budget also includes a Community College Access grants initiative to support expansion of "dual-enrollment" programs under which high school students take postsecondary courses and receive both secondary and postsecondary credit. This initiative would also help ensure that students completing such courses can continue and succeed in 4-year colleges and universities.

#### *Federal TRIO Programs*

Answer. The President's fiscal year 2006 budget does not include funding for TRIO's Upward Bound and Talent Search programs because we believe our proposed \$1.2 billion High School Intervention initiative would do a better job of improving high school education and increasing student achievement. Today, just 68 out of 100 9th graders will receive their diplomas on time. Moreover, only 51 percent of African-American students and 52 percent of Hispanic students will graduate from high school. Less than a third of students will leave high school ready to attend 4-year colleges. We believe a targeted and comprehensive approach is necessary to overcome these challenges.

The new High School Intervention initiative would require each State to develop a plan for improving high school education and increasing student achievement, especially the achievement of low-income students and students who attend schools that fail to make adequate yearly progress. States would be held accountable for improving the academic performance of at-risk students, narrowing achievement gaps, and reducing dropout rates, but States would have flexibility to provide the full range of services students need to ensure they are academically prepared for the transition to postsecondary education and the workforce. The initiative also would deepen the national knowledge base on what works in improving high schools and

high school student achievement by supporting scientifically based research on specific interventions that have promise for improving outcomes.

We believe this High School Intervention initiative would be more effective than our current, disjointed approach that has not served all students well. Upward Bound has been found to serve low-income students who have unusually high educational expectations and who would enroll in college regardless of their participation in the program. The high college enrollment rate for these Upward Bound students (65 percent) hides the reality that only 34 percent of the neediest students served by Upward Bound enroll in college. Although the program could have a significant impact if it served more students who truly need help, we do not have evidence to show that our efforts to target more of the neediest students have been successful. And the Administration's assessment of Talent Search did not find evidence that it is effective in helping disadvantaged students enroll in college.

Replacing Upward Bound and Talent Search with the new High School Intervention initiative would help us reach our strategic goals of improving the performance of all high school students and increasing access to postsecondary education. The more comprehensive approach would give States the flexibility to incorporate the best elements of these programs to achieve better results. However, in the interest of minimizing the disruption of services to students, funding for the High School Intervention initiative would support existing Upward Bound and Talent Search projects that would be eligible for continuation funding in fiscal year 2006.

#### *GEAR UP*

Answer. The President's fiscal year 2006 budget proposes to cut funding for GEAR UP for the same reasons—the new High School Intervention initiative would be a more targeted and comprehensive approach to improving high school education and increasing the achievement of all students. Although the Administration's assessment of GEAR UP found positive early results, there are no data regarding the program's effects on high school outcomes and college enrollment. The High School Intervention initiative would require States to focus on results, and it would provide support for rigorous, scientifically based research to determine the best methods for helping all students prepare for and succeed in college. In fiscal year 2006, continuing GEAR UP projects would be funded under the new initiative. In future years, the types of services currently provided under programs like TRIO and GEAR UP may be continued by States as part of their coordinated plans for improving high school education and increasing student achievement.

#### PER PUPIL EDUCATION COSTS IN THE UNITED STATES

*Question.* Every year when the budget comes out, there seems to always be an uproar from some of us on Capitol Hill that not enough funding was dedicated to the Department of Education. I appreciate that during this period of record high budget deficits, fiscal responsibility is a necessity. It also occurs to me, however, that regardless of how "tight" the budget is, there is a bottom dollar amount that it costs to educate a child. In your opinion, what is that amount for an elementary school student, a junior high school student, and a high school student? In asking this, I am asking for your expert opinion as the Secretary of the Department of Education and am referring to the total amount it costs to provide a public school student with the most basic education, regardless of funding source (i.e. Federal, State, or local government). Also, this question does not refer to how much is currently being spent per student, but how much do you believe is the bottom dollar amount that we should be spending per student.

Answer. It is not possible to develop such a number for several reasons. The most fundamental reason is that what constitutes an appropriate education differs from State to State. As each State develops its own system of standards, it implicitly creates a different system of education needed to meet those standards with different costs. Additionally, differences in children mean differences in costs. The resources necessary to educate a third-grader who is blind are different from that necessary to educate a third-grader whose parents have just immigrated from a foreign nation.

Goods and labor market conditions also affect costs. Fuel costs are higher in some States, making bus transportation more expensive. In some school districts, distances are great, similarly raising transportation costs. Economies of scale make education cheaper in some locales. A district that can take bids from several speech-language pathologists for services likely will have lower costs than a district with only one or two from which to choose. For all of these reasons, it is simply not possible to develop a meaningful measure of minimum costs necessary to educate a child at any age.

## READING BY THIRD GRADE

*Question.* Numerous studies, including those funded by the Department of Education, show that parents' low literacy affects their children's performance in school. The single most significant predictor of children's literacy is their mother's literacy level. Children of parents who have less than a high school education tend to do poorest on reading tests, while children of high school graduates do much better. These differences in test scores have held constant since 1971, and the same differences show up in the scores of 3rd, 8th, and 11th graders. We also know that the more literate parents are, the more they support and participate in their children's education. With the President's proposed cuts to Adult Basic and Literacy Education funding, how will parents with low literacy levels or limited English skills help their children achieve at the levels established by No Child Left Behind?

*Answer.* The Department agrees that parents play a vital role in determining the success of a child's education. The parental involvement requirements under Part A of Title I, Title III, and other NCLB programs, encourage parents to become full partners in their child's education. NCLB provisions not only require schools to reach out to parents, through parental involvement activities, but also to provide information on school performance, school choice options, supplemental educational services, and other key elements of Title I to all parents and in a language and form that parents can understand.

In addition, the Department remains committed to addressing the needs of immigrant and limited English proficient (LEP) students and their parents. The fiscal year 2006 request includes level funding at \$68.6 million for English Literacy and Civics Education grants, which serve a vital purpose in States with large numbers of non-English-speaking immigrants.

## IMMIGRANT EDUCATION

*Question.* According to the Aspen Institute, immigrants supplied half of our workforce growth in the 1990s and will account for all of our net workforce growth over the next 20 years. More immigrants arrived in the 1990s—13 million—than in any other decade in U.S. history. In light of these statistics, based on the 2000 Census and Bureau of Labor Statistics projections, the President's proposed budget cuts to Adult Basic and English Literacy programs do not make sense. Doesn't it appear that English as a Second Language funding for adults is more important than ever before?

*Answer.* The Department agrees that there is a considerable need to address the needs of the immigrant population, both at the elementary and secondary levels as well as at the adult level. This is reflected in current budget request, which includes level funding at \$68.6 million for English Literacy and Civics Education grants to support States with large numbers of non-English-speaking immigrants. Unlike regular Adult Education State grants, which rely upon decennial U.S. Census data, English Literacy and Civics Education grants are based on a combination of 10-year Census averages and recent population data and are, therefore, more responsive to fluctuations in immigration patterns. English Literacy and Civics Education grants will enable limited-English-proficient (LEP) immigrants to attain the language skills that are central both to their integration into society and to their success as members of the workforce.

## QUESTION SUBMITTED BY SENATOR ROBERT C. BYRD

## ROBERT C. BYRD SCHOLARSHIPS

*Question.* President Bush's fiscal year 2006 budget submission proposes to eliminate funding for the National Robert C. Byrd Honors Scholarship program. The scholarship program, which was established by Congress in 1986, makes awards to students in all 50 States, the District of Columbia, and Puerto Rico, and is the only merit-based form of Federal financial aid. According to the U.S. Department of Education, the program has made available a total of 336,525 1-year scholarships. The President's budget justification states that the National Robert C. Byrd Honors Scholarship program duplicates State, local, and private efforts. Madam Secretary, I recognize that the President's budget includes an increase in funding for Pell Grants, and that is welcome. But does the Bush Administration believe that we should not recognize and reward academic excellence, solely because some States, localities, and private institutions also recognize academic excellence?

*Answer.* While the Administration agrees that it is important to reward academic excellence, the Administration believes that it is critical to focus such merit-based

assistance on students with the highest financial need in order to target Federal assistance where it can be most effective. As a result, the Administration has requested \$33 million for the Enhanced Pell Grants for State Scholars program. This program would provide up to an additional \$1,000 in Pell Grants to students who complete a rigorous State Scholars curriculum in high school.

The National Robert C. Byrd Honors Scholarship program was assessed using the Program Assessment Rating Tool (PART) for fiscal year 2006 and received a rating of "Results Not Demonstrated." The PART assessment identified several major design deficiencies that limit the program's effectiveness or efficiency. The PART assessment found the Byrd Honors Scholarship program to be duplicative of programs at the State, local and institutional level, noting that numerous non-Federal programs provide merit-based aid for outstanding students entering or continuing postsecondary education. All other Department scholarship programs are need-based, supporting those students who have a demonstrated financial need. This approach is central to one of the Department's strategic plan goals, which calls for the agency to increase access to quality postsecondary education especially to students with high financial need. The PART assessment noted that there is no evidence to suggest that scholarship recipients would otherwise be unable to attend college and that this program may subsidize activities that would have occurred without the program.

In response to these findings, the Administration determined that the resources previously used to support this program should be shifted to higher priority programs that target funds more effectively. The Administration's budget request for other Federal student financial assistance programs demonstrates its commitment to ensuring that all Americans have access to and financial assistance for lifelong learning.

#### SUBCOMMITTEE RECESS

Senator HARKIN. Thank you very much, Madame Secretary.

The subcommittee will stand in recess to reconvene at 10:30 a.m. on Tuesday, March 15 in room SD-124. At that time we will hear testimony from the Honorable Elaine Chao, Secretary, Department of Labor.

[Whereupon, at 10:38 a.m., Wednesday, March 2, the subcommittee was recessed, to reconvene at 10:30 a.m., Tuesday, March 15.]

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, AND EDUCATION, AND  
RELATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

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**TUESDAY, MARCH 15, 2005**

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

The subcommittee met at 10:30 a.m., in room SD-124, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Craig, Harkin, and Inouye.

**DEPARTMENT OF LABOR**

**OFFICE OF THE SECRETARY**

**STATEMENT OF HON. ELAINE L. CHAO, SECRETARY**

**OPENING STATEMENT OF SENATOR ARLEN SPECTER**

Senator SPECTER. Ladies and gentlemen, the hour of 10:30 having arrived, the Senate Appropriations Subcommittee on Labor, Health, Human Services, and Education will now proceed. We have as our witness Secretary Elaine Chao, first Asian-American woman appointed to the President's Cabinet in U.S. history, a very, very distinguished record prior to coming to the position of Secretary of Labor: President and CEO of the United Way Foundation; Director of the Peace Corps; Deputy Secretary of Transportation for President Bush the first; distinguished fellow at the Heritage Foundation; and MBA from the Harvard Business School; an undergraduate degree from Mount Holyoke College.

So the Secretary has brought very distinguished credentials to the job and now she's in her second term, and has gained a lot of experience on how to handle a very tough Department. And in the ante room I asked her how she's going to get along on so little money, and she said she'd rather answer that question only once. So in a few minutes I'm going to ask her that question.

The budget is for \$11.6 billion, \$425 million below the level for fiscal year 2005, which is a 3.5 percent reduction and when you figure in the inflation rate, it'll be somewhere near 6 percent. There is no doubt that we have to economize, but this budget is going to be very, very challenging, Madam Secretary, and we will work with you on the priorities.

## PREPARED STATEMENT

I see that there is \$1.38 billion for worker protection programs and \$250 million to continue the community college initiative. This is most days very busy on Capitol Hill with the budget under consideration, and I am due to offer an amendment to try to get a little extra funding for this subcommittee. So I will ask that my full statement be made a part of the record and will yield to the distinguished chairman of the full committee, Senator Cochran.

[The statement follows:]

## PREPARED STATEMENT OF SENATOR ARLEN SPECTER

This morning, the subcommittee on Labor, Health and Human Services and Education will discuss the President's \$11.6 billion 2006 budget request for the Department of Labor, which is a net reduction of \$425 million below the fiscal year 2005 level. We are delighted to have before us the distinguished Secretary of Labor, the Honorable Elaine Chao, our Nation's 24th Secretary of Labor.

This subcommittee is pleased to see several shared priorities funded in the fiscal year 2006 budget, including worker protection programs, and the Community College Initiative.

However, I am concerned that at the same time, there is \$575 million of program reductions and eliminations. For example, the \$49.4 million program for Responsible Reintegration of Youthful Offenders is eliminated; the \$76.2 million program for Training Migrant and Seasonal Farmworkers is also eliminated; Dislocated Worker State grants are reduced by \$132.5 million, and the Job Corps is cut by \$34.8 million.

I know, Madam Secretary, that you can appreciate the difficult tradeoffs that this subcommittee will need to negotiate in the coming months as we balance the competing pressures of education, biomedical research, worker protection programs and continued investment in our Nation's youth. Madame Secretary, I look forward to working with you to craft an appropriations bill that maintains our commitment to fiscal restraint while preserving funding for high priority programs.

## OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Mr. Chairman, thank you very much. Madam Secretary, welcome to the hearing of our Appropriations Committee, specifically the Subcommittee on Labor, Health and Human Services. We appreciate your distinguished service as Secretary of Labor. It's one of the tough jobs in the Government, though we know with your experience you bring a great deal of expertise and knowledge that will be very helpful to not only the President but our country as you carry out the duties of this important office.

## BUDGET REQUEST

We know the budget request is lean and difficult to imagine being implemented as it's presented because there's some tightening of the budget, because we are working hard to control the deficit and make sure that there's room in this economy for continued growth, expansion, and creation of jobs. The Department of Labor, as much as any Department of Government, understands the importance of trying to hold the line on spending. And so some very difficult choices are obvious.

We are looking forward to working with you and getting the benefit of your advice and suggestions as we proceed to review the budget request to make sure that we don't make mistakes and cut programs that we shouldn't, but we know we are going to have to make some tough choices. So we thank you for your being here and your distinguished service.



Senator SPECTER. Thank you very much, Mr. Chairman, Senator Cochran. Secretary Chao, now we look forward to your testimony.

SUMMARY STATEMENT OF HON. ELAINE L. CHAO

Secretary CHAO. Thank you very much. Mr. Chairman, I know that you are pressed for time, so I'm just going to summarize my—

Senator SPECTER. That would be fine, leaving us the maximum amount of time for dialogue, questions and answers.

Secretary CHAO. But I do want to emphasize a couple of points.

Senator SPECTER. Fine.

PRESIDENT'S BUDGET

Secretary CHAO. One is that the President's budget will enable the Department to continue to build upon our precedent-setting record of worker protection, which you have mentioned.

Senator SPECTER. Madam Secretary, would you pull the microphone a little closer to you? Senator Thurmond always used to say, would you pull the machine closer?

Secretary CHAO. I do want to emphasize that the President's budget will enable the Department to continue our precedent-setting record on worker protection, and it will help us implement some bold new training initiatives, which I look forward to discussing. And we are looking forward to reforming the workforce investment system so that it will serve more individuals and achieve even better results.

PREPARED STATEMENT

I've got some—again, some other statements, but I think I can submit that for the record in light of the fact that your time is so tight.

[The statement follows:]

PREPARED STATEMENT OF HON. ELAINE L. CHAO

Good morning Mr. Chairman, Senator Harkin, distinguished Members of the Subcommittee, ladies and gentlemen. Thank you for the opportunity to appear before you today to present the Department of Labor's fiscal year 2006 Budget.

The total request for the Department in fiscal year 2006 is \$54.5 billion and 16,945 FTE, of which, \$14.3 billion is before the committee. Of that amount, \$11.6 billion is requested for discretionary budget authority. Our budget request will allow us to build on the accomplishments achieved in recent years while meeting the President's call to hold Federal programs to a firm test of accountability and to focus our resources on top priorities. In fiscal year 2006, the Department will continue its record-setting enforcement of worker protections and provide innovative and effective training programs to help prepare workers for good jobs in the 21st Century economy.

In his February 2nd State of the Union Address, the President underscored the need to restrain spending in order to sustain our economic prosperity. As part of this restraint, it is important that total discretionary and non-security spending be held to levels proposed in the fiscal year 2006 Budget. The savings and reforms in the Budget are important components of achieving the President's goal of cutting the budget deficit in half by 2009, and I urge the Congress to support these reforms. The fiscal year 2006 Budget includes more than 150 reductions, reforms, and terminations in non-defense discretionary programs, of which 11 affect the Department of Labor's programs. The Department wants to work with the Congress to achieve these savings.

## RECENT ACCOMPLISHMENTS

To set the stage for our fiscal year 2006 budget, I would like to highlight some of the Department's accomplishments over the last year. I am happy to report that our programs have been getting results and we continue to make steady gains in protecting America's workforce.

Under the Department's new Overtime Security Rule, we strengthened overtime protection for 6.7 million workers. Today, more workers are getting overtime pay and the rules are clearer and easier to understand and apply.

We have also set records in enforcing worker protection laws. For example, worker fatalities are at an all time-low, and the Occupational Safety and Health Administration (OSHA) has consistently exceeded its inspection targets. Workplace fatalities among Hispanic workers have fallen by 11.6 percent since 2001. And fatalities in the mining industry have now dropped to the lowest level since records were first kept in 1910.

In 2004, more than 288,000 workers received nearly \$200 million in back wages, including overtime, as a result of the Wage and Hour Division's enforcement.

The Employee Benefits Security Administration achieved more than \$3 billion in monetary results in fiscal year 2004, protecting workers' health, benefit, and retirement plans—a 121 percent increase from fiscal year 2003.

We have also enhanced the transparency and accountability of labor union finances so that union member rights are better protected and they know much more about how their dues money is being spent. Under our union transparency reforms, meaningful information about union financial transactions will be available and easily accessible to union members.

## FISCAL YEAR 2006 PRIORITIES

While we are proud of our accomplishments, we realize that more must be done to improve the lives of America's workers. Our fiscal year 2006 budget focuses on four overall priorities: protecting workers' safety and health; protecting workers' pay, benefits and union dues; protecting veterans' reemployment rights; and preparing workers for new opportunities.

## PROTECTING WORKERS

In fiscal year 2006, \$1.4 billion is requested for DOL's worker protection activities. This increase of \$27.6 million will enable the Department to continue our record-setting protection of workers' health, safety, pay, benefits and union dues.

*Occupational Safety and Health Administration*

The fiscal year 2006 budget request for OSHA is \$467.0 million and 2,208 FTE, an increase of \$2.8 million over fiscal year 2005.

OSHA will continue to target inspections on the worst hazards and the most dangerous workplaces, while providing compliance assistance to workers and employers as they create safe and healthy workplaces. The request for OSHA includes an increase of \$1.0 million for expanded compliance assistance activities in the State plan states. These funds, when matched by OSHA's state plan partners, will enable states to establish more Voluntary Protection Program sites, develop new agreements similar to OSHA Strategic Partnerships and Alliances, and provide additional outreach to workers and employers. An additional increase of \$1.0 million is requested to enhance OSHA's data analysis and performance measurement capability.

*Mine Safety and Health Administration*

MSHA protects the safety and health of the Nation's miners through enforcement of the Federal Mine Safety and Health Act of 1977. The fiscal year 2006 budget request is \$280.5 million and 2,187 FTE, representing a funding increase of \$1.4 million over fiscal year 2005.

The Administration will seek to strengthen existing enforcement by asking Congress for higher civil monetary penalties. Legislation will be pursued to increase the fine for mine safety violations from \$60,000 to \$220,000.

## PROTECTING WORKERS' PAY, BENEFITS, AND UNION DUES

The Department will also continue its high priority programs to protect workers' pay, benefits and union dues.

*Employment Standards Administration*

The Department's Employment Standards Administration (ESA) administers and enforces a variety of laws designed to enhance the welfare and protect the rights of American workers. The fiscal year 2006 budget request before the Committee for

ESA is \$610.7 million and 4,282 FTE. This amount excludes and additional \$31.0 million of H1B fees and \$45.0 million in FECA Fair Share funding available to the agency. This represents an increase of \$81.7 million and 162 FTE from fiscal year 2005, primarily due to the additional responsibilities associated with the Energy Employees Occupational Illness Compensation Program (EEOICPA).

#### *Wage and Hour Division*

The fiscal year 2006 budget request for the Wage and Hour Division totals \$167.4 million and 1,346 FTE which excludes \$31.0 million in estimated fee revenue from DOL's portion of an H-1B visa fraud prevention fee authorized by the 2004 H-1B Visa Reform Act. The resources requested will support the Wage and Hour Division's Overtime Security Task Force and its "Off-the-Clock" Initiative to promote compliance through education and enforcement efforts in low-wage industries. It will also support Wage and Hour's YouthRules! Initiative to promote compliance with the youth employment provisions of the Fair Labor Standards Act; enable expansion of enforcement to protect vulnerable workers in low-wage industries; and increase technical assistance and education to encourage compliance with labor laws. The budget also includes a legislative proposal to increase civil monetary penalties for violations causing death or serious injury to youths in the workplace from \$11,000 to \$50,000, and to \$100,000 for repeat or willful violations.

#### *Office of Federal Contract Compliance*

The fiscal year 2006 budget request for the Office of Federal Contract Compliance Programs (OFCCP) totals \$82.1 million and 691 FTE. OFCCP is responsible for ensuring equal employment opportunity and non-discrimination in employment for businesses contracting with the Federal Government. OFCCP carries out this mandate by conducting compliance reviews to discover instances of systemic discrimination, taking appropriate enforcement action, and providing relevant and effective compliance assistance programs. During fiscal year 2006, the implementation of Active Case Management and Functional Affirmative Action Programs will improve OFCCP's results, meaning more workers will be protected.

#### *Office of Workers' Compensation Programs*

The fiscal year 2006 budget request for the Office of Workers' Compensation Programs (OWCP) totals \$341.8 million and 1,758 FTE and supports the Federal Employees' Compensation Act, the Longshore and Harbor Workers' Compensation program, and the Black Lung Benefits program. Included in this request is a \$5 million increase in Fair Share funding to effectively implement the new centralized medical bill processing contract.

The OWCP budget also includes \$96.1 million and 275 FTE to administer Part B of the Energy Employees Occupational Illness Compensation Program, and \$59.9 million and 219 FTE for the Part E program that was established in fiscal year 2005. The two Energy programs provide compensation and medical benefits to employees or survivors of employees of the Department of Energy, and certain of its contractors and subcontractors who suffer from a radiation-related cancer, beryllium-related disease, chronic silicosis or other covered illnesses due to exposure to toxic substances as a result of their work at Department of Energy facilities or those of certain of its contractors.

The 2006 budget also includes two legislative proposals affecting OWCP programs. The first is a proposal to reform FECA to update its benefit structure, adopt best practices of State workers' compensation systems, and strengthen return-to-work incentives. This proposal is expected to generate Government-wide savings of more than \$720 million over 10 years. The second is a proposal to restructure and eventually retire the debt of the Black Lung Disability Trust Fund (BLDTF), a debt that is estimated to exceed \$9.6 billion by fiscal year 2006, absent legislative action.

#### *Office of Labor-Management Standards*

The fiscal year 2006 budget request for the Office of Labor-Management Standards (OLMS) totals \$48.8 million and 384 FTE. OLMS enforces provisions of Federal law that establish standards for union democracy and financial integrity. OLMS conducts investigative audits and criminal investigations for embezzlement and other financial mismanagement; conducts civil investigations of union officer elections and supervises remedial elections where required; administers statutory union financial reporting requirements; and provides for public disclosure of filed reports.

To help restore OLMS after deep cuts during the 1990s, the budget request includes program increases of \$6.0 million and 48 FTE to enhance union financial integrity, union advisory services, and compliance assistance activities. The budget also supports legislation that would authorize OLMS to impose civil money penalties on unions and others that fail to file required financial reports on a timely basis.

#### *Employee Benefits Security Administration*

The Department's Employee Benefits Security Administration protects the integrity of pensions, health plans, and other employee benefits for more than 150 million workers. The fiscal year 2006 budget includes a \$5.8 million increase to strengthen the retirement security of workers and retirees. These amounts include additional resources for the E-FAST system to maintain current operations.

With regard to pension benefits, this Administration believes that pension promises made to workers and retirees must be kept. The current system does not ensure that pension plans are adequately funded. Underfunded plan terminations threaten workers' retirement security and are placing an increasing strain on the pension insurance system. These underfunded plans also impose an unfair and increasing burden on employers who sponsor healthy pension plans.

The President's Budget for fiscal year 2006 proposes to reform the funding rules, increase disclosures to workers, and protect the pension insurance system, on which 44 million Americans rely to protect their retirement security. The Administration's plan will promote simplicity, accuracy, stability, and flexibility. It will encourage employers to fully fund their defined-benefit pension plans and ensure that benefit promises are kept. It will also expand, and make more timely, disclosures to workers and the public.

The Administration's plan will reform the outdated premium structure to reflect more accurately the cost of the insurance program. The plan proposes to update flat rate premiums and index them to wage growth. We will also propose to shift the emphasis to risk-based premiums for all under funded plans in order to provide greater incentives for responsible funding.

The fiscal year 2006 budget reiterates the Administration's support for Association Health Plan legislation that will allow small businesses and others to pool together through their trade and professional associations to provide health benefits for workers and their families. By joining together, small businesses and other association members would benefit from similar economies of scale, uniform regulation and administrative efficiencies enjoyed by large employers and labor unions. Association Health Plan legislation is a key component of the President's plan to improve access to quality, affordable health coverage for all Americans.

#### PROTECTING VETERANS' EMPLOYMENT RIGHTS

This Nation's commitment to our veterans must be honored. No veteran should return home without the support that is needed to make the transition back to private life a smooth and successful one.

#### *Veterans' Employment and Training Service*

For the Department's Veterans' Employment and Training Service (VETS), we are requesting \$224.3 million and 250 FTE to maximize employment opportunities for veterans and protect their employment rights.

The Department recently issued a notice of proposed rulemaking to strengthen and clarify veterans' rights and employers' responsibilities under the Uniformed Services Employment and Reemployment Rights Act (USERRA). The rule is expected to be finalized during fiscal year 2006. Our budget request also includes \$22 million for the Homeless Veterans Reintegration Program, an increase of \$1.2 million. This program will provide employment and training assistance to homeless veterans, with expected job placements and retention of approximately 10,600 veterans.

#### PREPARING WORKERS FOR NEW OPPORTUNITIES

#### *Reforming the Workforce Investment System*

Overall, the fiscal year 2006 budget request for the Department's Employment and Training Administration is \$9.2 billion in discretionary funds and 1,216 FTE. Our budget request will allow the Department to fulfill the President's call to improve job training and prepare more Americans for the growing and changing economy, ensuring that no worker is left behind. In 2006, we want to double the number of individuals trained under the Workforce Investment Act's major grant programs—including State formula grants and the new Community College Initiative—from 200,000 to 400,000. Just as important, we want to help provide workers with training that prepares them for the jobs of the 21st century.

Under the President's job training reform proposal, we seek legislation to reform the Workforce Investment Act (WIA) that would consolidate four compartmentalized programs into a single funding stream so that Governors and local officials will be able to utilize resources in a way that best meets their communities' specific needs. This proposal, called "WIA Plus," would provide Governors the option of adding resources from up to five additional federally-funded employment and training pro-

grams to this consolidated State grant. The major goals include providing flexibility to States and localities and reducing overhead so that more workers can receive training.

In return for this increased flexibility, States will be required to develop strategies to meet increasingly rigorous performance standards each year, leading to a goal in the 10th year of placing in employment 100 percent of the workers trained with Federal funds.

The President's WIA reform proposal would also establish Innovation Training Accounts to provide workers ownership over the education and training they pursue by:

- Allowing individuals to access a broad range of public and private training resources through a single, self-managed account;
- Authorizing longer-term training opportunities, since many skills needed for today's jobs require more than just short-term attention and exposure;
- Providing access to improved labor market information to help individuals make training decisions based on the jobs available in their local area;
- Holding training institutions accountable for results;
- Acknowledging the need for incumbent worker training so workers can update their skills and advance their careers; and,
- Promoting the attainment of industry-recognized credentials and certifications.

#### *High Growth Job Training Initiative*

The President's High Growth Job Training Initiative is designed to develop a demand-driven workforce training system. This initiative, which began in 2002, prepares workers to take advantage of new job opportunities in growing industries and sectors of the American economy. The approach is based on grants to partnerships that include the workforce investment system, business and industry, education and training providers, and economic development entities working collaboratively to develop industry-specific workforce solutions. Under this initiative, the Department has awarded \$164.8 million in 88 grants for innovative training programs in high growth industries, such as health-care, biotechnology and advanced manufacturing. By training workers with skills that are in demand, more workers will be able to obtain quality jobs with higher wages and enhanced career opportunities. At the same time, employers will be able to fill critical workforce needs.

#### *Community College Initiative*

The budget also provides \$250 million to continue the President's Community College Initiative, which provides for Community Based Job Training Grants. For 2005, the Congress approved and financed this new initiative, and the first grants will be awarded beginning in the summer of 2005. Eighty percent of the jobs in the fastest growing fields require education and training beyond high school. The Community College Initiative will help fully utilize the expertise of America's community colleges as part of our job training programs and better train workers for jobs in high growth sectors. These competitive grants will build on the High Growth Job Training Initiative and strengthen the role of community and technical colleges as partners of the workforce investment system.

#### *Youthbuild*

The President's Budget includes a legislative proposal to transfer the Youthbuild program from the Department of Housing and Urban Development to DOL. This change was recommended by the White House Task Force on Disadvantaged Youth. The Youthbuild program targets disadvantaged youth ages 16–24. The program provides grants to local organizations that train participants for well-paying construction jobs. Their training also results in the building of affordable housing units. Transferring Youthbuild to DOL would provide the program with better contacts with One Stop Career Centers, stronger ties to DOL's Job Corps and apprenticeship programs, new links to the President's High Growth Job Training Initiative, improved access to the post secondary and community college system, and stronger connections to employers and local labor markets. It also promises to offer greater placement opportunities for the youths involved.

#### *Prisoner Re-Entry Initiative*

In fiscal year 2006, \$75 million is provided for the second year of the President's 4 year, multi-departmental Prisoner Re-Entry Initiative. Of this total, \$35 million is for the Department of Labor, \$25 million is for the Department of Housing and Urban Development, and \$15 million is for the Department of Justice. This initiative is designed to strengthen urban communities through an employment-centered program that incorporates job training, short-term housing, mentoring, and other transitional services to help recently released prisoners make a successful transition

back to society and long-term employment. It taps the unique contributions and capacities of America's faith-based and community organizations.

*Strengthening the Integrity of the Unemployment Insurance System*

Building on previous proposals to strengthen the Unemployment Insurance (UI) system and reduce erroneous UI payments, the fiscal year 2006 budget proposes a \$10 million increase in beneficiary eligibility reviews in One-Stop Career Centers. This is projected to save up to \$225 million annually. In addition, a \$30 million increase is requested to prevent and detect fraudulent unemployment benefit claims using stolen personal information—otherwise known as identity theft—that would result in annual trust fund savings of as much as \$105 million. These two discretionary proposals are part of the Administration's proposal to fund efforts to reduce improper payments across several agencies using a new budget enforcement mechanism of spending cap adjustments. In addition, the Budget includes a package of legislative changes to prevent and recover overpayments of Unemployment Insurance benefits, saving an estimated \$4.7 billion over 10 years. These budget and legislative proposals are not only an important protection for American workers, but are also a responsible use of public funds.

OTHER PROGRAMS

*Bureau of Labor Statistics*

In order to maintain the development of timely and accurate statistics on major labor market indicators, the fiscal year 2006 budget provides the Bureau of Labor Statistics with \$542.5 million and 2,475 FTE, which is an increase of \$13.5 million over fiscal year 2005. This funding level provides the BLS with the necessary resources to continue producing sensitive and important economic data, including the Consumer Price Index, the Producer Price Index, and the Quarterly Census of Employment and Wages.

*Office of Disability Employment Policy*

The 2006 budget request provides the Office of Disability Employment Policy (ODEP) with a total of \$27.9 million and 59 FTE. In past years, the request for ODEP included a large research and grant making function. ODEP has invested these funds in testing a variety of pilot projects, and we now have several years of results to determine which of these pilots work, and which ones don't. ODEP will now focus on improving access by disabled Americans to DOL's programs, and on developing proven approaches to helping Americans with disabilities find meaningful employment opportunities.

*Women's Bureau*

To continue its outreach to working women, the fiscal year 2006 budget includes \$9.7 million and 60 FTE for the Women's Bureau, an increase of \$0.3 million above fiscal year 2005.

*International Labor Affairs Bureau*

The request for the International Labor Affairs Bureau (ILAB) in fiscal year 2006 is \$12.4 million and 95 FTE. The budget returns ILAB to its core mission of developing international labor policy, and performing research, analysis, and advocacy.

The requested funding levels would allow ILAB to implement the labor supplementary agreement to NAFTA and the labor provisions of trade agreements negotiated under the Trade Act of 2002, participate in the formulation of U.S. trade policy and negotiation of trade agreements, conduct research and report on global working conditions, assess the impact on U.S. employment of trade agreements, and represent the U.S. Government before international labor organizations, including the International Labor Organization.

ILAB will continue to implement ongoing efforts in more than 70 countries funded in previous years to eliminate the worst forms of child labor and promote the application of core labor standards, and reduce employment discrimination against persons living with HIV/AIDS.

*President's Management Agenda and Department-wide Management Initiatives*

Before I close today, Mr. Chairman, I also want to highlight the Department's ongoing efforts to implement the President's Management Agenda. In August 2001, President Bush sent to Congress his President's Management Agenda (PMA), a strategy for improving the management and performance of the Federal Government. The agenda called for focused efforts in the following five government-wide initiatives aimed at improving results to citizens: Strategic Management of Human Capital, Competitive Sourcing, Improved Financial Performance, Expanded Elec-

tronic Government, and Budget and Performance Integration. DOL is also responsible for three of the PMA initiatives that are found only in selected departments. The first of these three is Faith-Based and Community Initiatives. In the fourth quarter of 2004, DOL began working in earnest on another selected PMA component, Real Property. Also, in the first quarter of 2005, DOL began tracking its status and progress on a new PMA initiative to Eliminate Improper Payments.

The Department is one of only three cabinet departments that earned "green" status ratings on four of the five government-wide scorecards for the first quarter of 2005, without a single red score. For progress during this period, DOL achieved five of five green scores. On the basis of its favorable ratings for status and progress in implementation of these initiatives, DOL was honored with two Presidential Quality Awards and is recognized as one of the best managed Cabinet agencies.

#### CONCLUSION

With the resources we have requested for fiscal year 2006, the Department will continue to improve its protection of workers' safety and health, protect workers' pay, benefits, and union dues, secure the employment rights of America's veterans, and prepare workers for the jobs of the 21st Century.

Mr. Chairman, this is an overview of the programs we have planned at the Department of Labor for fiscal year 2006.

I would be happy to respond to any questions members of the subcommittee may have.

Thank you.

#### MEDICAL LEAVE PROGRAM

Senator SPECTER. Okay. Well, thank you, Madam Secretary. The medical leave program has been challenged with some 68 Federal lawsuits raising issues on the interpretation of when employees are eligible for leave under the 1993 Family and Medical Leave Act. Last December, your Department announced its intention to publish a rule to revise the Act's regulations.

There are many in the labor area who like the way the program is being administered and there are some in the business area who would like to see their restrictions tightened. We have been studying the issue, but we would be very interested in your view as to how the regulations are being administered, whether you intend to put up new regulations, and what your evaluation is as to the equitable balance as you see it.

Secretary CHAO. First of all, let me say that the Family and Medical Leave Act is an important law that basically benefits a lot of workers and their families, and we take our responsibilities under this law very seriously. Let me also say that in the last 10 years that the regulations have been in effect, there have been numerous lawsuits challenging various provisions of the regulations. And some of these provisions in the regulations that were set out have in fact been struck down, including one by the Supreme Court in a decision in 2002, *Ragsdale v. Wolverine*.

So we are mandated by the Court to revisit certain aspects of the Family and Medical Leave Act, and we've, in response to the Supreme Court decision and other case law developments, we have held a number of stakeholder meetings throughout the last 2 years with both employees and employers, with the unions, with non-profit groups. And we have been considering a number of informal comments and the feedback that we have received from these shareholder meetings. We've been reviewing the development in case law and we are looking at a number of areas where we could possibly provide better guidance.

But let me say that no final decision has been made on this issue. We do have outstanding the 2002 Supreme Court decision on *Ragsdale*, and so something needs to be done on that.

Senator SPECTER. Well, let us work together and stay in touch to see how—what you're thinking about, have an equitable balance so that we do our best to strike a balance between what the workers have in mind on leave and what the employers are concerned with.

#### YOUTHFUL OFFENDER PROGRAM

You are again proposing to eliminate the responsible reintegration of youthful offender program, replacing it with a prisoner re-entry initiative. I was with the President and the First Lady in Pittsburgh 1 week ago yesterday, and she has a program to help troubled youth, and we have these programs sprinkled all over the map, Secretary Chao.

This prisoner re-entry initiative, you really need a score card to keep track of what's going on. It's going to be funded through three Departments, \$35 million from the Department of Labor, \$25 million from HUD, and \$15 million from the Department of Justice. Does all this alphabet soup make sense?

Secretary CHAO. I know that the youth offender program is very near and dear to your heart and it's one of your—

Senator SPECTER. Well, it has been near and dear to my heart since I worked with youthful offenders many years ago as district attorney, and it continues to be an atrocious problem. There were 11 murders in Philadelphia over the weekend. The chief of police decried the situation yesterday, noting that there were more murder—more people killed in Philadelphia over the weekend than in Iraq. So there really needs to—we really need to do something. It is a bottomless pit. What do you think?

Secretary CHAO. We know that this is a program that you place a great deal of emphasis on, and in fact we share your concern that there seems to be a great many different venues through which focus on this issue was taken, which was why we took the impetus—we took the initiative initially to try to work the young offenders program into a larger program. And so we have tried to integrate the funding. We have tried to work this program into the prison re-entry initiative.

Our concerns are the same as yours. It's too fragmented. And so we thought that, again, with the young offenders program, if we work together through the prisoners re-entry, along with a more coordinated and coherent approach with other Departments that are also involved in facing this—addressing this challenge, that we would do a better job.

Senator SPECTER. My red light is on, and I like to observe the time, but it would lose continuity if I didn't ask you one more question. We could solve this fragmentation by simply moving the Department of HUD and Urban Development and the Department of Justice under your Department of Labor, under your overall Secretaryship. Would you think that would eliminate the confusion and duplication and overlapping?

Secretary CHAO. I never refuse an offer to expand my empire. I'm only joking, of course.



Senator SPECTER. Madam Secretary—

Secretary CHAO. I think there's a larger issue here: This is very much geared toward training and getting young people together with community and faith-based organizations who support, in a holistic way, the full integration of young people back into the community. And so we thought that a more holistic, coordinated, and comprehensive approach with other Departments that are also doing the same thing would yield actually a better result for these young people.

Senator SPECTER. I want to now yield to the distinguished chairman of the full committee who may be able to solve all of our problems when he makes the allocations.

Senator COCHRAN. Mr. Chairman, thank you very much for your confidence in our decision-making capabilities. I hope that we are able to reach a decision that enables the Department of Labor to carry out its important responsibilities, particularly in job training and their programs in my State.

#### JOB CORPS PROGRAM

I had the pleasure of visiting last year a Job Corps site where they're doing very commendable work in preparing students for real jobs that exist in our State. I noticed there's a decrease in the budget request for the Job Corps program, a decrease of \$29 million below last year, and also a suggestion for rescission of funds in the construction area for the renovation and repair of buildings. I think my State has a backlog of that kind of work as well.

I hope we will be able to work with the Department to identify some changes that we can make in the budget without disrupting the overall goal of holding the line on unnecessary spending. But I mention that program, and I wonder what your impression has been of the Job Corps program, specifically its efforts to train those who don't come to the program with a high level of education, some of them don't, and so this job-training activity may be their only hope for having a good-paying job.

Secretary CHAO. The Job Corps is a very popular program. It is liked by Members across—on both sides of the aisle. It's a very popular program. The specific line item that you're referring to impacts only the construction, the rehabilitation, and acquisition account for buildings. So we do not anticipate any service reductions at all.

We will continue to pursue the acquisition of the new sites in Pinellas Park, Florida, and Milwaukee, Wisconsin. I think what we're talking about here is again, we do not expect that current funding requests will impact the current service level at all.

#### LOAN GUARANTEE

Senator COCHRAN. There is one request I called in the other day by telephone to your office. It has to do with an application for a Department of Agriculture loan guarantee submitted by a company that is planning to build a steel manufacturing plant in Columbus, Mississippi. They've applied for a loan guarantee from the Department of Agriculture under a program that I'm familiar with.

But before the Department can approve that, they're required to submit the application or notice of the application to the Depart-

ment of Labor. And the Labor Department's role is limited to making two findings: That the approval of the loan guarantee does not involve the relocation of jobs; and there will be no adverse impact on competitors in the immediate area.

In the immediate area of Columbus, there is no other steel manufacturing plant. There is no other steel manufacturing plant that will provide the material that this company will provide in the entire Southeastern United States. To my knowledge, and I'm assured that this is the case, there is no question about relocating jobs from some other area.

I had a very difficult time getting information from your office as to what the status of the matter was. I asked for additional information. I was assured that my call would be returned by somebody who could provide me with that information. I haven't received a call yet. Somebody on my staff may have gotten a call, but I haven't been advised about it until now.

I hope that you will look at this request. The company's name is Steelcorr Corporation. It would manufacture steel plates for automobile construction. We have several new automobile construction facilities that have been located in our State, in the State of Alabama, and in that region, but this would be the first plant that would be actually making steel plates to be used in the construction of these automobiles.

If this company is able to get the loan guarantee, they'll build that plant and it will provide a lot of new jobs and a lot of new industries that are compatible with it. Suppliers and the like would also likely move into our area.

So we have a great deal of interest in this, and we hope that the Department of Labor won't just continue to hold this application. It's a matter of some urgency, I'm told, so that they can move forward with the construction of this facility. I'm sorry to have to spend so much of my time talking about the importance of that. It sounds like it's something that the Department could handle very quickly.

Senator SPECTER. Senator Cochran, if you'd like more time, you're welcome to it.

Senator COCHRAN. Thank you, Mr. Chairman. I don't think I need it.

Secretary CHAO. May I answer that? May I just make a few comments about that if I could? First of all, I'm sorry that you have the impression that our Department is not responsive in answering, because when the chairman calls, both chairmen, we answer the calls right away, so again, I don't know what happened. I will check into that.

Second issue, we understand that this is a—we know that you are concerned about this issue, and we're very focused on it. We play only a very small part as you mentioned in the whole process. The Department of Labor is required by law to evaluate the impact of this financial assistance. We have about 30 days. The application was submitted on February 24 with USDA, and it was forwarded to the Department of Labor for consideration—I'm sorry—on February 24. So the Department has about 30 days and we're still in the evaluation process.

Please be assured that your interest in this is noted, and again, we are just responsible for the assessment, and then we go back to USDA and then they, of course, make the final decision.

Senator COCHRAN. I thank you for your response and hope that we will see the timely handling of the Department of Labor's responsibility for this application. Thank you, Mr. Chairman.

PERSONAL RE-EMPLOYMENT ACCOUNTS

Senator SPECTER. Thank you very much, Senator Cochran. Madam Secretary, in fiscal year 2004, Congress did not approve your request for \$50 million to initiate a new personal re-employment account program, but you used transfer authority to spend \$9 million on this program anyway. I think it is very important that when there is a refusal by the Congress on the appropriations process under the Constitution that the funding not be used in any collateral way, and I would be interested in your comments on the matter and your assurances that the Department does not intend to use the collateral way with transfer authority, where there has been an expressed declination by the Congress.

Secretary CHAO. As you know, the administration strongly supports the personal re-employment accounts, and the House passed one version and the Senate did not. Because the original larger scale personal re-employment accounts were not funded, it was decided to test the approach on a smaller pilot basis, through some demonstration projects, and I believe we notified the Appropriations Committee that we were intending to do so. And I think, as you mentioned, there's about \$7.9 million out of a huge project that was the original intended amount.

So we hope that we at least—we will get better information and test this approach on a—with some communities have voluntarily wanted to participate. And we hope that again that will yield better information on whether this works or not.

Senator SPECTER. Well, Secretary Chao, even though it's a relatively small sum of money, although we might discuss whether \$7.9 million is a relatively small sum of money, and even though it's a pilot project, and even though the administration very much wants it, and even though some communities would like to do it, it's really, really beyond the separation of powers.

Listen, you've done such a good job that I'm not going to dwell on the point. But I just want to drop a big red flag.

Secretary CHAO. Okay.

Senator SPECTER. Okay? It doesn't have any stars and stripes on it.

Secretary CHAO. I understand.

APPALACHIAN COUNCIL AND THE WORKING FOR AMERICA INSTITUTE

Senator SPECTER. Big red flag. I appreciate the work of the Department in working through the statutory deadline of January 31 to put grants into effect for several projects, including the Appalachian Council and the Working for America Institute. There have been some differences of opinion as between—these occur inevitably between the executive and the legislative branches, and that's why we have separation of powers.

But I would like you to take a look at those programs, a personal look, and let me know what you think of them, because if there are any problems there, I would like to be personally informed.

Secretary CHAO. Okay.

Senator SPECTER. An effort made to work them out. Those projects have been in effect for a long time, and they provide sort of a classic confrontation in the political field. You and I are both dedicated to service and doing what is good, so that's something that I would like something between Elaine Chao and Arlen Specter. If you would take a look at them, we can see what they're doing and try to work out any problems.

Secretary CHAO. So it's Working for America and the NCEE?

Senator SPECTER. Yes, and the Appalachian Council.

Secretary CHAO. The Appalachian Council, okay.

Senator SPECTER. And the Working for America Institute.

Secretary CHAO. These are sole-source contracts. We can talk more about them, but the main problems are sole source criteria.

Senator SPECTER. Well, we do still use them to some extent.

Secretary CHAO. But we did fund—the committee earmarked and it went out on time.

Senator SPECTER. No, no, I know you've done it, and I started off by thanking you for doing that. This initiative for the black clergy, which Senator Santorum and I were so enthusiastic about, looked like it was all going through until late in October, and we had a problem, which could have had some very serious repercussions. We were able to work it out. And I'd like you to take a look at that one too as to how they are doing.

#### FAITH-BASED INITIATIVE

This goes back to the problem we talked about, juvenile delinquency, and this is a faith-based initiative. These are churches and they've set up six job training programs. And here again is something which reaches the level where I would like the Secretary and the chairman to work together.

Secretary CHAO. I'd be pleased to do so.

#### ASBESTOS VIOLATIONS

Senator SPECTER. Madam Secretary, the issue has arisen on increasing the penalties for a willful violation of the Occupational Safety and Health Act on asbestos violations. And I would be interested—I'm considering legislation on that field. Asbestos is a terrible problem which we all know about, and I'd be interested in your views as to whether you think enhanced penalties would be a good idea there.

Secretary CHAO. I think the current discussions about the asbestos bill, which you have taken quite a leadership position on, is evolving, and we want to thank you for your leadership. It's a difficult issue. There are obviously a great array of different stakeholders. And the administration has not really taken a position on a number of these issues pending these working groups and outside stakeholder groups to come to some kind of an agreement.

Senator SPECTER. Well, we are working very hard on the asbestos bill. I had a chance to talk to the President about it when I traveled with him to Pittsburgh a week ago yesterday, and he's

looking for a bill which he can sign, and we're trying to get bipartisan activity. And your Department has had phenomenal success in administering matters.

The way it works is, if you do a good job, people come back to you and say, you've done such a good job and we'd like you to do more. We find that with this subcommittee and I find that on the Judiciary Committee. And on the legislation which we are working on to create a trust fund, there's not going to be any Federal money going into the fund.

The insurance and manufacturing industries have agreed to put up \$140 billion, which we're projecting will be sufficient. And we're working very carefully on directing it only to the sick people, so that we're not going to have any expanded coverage. It's going to people who really are sick.

The Supreme Court handed down a decision that—5 to 4—that if you were exposed to asbestos you would collect money whether you were sick or not. And thousands of people are dying of mesothelioma and asbestosis. Companies are going bankrupt, can't pay them. Seventy-four companies are going bankrupt. But there's not going to be any extended coverage, and the Department will not be called upon to be a tax collector or banker.

I'm meeting with the Attorney General later today and we're giving him a lot of new jobs too on enforcement. And it is sort of axiomatic that everybody is overworked, but this is a problem which is overwhelming the economy, and we are searching very, very hard for remedies.

I'm delighted to be joined by my distinguished ranking member, also delighted to be joined by Senator Inouye, who beat the ranking member here by 30 seconds. Senator Inouye, with his customary grace and aplomb, has gestured to take Senator Harkin first. Senator Harkin has just acceded.

As I said at the beginning of the hearing, I'm due on the floor to offer an amendment to increase the funding for our subcommittee, so I'm going to—well, we were—we've been cut everywhere, and I want to bring the funding back up to level for education, which would be a little over \$500 million and NIH \$1.5 billion. So I'm going to leave the seamless gavel in the hands of Senator Harkin.

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

Senator SPECTER. Thank you for the very good work you're doing, Madam Secretary.

Secretary CHAO. Thank you.

Senator SPECTER. We'll be working with you to tackle the tough issues which we talked about, and we will have some more questions for the record. Thank you.

Secretary CHAO. Thank you.

#### OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN [presiding]. Madam Secretary, again, welcome and I appreciate your work at the Department of Labor and your continuing efforts in that regard. I just want to join our distinguished chairman in welcome you again to this committee.

Madam Secretary, I'm just going to make a short opening statement and then we'll get to some questions and I'll yield to Senator

Inouye. Madam Secretary, I know you appreciate frank exchanges. We've had many in the past. So I must tell you up front that I am very disappointed in the administration's 2006 budget request for your Department. I appreciate that you're being a good soldier and going along with the OMB's marching orders, but I must for the record say that the proposed 2006 budget from the Department of Labor is seriously out of synch with the needs of our labor force.

#### UNEMPLOYED

Right now, 7.7 million workers are officially unemployed. Another 1.8 million are too discouraged to look for jobs, so they aren't even included in the official unemployment rate. Long-term joblessness is at record levels. Yet despite these challenges, the administration proposes to cut DOL's budget by \$400 million.

Let me mention some specifics. A 2003 General Accounting Office report found that the employment services, the principal source of employment and training programs for American workers. But the White House proposes to eliminate this proven agency and replace it with a generic block grant to the States.

#### MIGRANT FARM WORKERS

Second, the number of migrant farm workers with immigration issues has increased from 7 percent to 52 percent in the last decade. Yet the White House proposes to eliminate not only the migrant and seasonal farm worker program, but also the source of the information, the national agricultural workers study, where we get the data and the information.

#### VETERANS

Third, our soldiers are coming back from Iraq wounded in record numbers, many with amputations that will affect their employment options for the rest of their lives. Yet the White House has proposed an insignificant increase in the veterans employment and training service, and proposes to cut the Office of Disability Employment Policy by almost half.

Next, the President is promoting both the Central American Free Trade Agreement and the Andean Trade Agreement, both of which will require technical assistance on core labor standards. But this budget proposes to essentially gut the International Labor Affairs Bureau, ILAB, which provides that technical assistance.

#### WORKFORCE CHALLENGES

So as I said, Madam Secretary, these budget proposals, I believe, are out of synch with the needs of our workforce. In some cases, the budget is out of synch with the administration's own professed priorities. Our workforce today faces more challenges than at any time since the Great Depression—globalization, outsourcing, the continuing shift from manufacturing to services. I would argue the Department of Labor needs more resources, not less. Rather than downsizing, the Department should be playing a much more robust role in guiding the American workforce through this period of change.

So I am disappointed with this proposed budget and hopefully through the efforts of Senator Specter on the floor and as we move ahead with the appropriations, I am hopeful that we can provide a more appropriate funding for the priorities in the Department's budget, Madam Secretary.

HALLIBURTON

Now, I had some questions, but I would certainly—first, Madam Secretary, Dresser-Rand employees from Olean, New York, called the Department of Labor 2 years ago with questions about the legality of Halliburton confiscating the early retirement subsidy to their pension when Halliburton sold the Olean plant. To date, these employees have received no response from your Department. So I'd like to ask if you could please submit for the record a timeline of what your Department has done in the past 2 years to respond to these calls and when you anticipate being able to respond definitively. I'm particularly interested in the activities of DOL investigators located in Texas.

Now, the reason I mention this, Madam Secretary, is that I, along with others, have sponsored legislation since 1999 to create an office in your Department to respond to pension participants to be an advocate for them within the Government. Yet your Department keeps saying it's not necessary, that we already respond adequately to pension participants.

Again, Madam Secretary, if that's your position, can you please comment on the experience of the Olean workers in New York?

Secretary CHAO. Actually, EBSA, that's the Employee Benefits Security Administration—

Senator HARKIN. Is that mike on? Okay, now I hear it.

Secretary CHAO. My opening statement, which I submitted for the record, talked about the great—the very strong enforcement record we've had ensuring worker safety and health and also retirement security. In fact in 2004, EBSA has achieved more than \$3 billion in monetary results for workers' retirements and also pension funds. This is a 121 percent increase over the previous year.

I'm not familiar with the case that you mentioned and I will certainly take a look at it. But we have also about 108 of these participants' advocates, benefit advisors, within EBSA, and that's what these people's jobs should be, and that is they're case workers. They're supposed to be helping individuals who call in. And so we don't really think that the advocacy office is necessary, and I think the results speak for themselves. But I'd be very open to showing you what we've been doing, and I certainly will get back to you on the information concerning the case that you mentioned.

Senator HARKIN. Please do so, because evidently it's been 2 years, and according to my information—that's all I can go on—nothing has been done and they have received no response from your Department after 2 years on this issue.

Secretary CHAO. We'll look into it.

Senator HARKIN. So I'd just like to know—

Secretary CHAO. We actually have a good record—

Senator HARKIN. Pardon?

Secretary CHAO. We actually have a good record in recoveries and—

Senator HARKIN. But do you have a record on what's happened with Olean?

Secretary CHAO. We will look into it.

Senator HARKIN. And you will submit that to us then?

Secretary CHAO. Yes.

#### CHILD LABOR VIOLATIONS

Senator HARKIN. Okay, I appreciate that. Next I'm—Madam Secretary, I'm disturbed by reports of an unprecedented agreement, really unprecedented, between the Department of Labor and Wal-Mart in a settlement on child labor violations.

On January 11 of this year, the Department of Labor signed an agreement with Wal-Mart settling a case against the company on violations of child labor laws, in which 85 minors operated hazardous equipment. As part of the settlement, Wal-Mart was granted an unprecedented concession, 15 days advance notice of any future audit or investigation into the company's labor practices.

Well, there's been a lot of stories about this in the press. There was a story printed in the American Progress that DOL had retracted their initial press release on the settlement and re-issued the release with changes that Wal-Mart insisted on. Now these are all in the popular press out there. But again, I must say I'm disappointed the administration is sending the wrong signal on child labor laws, eroding protections by providing advance notification of inspections domestically, while eliminating support for programs to eradicate child labor internationally.

Madam Secretary, are you aware of this agreement with Wal-Mart?

Secretary CHAO. Not initially. This is actually done by—

Senator HARKIN. Are you telling me right now you're not aware of it?

Secretary CHAO. No, I am aware of it.

Senator HARKIN. Oh, you are—you said not initially.

Secretary CHAO. Not initially. This is a—this is consistent with past practices in different regions of Wage and Hour division to enter upon these settlement agreements. In fact, during the previous administration they were called partnership agreements. So claims that this agreement is lenient are totally false. This agreement is consistent with other settlements of other enforcement actions. It is a good settlement. The terms apply company-wide, not just the stores where the violations occur.

Wal-Mart was assessed a higher fine than the average penalty. There was no coordination of any press agreements. The 15 day was actually quite normal and usual. In fact, in the previous administration there have been cases where the previous administration gave up to 90 days of notice. The purpose of the notice is not to allow the company to not comply. The purpose of the period is—of this time period is to allow the—is to remove whatever is the harmful action to occur quickly and then it also benefits the Government to be able to go in and have the company or the employer be prepared to answer questions.



So again, this particular agreement, while I admit is not well written, is consistent with past practices, and the time period, 15 days or whatever given, is quite consistent, in fact is on the lower end of some of the other agreements which we have seen executed under the previous administration. Labor union organizations are also given a period of time in which they are required to compile the necessary documentation so that they can come speak in a more—they can have the documents that they need to be able to speak to the Government. So this is not—this is again—

Senator HARKIN. I'm told—

Secretary CHAO [continuing]. Consistent case. This is consistent with past cases, and it's how it's handled.

Senator HARKIN. I'm told that advance notification has only been given for voluntary enforcements in past agreements, but never in mandatory type of settlements, that this is the first time that this has been done.

Secretary CHAO. This is different from OSHA. This is Wage and Hour. This is not OSHA. This is Wage and Hour and particular—these apply to Wage and Hour infractions. They're very different from OSHA.

And second—

Senator HARKIN. Well, I thought these kids were involved in operating hazardous equipment.

Secretary CHAO. This is not an OSHA issue. This is a Wage and Hour issue, so it's not OSHA.

Senator HARKIN. Well, it was a violation of child labor laws. Eighty-five minors were operating hazardous equipment.

Secretary CHAO. No, the equipment itself is not hazardous.

Senator HARKIN. Oh.

Secretary CHAO. People can—people can operate them, but it was just that these young people operated the—they were bale machines.

Senator HARKIN. Yeah, and kids are not supposed to operate them.

Secretary CHAO. Kids are not supposed to operate that.

Senator HARKIN. I've been through this before with grocery stores.

Secretary CHAO. But this was a—this is not a consistent basis. It was a once—it was an infrequent occurrence which is documented. So when the Government goes in, we need documentation, because it's not as if the child—the young person is standing there at the machine the whole time. It was an infraction at a particular time and a particular day. It was not a consistent pattern of behavior.

But nevertheless, the 15-day notice, or the advance notice, is not unusual. As I mentioned, there were past settlements, in fact—

Senator HARKIN. That involved violations of child labor laws?

Secretary CHAO. Yes. And they also gave much longer periods of—

Senator HARKIN. So there have been past violations of child labor laws in which the Department has agreed to an advance notice of 15 days—

Secretary CHAO. More than that. Under Wendy's and there's another one called Genesis, those are two that come to mind imme-

diately, they were in the previous administration and they gave up to 90 days. This is different from an OSHA violation, because when you have an OSHA violation, there is consistent hazardous behavior. This is—Wage and Hour infractions are intermittent and they're documented much more by paperwork, so it's different. But again, the advance notice has been terribly portrayed in the press. It is not unusual.

Senator HARKIN. So you're saying that Wal-Mart was not given preferential treatment?

Secretary CHAO. No, it was not, and there was no press coordination.

#### INTERNATIONAL LABOR AFFAIRS BUREAU

Senator HARKIN. Okay. When you came before our subcommittee to discuss the 2004 budget, we discussed funding for the elimination of the worst forms of child labor, as you and I often do. This has been a constant communication between us. At that time, you were requesting \$54.6 million in funding for ILAB, the International Labor Affairs Bureau, because you said that more than that amount was then beyond the capacity of one office to absorb. You assured me at the time that we had the same goal, that you wanted to work towards increasing the capacity of the office to administer these programs. I quote, you said, "please be assured that we are not differing at all in the terms of the goal." Further on the record you said, "if you want to build the infrastructure internally, it will take some time. The commitment I assure you is absolutely there." These were your words, Madam Secretary.

Well, what am I to make of the 2006 budget, which proposes a measly \$12 million for these activities? This is an 86 percent reduction from \$54.6 million down to \$12 million. I mean, help me understand this.

Secretary CHAO. We're very concerned obviously with child labor, and I went to Africa, as you know, in December 2003 to review some of the projects which we are in coordination and partnership with the ILO. I have to say, Mr. Chairman, the results of those visits were not very positive.

But nevertheless, the current budget in ILAB does not reflect our reduced commitment to child labor, but perhaps the increasing awareness that we are not the best place to administer these programs, and that the best place for—the best thing for ILAB is to return to its core mission of working on core labor standards and on advocacy, and that's something that this budget reflects.

Senator HARKIN. But I don't see it being picked up anywhere else. I don't see any—you know, it would be one thing if it was cut here but was added some other place and the responsibility was shifted, but I don't see that happening anywhere in the budget.

Secretary CHAO. Well, I think the State Department, AID, and the Peace Corps also does some of these and there are other areas we are told that do have an emphasis on this population as well.

Senator HARKIN. Well, I don't know about that. AID has been focused a lot on disability issues, that's for sure. Mr. Natsios has done a very good job in moving AID towards making sure that U.S. tax dollars are not used to build facilities that are inaccessible. He's done a great job and also the Secretary—I should—also did

that, Secretary Powell, and implemented procedures for disability issues on AID. But I—this is one area though in terms of core labor standards, child labor, worst forms of child labor, where the Department of Labor has had, well, I think some pretty long experience in this area for some time. The State Department hasn't. AID, I think, yeah, in terms of what they're doing for development purposes and responding to issues of disability rights, that's fine.

But in terms of child labor, this is the Department of Labor, not the State Department. And so—I mean, I might argue with you about where it ought to be located, but if the administration wanted to shift it, again, I don't see the money anywhere for it. I don't see any line item authority in the State Department or anywhere else for this to take place. I do see in AID for disability, like I said, but not for these child labor issues.

Secretary CHAO. The other issue is a lot of the monies that were supplemented in the last few years were grant-making, and so I think there was an effort to perhaps bring back ILAB to its original mission of international labor policy, our research, advocacy, and analysis.

Senator HARKIN. Well, I guess that's just a policy difference we have. I mean, I think this Congress, Senate, House, in the past few years, and I think pretty bipartisanly, has spoken strongly both in the previous administration and in this one that we want the Department of Labor to be actively involved in the issue of child labor.

There have been a number of reports from your Department on that that have gone back a number of years. I think it's been recognized in many places that DOL has really moved aggressively on this. Now if you want to say you want to go back to the start, gee, we've come a long way and we still see instances of gross violations, basic decent child labor standards around the globe. And this is leadership. This is the United States of America talking about our role, our moral leadership, our ethical leadership in talking about child labor. And I just hope that it would continue on rather than trying to go back to where we were 10 years ago or 12 or 15 years ago on this.

Secretary CHAO. I think we can still do a great deal. We do take the leadership, for example, we hosted the first worldwide convention of child labor delegates, and through promoting a greater awareness of the problem, through convening the right mix of stakeholders, I think we can do a lot. I'm just not sure that the grant-making part of the resources is something that we can—that we're going to place very much emphasis on as we go forward.

Senator INOUE. Madam Secretary, I'm here to greet you and to welcome you to the committee. I'm trying to save my voice. I just got out of bed with the flu, so I've been advised to maintain a low profile.

If I may, I'd like to submit my questions to you in writing and request some written response.

Secretary CHAO. Of course.

Senator INOUE. Your assignment is a very difficult one, because the policies that you have to work under are oftentimes generated by other Departments, Department of Defense, Department of State, over which your influence may be at best limited. And so,

having served on subcommittees that deal with these two Departments, I'm well aware that oftentimes decisions that you render may have to be determined by our relationship with certain countries. I know that it may not be to your liking, but such are the facts of life, and for that I thank you for your patience and your understanding.

I will be submitting my questions, but I have to save my voice. Thank you very much.

Secretary CHAO. Thank you for coming.

Senator HARKIN. Thank you, Senator. Senator Craig.

Senator CRAIG. Thank you very much, Mr. Chairman. I apologize to the committee and to the Secretary for trafficking late this morning, but there was a bigger billing in a different committee, Elaine. Alan Greenspan was here and we're talking about retiring and the demographics of a workforce. And it's certainly part of your charge and your responsibility, and I understand that.

I think one of the things most significant said, and it will be my only question, I'll review your testimony, and I must tell you I applaud the work you have been doing and the successes you've had in relation to America's workers and the enforcement of law in a clear and transparent way that I think all of us recognize is tremendously important for the credibility of government and for your agency, and you're to be recognized and applauded for that.

I think one of the things the chairman said a few moments ago that I found interesting was really no way to fix the system, and we were discussing Social Security, and look at older Americans' financial security than to keep them a little longer in the workforce. The reality is out there no matter what we do that the demographics are so overpowering as it relates to where we are traveling as a culture. We're going to live longer. We're going to be much healthier living longer. Americans feel much more productive usually if they're in the workforce. And that early retirement is a relatively new phenomenon, that the numbers we're seeing and have seen for the last good number of decades are really products of a difference that 30, 40, 50 years ago was simply not the case.

I found that quite fascinating. He had, as is quite typical of Chairman Greenspan, all the facts, figures, and statistics to back that up. But having said that, in the programs that you look at today in your charge and responsibility, what areas do you believe most effective for those who find the need to stay in the workforce, those that might need some additional training? We may be looking at some, if you will, bumping up, if the skills of 55, 60, 65-year-old people who might choose to stay in the workforce another 5 or 6 years or more, that will be beneficial to them. Is it possible for you to address those programs and what you see in the future?

Secretary CHAO. It's interesting that you mention this topic, because I just—because it's very timely and very relevant. I just got back from the G-8 labor ministers meeting where the theme, interestingly enough, was aging populations. Among the industrialized nations of the world, the graying of the workforce is a huge concern for policy makers.

You are right. Workers these days are living longer, they're in better health, and they don't view retirement as the ending phase of their life, but rather the beginning of a fourth of a fifth phase

of their life. And so we want to ensure that our policies are open and flexible so that individuals who want to remain in the workforce can do so, especially since our workforce is going to be facing a shortage of workers after the—as the baby boom generation retires.

We do have training programs that will re-skill a person to a field in which he or she has not been familiar with. That's all part of the workforce development and training that we are focused upon.

#### HIGH GROWTH JOB TRAINING PROGRAM

Then third, I think with the President's high growth job training program, we have matched resources and individuals with the opportunities that are coming up. We have a need for, you know, 3.4 million health care workers in the next 8 years. We have a need for 1.5 million nurses in the next 10 years. So there are pockets of disequilibrium in our labor market which we've got to address, and older Americans are a very valued segment of our population.

#### UNEMPLOYMENT RATE

By the way, I should mention also the unemployment rate is 5.4 percent nationally this past month. The unemployment rate of seniors is about 3.7 percent. So having said all of that, and given the tremendous interest that the G-8 labor secretaries have on aging workforces, I think it's very timely that our Nation is having this discussion as well on Social Security and also on pension security as well.

Senator CRAIG. Well, I would have loved to have been your travel partner and listened to those discussions, because I've spent a good deal of time looking at what has happened in Japan, and certainly some of the countries of Europe are really well advanced in their aging, if you will, and therefore finding tremendous impact on their social programs within their governments and how they fund them and do all of those kinds of things.

How much of a bias do we still have built in the system to force retirement?

Secretary CHAO. If you're an older American and you want to work, our country had made great progress. We've abolished—we've fought against age discrimination, so that is illegal, and we've done away with mandatory retirement age, and we've raised the Social Security earnings limits.

#### RETIREMENT

But our workforce is still not as flexible as many older Americans would like. Again, retirement is no longer this twilight of one's life where one retires to the veranda and sits on a rocking chair. It is a very active phase of our workforce's life, and people also rebel against—a lot of people are also rebelling against the cliff effect, where one day they're at work and then the next day they're totally disconnected with the only community that they know. So there should be greater flexibility and more openness in our workforce to be more welcoming of those older Americans who still want to—who want to still remain in the workforce.

## SOCIAL SECURITY

Senator CRAIG. Well, I thank you very much for those comments. I think they are very real hurdles for us. We're in the business of trying to get our hands around, and better understand and cause the American people to better understand, the problems of Social Security.

What I think is fascinating about that whole debate that we're now engaging in is that it's—it is a piece of a much larger issue of workforce and aging and all the dynamics of how we keep this country running economically and the security of retirement and the reality of so many other things that now have to be added to it, and the dynamics of the current and future cultures in this country.

So thank you very much. I appreciate you being here.

Secretary CHAO. Thank you.

Senator CRAIG. I guess we're ready to wrap up. Please proceed.

## CHILD LABOR ISSUE

Senator HARKIN. This has been a good discussion listening to Senator Craig, but I want to follow up one last time on the child labor issue, on the \$12 million for all these activities. In the Bipartisan Trade Promotion Authority Act of 2002, it is the statutory obligation of the U.S. Government to: "strengthen the capacity of U.S. trading partner to promote respect for core labor standards." This is the obligation by law of the International Labor Affairs Bureau. So again it's not just research, but this is part of the law, it's an obligation.

So again my question comes back, how do we fulfill this obligation with \$12 million? And do you feel that you can do that with \$12 million? I guess that's really what I'm getting at. I mean, it's not just something we'd like to do. It's now an obligation under law.

Secretary CHAO. We're very concerned about child labor and we will continue to work on that. Again around 1996 ILAB's budget was about \$12 million and then in subsequent years it rose to about \$149 million in 2001. And these were primarily grants, and based on an assessment as to what these grants do and whether they are as effective as they should be, there was some feeling that ILAB should really return to its core mission again of promoting core labor standards, going into research, analysis, and advocacy and more of that.

So there will not be any, for example, any FTE—

Senator HARKIN. I'm sorry?

Secretary CHAO. There will not be large FTE reductions. We expect to have people who will carry on continuing work. But these are—

Senator HARKIN. If there's going to be that big of a cut—

Secretary CHAO. But the ones—but the additional monies are much more grants.

Senator HARKIN. I would think if there was that much of a cut, there ought to be some FTE reductions.

Secretary CHAO. There won't—I don't think there will be.

Senator HARKIN. Again, this is a question I don't know the answer to, but were there assessments made either by your Department or GAO about these grants and the effectiveness of them?

Secretary CHAO. I know that IG has made—

Senator HARKIN. The IG?

Secretary CHAO [continuing]. Has made a study.

Senator HARKIN. Well, maybe I'll get my staff to get a hold of that and see what they said on it, because I'm just not familiar with that. But I just wanted to point out that there is a statutory obligation for ILAB now, and I'm not certain it can fulfill it with \$12 million. If all you were going to do is research, maybe so. But if you have to fulfill this, especially with CAFTA coming up and Andean Trade, all that coming down the pike, I would still think this would be an area where you're going to require more than that.

Secretary CHAO. Well, we want—we want to work with you on it. But it was kind of the assessment that we'd be able to provide this kind of assistance with our in-house Department of Labor employees, that we would be able to offer technical assistance and also coordinating with other grant-making agencies as well.

#### ADDITIONAL COMMITTEE QUESTIONS

Senator HARKIN. Madam Secretary, you've been very gracious with your time. I have some questions I will submit for the record, especially as it deals with the Office of Disability Employment Policy and the veterans employment and training programs. I'll just submit those in writing.

Secretary CHAO. We'll be pleased to answer them. Thank you.

[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

##### SUBSTANCE ABUSE TREATMENT WORKFORCE

*Question.* I have heard from my constituents that in Pennsylvania and throughout the nation, the substance abuse treatment workforce is undergoing turnover rates of 50 percent or higher and there is real question whether the remaining workforce can get the training needed to implement the most effective treatments. This would be a serious problem for any industry but given the alarming public health and public safety issues associated with addiction it is a particularly serious workforce development issue.

I know that your department has initiated effective workforce development programs in several industries such as agriculture, mining and nursing. Do you have any plans to implement such programs for the substance abuse treatment industry?

*Answer.* Health care has been targeted as one of the high growth industries in the President's High Growth Job Training Initiative, and through that initiative the Department has funded a broad array of occupational workforce solutions. This includes such occupations as direct support specialists and paraprofessionals, and we would consider the substance abuse treatment workforce to be a component of this industry. The Department welcomes the contributions of the substance abuse treatment industry as part of the High Growth Job Training Initiative.

Additional opportunities are available to address local workforce shortages through the Community-Based Job Training Grants, which target high growth industries in local communities. Community colleges, as grant applicants, in partnership with industry, the workforce investment system, and the continuum of education providers, including K-12, can submit applications to meet local workforce challenges like the shortage of substance abuse workers under the formal Solicitation for Grant Applications.

## JOB CORPS MANAGEMENT FEE

*Question.* The Workforce Investment Act provides for a management fee of not less than 1 percent for each Job Corps operator and service provider. How much is budgeted for such fees for program year (PY) 2006 compared to 2005? What is the process for determining management fees, and what is the range of percentages currently being provided?

*Answer.* We estimate that management fees in Job Corps will cost about \$44.1 million in PY 2006, which is a very slight increase above the PY 2005 estimate of \$43.9 million. As a percentage of the expenditures under contracts in which management fees are included, such fees represent roughly 4 percent of the costs. In the framework of total Job Corps operating expenditures, fee payments represent only 3 percent of costs.

The fee amounts in individual contracts are determined during the procurement process. The greatest share of Job Corps contracts, in terms of dollar expenditures, contains performance-based fees. The fees in these contracts are structured so that the contractors are guaranteed a fee payment of 3.6 percent and then can earn as much as 2.4 percent above that based on objectively determined performance excellence. These types of performance-based fees are used in our center operating contracts and contracts for post-center career transition services.

## PROGRAM ADMINISTRATION

*Question.* Your budget justification material states that consolidated job training programs will save \$300 million in administrative costs, yet you are not proposing any reduction in Federal staffing. Please explain.

*Answer.* The \$300 million in administrative costs savings created by consolidating job training programs relates to savings realized at the State and local levels, not at the Federal staffing level. Savings realized by States and local areas will enable them to increase training enrollments and provide improved services to their participants.

The Program Administration account was reduced by \$842,000 to reflect program efficiencies created by the consolidation. The reduction in FTE associated with these efficiencies was offset by the anticipated need for FTE to administer the new H-1B job training grant program and the YouthBuild program, which is proposed for transfer from the Department of Housing and Urban Development, resulting in an equal need for FTE staffing in 2006. If the job training grant consolidation were enacted, we would expect further long-term Federal administrative savings would be possible.

## COMMUNITY COLLEGE GRANTS

*Question.* According to GAO, the Labor Department plans to obligate only \$13 million of the \$250 million requested for the Community College Initiative during fiscal year 2006, because unobligated funds from fiscal year 2005 can be used for most of its expected needs through September 30, 2006. Even though the funds are available for the program which extends through June 2007, how do you justify the need for the full \$250 million during this funding cycle?

*Answer.* The Department of Labor has provided GAO with information on the allocation of funds for this program pursuant to the Congressional appropriation process that is utilized for the Department's "forward funded" programs. The \$248 million appropriated in fiscal year 2005 for the Community College Initiative are program year funds and accordingly, none of the funds are available for Federal obligation until July 1, 2005, with a large portion of the funds only becoming available for obligation on October 1, 2005. In preparation to utilize fully these resources during the period of obligational authority, the Department is publishing two solicitations for grant applications—one in April 2005 and the second later during the 2005 calendar year. Each of these competitive solicitations will be for \$124 million. The purpose of these solicitations is to promote the development of strategic partnerships between business and industry and community colleges, and to train workers for the industries creating the most new jobs.

Businesses in high-growth, high demand industries face increased difficulty in finding workers with the skills they need as a result of globalization, the aging of America's workforce, and the fact that technology and innovation are continuously changing the nature of work. As a result, community colleges will be increasingly critical providers for workers needing to develop, retool, refine, and broaden their skills. The initial investment of \$248 million will be an important first investment and allow community colleges to train at least 100,000 workers. The fiscal year 2006



Budget proposes another \$250 million to continue this important new initiative and train at least another 100,000 workers.

One of the purposes of these resources is to build the capacity of community colleges to train workers. The accelerated pace of innovation and technology continuously require new sets of skills in the workplace, calling for a continued focus on capacity building. We must continue to support community colleges in their effort to ensure that workers have and maintain the skills they need to be competitive in a 21st century innovation economy.

#### ONE-STOP SYSTEM ELECTRONIC TOOLS

*Question.* Page ETA-12 of your Budget Justification Material lists a request of \$48,294,000 for “One-Stop System Electronic Tools.”

What exactly is being funded with this request, and how does it compare to the fiscal year 2005 funding level?

*Answer.* Although there appears to be a significant decrease in this line item in the fiscal year 2006 request as compared to the fiscal year 2005 enacted level (\$48,294,000 compared to \$97,974,000), the actual decrease is approximately \$10 million. Funding for this line item reflects the movement of the \$39,690,000 in funding to States for workforce information activities (Core Products & Services and LMI Research & Development) formerly housed in this budget line item into the WIA Plus State Consolidated Grants.

This line item has traditionally been utilized to support national electronic tools such as America’s Job Bank, America’s Career Information Network, America’s Service Locator, and the Occupational Information Network (O\*NET). These electronic tools help in the preparation of a competitive workforce to keep the United States viable in the global economy and support the President’s Temporary Worker Program. In addition, other funds in this line item were targeted to system building activities designed to enhance the delivery of services through the nation’s One-Stop Career Centers and to provide national infrastructure for performance accountability. The approximately \$10 million reduction in the 2006 request is in the system building activities.

DOL has been actively evaluating this line item to ensure that it provides the critical workforce information products and tools necessary to support the workforce investment system and the President’s Temporary Worker Program. We have also been actively identifying mechanisms to control the costs for the current tools. This has resulted in strategic changes to the suite of tools that are supported. For example, DOL now supports a new Web site—Career Voyages ([www.careervoyages.gov](http://www.careervoyages.gov))—that is designed to provide young adults and transitioning workers with a career exploration tool for careers in high growth, high demand industries. We have also developed a new Web space to promote the transformation to a demand-driven workforce investment system called Workforce One ([www.workforce3one.org](http://www.workforce3one.org)) where we feature new and innovative approaches to workforce development. We are currently in the process of developing a clearinghouse for industry developed competency models and skills standards.

Below is a brief description of each of the current electronic tools supported by this line item:

- The CareerOneStop (COS) Electronic Tools—a suite of Internet-based tools that consists of:
  - America’s Job Bank.*—An electronic job board where businesses can search for candidates and post job listings and job seekers can search for jobs and post their resumes;
  - America’s CareerInfoNet.*—A site that provides access to occupational projections and other workforce information for career exploration;
  - America’s Service Locator.*—A site that provides location information for One-Stop Career Centers and other workforce services;
  - CareerOneStop Portal.*—The home page that provides a central access point to all the content of the COS sites, by topic and customer group;
  - Workforce Tools of the Trade.*—A Web site designed to support the professional growth of workforce investment professionals that help business and citizens meet their workforce needs;
  - On-Line Coach.*—A tool that is integrated into the COS to help individuals not as familiar with the COS sites to navigate through the numerous resources available based on common issues or problems they may be facing—the tool then walks them step-by-step through the appropriate resources; and
  - Toll Free Help Line.*—The TFHL (1-877-US2-JOBS) provides telephone access to job seekers and businesses on a wide-range of workforce issues.

—*Occupational Information Network (O\*NET)*.—An occupational classification system that provides detailed information on occupational characteristics and skill requirements and serves as the common occupational language for the COS as well as the workforce investment system as a whole.

LEGISLATIVE SAVINGS

*Question.* The Administration is proposing legislation to save both unemployment compensation and workers’ compensation funds. Provide an estimate of savings from each component of these proposals for each year, from fiscal year 2006 through 2015 (10 years). Provide the legislative text for these proposals.

*ETA’s Response*

Answer. The unemployment insurance (UI) integrity proposal is made up of five amendments. Amendment 1 would allow States to use up to 5 percent of recovered overpayments for benefit payment control. Amendment 2 would allow States to permit collection agencies to keep up to 25 percent of recovered overpayments and delinquent taxes. Amendment 3 would require a minimum 15 percent penalty on fraud overpayments, to be used for benefit payment control. Amendment 4 would prohibit non-charging benefits when an overpayment is the employer’s fault. Amendment 5 would allow intercept of Federal income tax refunds for recovery of overpayments. The savings breakdown, in millions of dollars, for this proposal is as follows:

[In millions of dollars]

	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2006–15
Amendment 1 .....	.....	12	23	24	25	26	28	29	30	32	229
Amendment 2 .....	.....	4	9	9	10	9	10	11	12	13	87
Amendment 3 .....	.....	39	80	84	88	93	97	101	105	111	798
Amendment 4 .....	.....	10	22	24	25	26	28	29	31	32	227
Amendment 5 .....	.....	281	282	284	288	302	317	331	347	362	3,082
Total Proposal .....	.....	281	347	418	429	436	456	480	501	525	4,423

These are our best estimates of the savings and delinquent tax collections which would result from this proposal. However, of the total 10-year savings, only \$3.082 billion is scorable under CBO and OMB scoring rules. We also estimate that the proposal would produce tax reductions of \$2.856 billion over 10 years.

Draft legislation for these proposals was sent to Congress in June.

*ESA’s Response*

Answer. The 2006 Budget includes two reform proposals affecting Federal workers’ compensation programs: Federal Employees’ Compensation Act (FECA) reform, and Black Lung Disability Trust Fund debt restructuring.

*FECA Reform.*—The Budget proposes to reform FECA to improve program fairness, speed claims processing, adopt best practices of State workers’ compensation programs, and implement recommendations of DOL’s Inspector General. Attached is a spreadsheet that shows the FECA Reform savings by provision and fiscal year. Legislation is expected to be transmitted to Congress this fall.

*Black Lung Trust Fund Debt Restructuring.*—The proposed legislation seeks to restore solvency to the Black Lung Disability Trust Fund, which currently has a \$9 billion debt to Treasury. The Administration’s legislative proposal would: (1) refinance the debt to take advantage of current, low interest rates; (2) extend until the debt is repaid the Fund’s excise tax levels, which are set to revert to lower levels in January 2014; and (3) upon enactment of the bill, provide a one-time appropriation for a payment to the U.S. Treasury to cover the forgone interest payments. Because this is an intragovernmental transfer, there is no net government-wide budgetary effect until the 2014 (when the current excise tax rates are extended). The following chart provides the year-by-year estimates:

	Approp	Advances	Excise tax effect
2006 .....	\$3,808	(\$452)	.....
2007 .....	.....	(443)	.....
2008 .....	.....	(433)	.....
2009 .....	.....	(429)	.....
2010 .....	.....	(430)	.....
2011 .....	.....	(433)	.....

	Approp	Advances	Excise tax effect
2012 .....	.....	(434)	.....
2013 .....	.....	(436)	.....
2014 .....	.....	(700)	\$261
2015 .....	.....	(833)	378

Legislation is expected to be transmitted to Congress this fall.

For FECA Reform:

The following chart provides the year-by-year estimates for each provision:

	Conversion benefit	Three-day waiting period	Eliminate augmentation	Survivor cap at 70 percent	Concurrent schedule award and disability compensation	Subrogation rights for COP (savings to Gov't)	Increase burial benefit	Increase maximum disfigurement award	Net savings to special fund/ Government
2006	.....	(\$4,909,020)	(\$12,015,616)	(\$106,496)	.....	(\$1,903,104)	\$640,000	\$345,000	(\$17,949,236)
2007	.....	(5,026,836)	(31,803,310)	(305,136)	\$2,385,956	(1,948,778)	640,000	345,000	(37,261,852)
2008	(4,546,223)	(5,147,480)	(39,920,647)	(492,847)	4,759,088	(1,995,549)	640,000	345,000	(46,358,659)
2009	(7,431,599)	(5,271,020)	(48,033,265)	(671,802)	7,255,545	(2,043,442)	640,000	345,000	(55,210,584)
2010	(10,260,326)	(5,397,524)	(56,146,377)	(841,047)	7,429,678	(2,092,485)	640,000	345,000	(66,323,082)
2011	(13,085,659)	(5,527,065)	(64,263,845)	(1,003,042)	7,607,990	(2,142,705)	640,000	345,000	(77,429,325)
2012	(15,908,472)	(5,659,715)	(72,392,698)	(1,156,980)	7,790,582	(2,194,130)	640,000	345,000	(88,536,412)
2013	(18,731,097)	(5,795,548)	(80,537,429)	(1,304,431)	7,977,556	(2,246,789)	640,000	345,000	(99,652,738)
2014	(21,553,774)	(5,934,641)	(88,703,356)	(1,447,152)	8,169,017	(2,300,712)	640,000	345,000	(110,785,617)
2015	(24,380,724)	(6,077,072)	(96,895,409)	(1,583,296)	8,365,073	(2,355,929)	640,000	345,000	(121,942,356)
Ten-year Total	(117,446,620)	(54,745,922)	(590,711,951)	(8,912,228)	61,740,483	(21,223,622)	6,400,000	3,450,000	(721,449,860)

## OSHA RESOURCES TARGET ERGONOMIC HAZARDS

*Question.* What level of funding has been targeted for worker protection from ergonomic hazards for fiscal year 2006 budget request?

*Answer.* The resources utilized to address ergonomics in the fiscal year 2006 budget request are contained within all of OSHA's budget activities and are not separately identified or earmarked to address ergonomics or any other specific issue.

*Question.* For what activities has funding been requested?

*Answer.* OSHA's approach to ergonomics involves focused activity by the entire agency in addressing the four prongs of the ergonomics policy: industry specific and task-specific guidelines, strong enforcement, outreach and assistance, and research.

*Question.* How many FTEs have been assigned to work on ergonomics?

*Answer.* The agency has not specifically identified the number of staff working on ergonomics. The staff necessary to address ergonomic concerns is available as needed within the ongoing enforcement, outreach, and regulatory activities of the agency.

*Question.* How many ergonomists does OSHA employ and what are their responsibilities?

*Answer.* Although there is no formal Federal job classification titled "ergonomist," OSHA currently employ four Certified Professional Ergonomists (CPE), one Certified Industrial Ergonomist, and one Industrial Engineer whose education and experience is Human Factors Engineering. Of these six, two are employed in two different Regional Offices and provide enforcement oversight; one works at our Salt Lake Technical Center; one works in the National Office on guidelines; one is a training and curriculum developer; and one is a Compliance Assistance Specialist whose job is to provide assistance on a broad range of safety and health topics. All of these positions include providing training and assistance to compliance staff and outreach and assistance to the regulated community.

*Question.* How many enforcement actions has OSHA taken pertaining to ergonomic hazards during fiscal year 2004 and fiscal year 2005 to date?

*Answer.* OSHA assessed ergonomic conditions in 707 inspections opened in fiscal year 2004. Of these 707 inspections, 108 were conducted under Regional or Local Emphasis Programs which focus inspection resources on industries in which high rates of musculoskeletal disorders are known to occur.

As of March 31, 2005, OSHA has assessed ergonomic conditions in 151 inspections conducted in fiscal year 2005. Of these, 41 were conducted under a Regional or Local Emphasis Program with a focus on evaluating musculoskeletal disorders.

*Question.* Specifically, how many hazard warning letters have been issued on ergonomic hazards, and how many general duty clause 5(a)(1) citations have been issued, and the date of their issuance?

*Answer.* Since the beginning of the Secretary's four-pronged approach to ergonomics in April 2002 through April 2005, OSHA has issued 380 ergonomic hazard alert letters. Many ergonomic inspections are still ongoing in fiscal year 2005; however, for those that have been concluded we have issued 26 ergonomics-related Hazard Alert Letters (EHALs). In fiscal year 2004, we issued 107 ergonomic hazard alert letters. Each EHAL recommends ways to reduce ergonomic hazards, and indicates that OSHA may conduct a follow-up inspection to assess the extent to which the employer has taken such action.

OSHA issued a total of 11 general duty clause citations between February 2003 and August 2003, and five citations were issued between November 2003 and August 2004.

*Question.* How many inspections on ergonomic hazards does OSHA plan in fiscal year 2004 and fiscal year 2005?

*Answer.* In general, OSHA does not have a pre-determined number of inspections under which we target ergonomics. In fiscal year 2004, OSHA assessed ergonomic conditions in 707 inspections. For fiscal year 2005, we estimate that our compliance staff will evaluate approximately 850 worksites for ergonomic issues.

*Question.* What ergonomic guidelines have OSHA issued to date, and what is planned through fiscal year 2006?

*Answer.* OSHA has issued ergonomics guidelines on nursing homes, retail grocery stores and poultry processing. A draft of the shipyard guidelines will be released for public comment shortly. The agency plans to finalize the shipyards document after considering the public comments. No decisions have been made regarding additional OSHA guidelines.

## FAITH BASED COMMUNITY INITIATIVES

*Question.* You are requesting a \$2,100,000 increase for a "Faith Based and Community Initiatives," for a total of \$37,432,000 (pg. DM-12). What distinguishes these

projects from faith-based initiatives of the Employment and Training Administration?

Answer. The total you refer to is for the entire Program Direction and Support budget activity in the Departmental Management appropriation. This activity includes funding for the Office of the Secretary as well as other Departmental policy organizations such as the Center for Faith-Based and Community Initiatives. For fiscal year 2005, approximately \$600,000 of the \$26,618,000 appropriated for this budget activity is used to fund the Center for Faith-Based and Community Initiative. This amount does not even fully cover the administrative needs for a staff of seven. Thus the entire amount in fiscal year 2005 is used to pay for the staff to implement the President's Faith-Based and Community Initiative.

The Center for Faith-Based and Community Initiatives does not have a program budget. The Center works with the Employment and Training Administration and other DOL grant-making agencies to improve funding opportunities for grassroots faith-based and community organizations. This includes implementing new pilot and demonstration programs as well as assisting agencies in simplifying grant application and reporting procedures.

DOL's request of \$2,100,000 in fiscal year 2006 will be used for State and local implementation of the Initiative by providing technical assistance to State and local workforce development entities undertaking projects that integrate faith-based and community organizations in workforce development service delivery.

*Question.* How much do you expect will be available for new starts and how many new projects in fiscal 2006?

Answer. Of the amount requested, one third of the funds will be used to provide the administrative costs of employing staff. The remaining two thirds of the requested increase will be used to provide technical assistance to fiscal year 2005 and fiscal year 2006 grantees. This funding will be used to ensure the success of ongoing projects.

New fiscal year 2006 grants will be funded from appropriations provided to the Employment and Training Administration for program purposes. The Center for Faith-Based and Community Initiatives is working with the Employment and Training Administration to determine the level of funding to be allocated for this purpose and the number of new grantees that these funds will allow.

#### MSHA COST DUST MONITORS

*Question.* What is the status of the Personal Dust Monitor being tested by the Mine Safety and Health Administration?

Answer. MSHA is currently participating in a collaborative study with the National Institute for Occupational Safety and Health (NIOSH) to examine the long-term mechanical, electrical, accuracy, and precision performance of the PDM in a variety of underground coal mine environments. As of May 26, 2005 MSHA and NIOSH completed all of the 10 detailed in-mine studies. For the special area sampling portion of the study, 47 of the 180 mechanized mining units remain to be sampled. MSHA expects the study will be complete by August 2005 and that NIOSH will issue a report by October 2005.

*Question.* Do you expect to issue new mine safety enforcement regulations as the result of this new technology being utilized?

Answer. On June 24, 2003, MSHA issued a News Release announcing its intention to suspend all work in the finalization of the proposed *Single Sample (SS)* and *Plan Verification (PV)* rules and to pursue accelerated research on the PDM. MSHA also declared its commitment to "move forward in a new and positive direction with a final rule" that incorporates new requirements for monitoring dust exposures that reduces miners' risk of black lung disease" upon successful completion of in-mine performance verification testing of the PDM units. The Department will review the various options, including rulemaking, for the eventual application of this novel monitoring technology in our Nation's coal mines.

#### OVERTIME REGULATIONS

*Question.* You are not asking for any increase in staffing for enforcement of Wage and Hour Standards, despite the major overhaul in overtime regulations that went into effect August 23, 2004. What is the Department doing to enforce compliance with the new overtime regulations?

Answer. The final rule went into effect on August 23, 2004. Since the final rules were published in April 2004, ESA staff has participated in over 630 compliance assistance seminars reaching some 63,000 employers, employees and others. ESA also launched the new FairPay web site, which provides online training seminars, model salary basis policy, numerous fact sheets and frequently asked questions. Recently,

the agency has updated its interactive on-line elaws advisor to include the new overtime rule. The advisor averages 35,000 users a month.

ESA's ongoing Overtime Security Task Force initiative involves 162 targeted investigations of employers with low-salaried employees. The initiative was designed to secure overtime protections for the 1.3 million salaried workers who are now entitled to overtime because of the salary increase. Five planned regional employer forums have already been conducted in connection with this initiative.

*Question.* What has been the experience to date with complaints and litigation?

*Answer.* Contrary to the dire predictions of some, the new rule has proved to be a catalyst for compliance. Media reports from around the country confirm that as employers have reviewed how they classify employees, many workers who should have been paid overtime under the old rules have gained overtime protection for the first time, in addition to the many workers who have gained overtime protection as a result of the higher salary level test. The new overtime security rules have put in place much needed overtime protections for millions of workers, especially lower-wage workers.

For example, a Wall Street Journal article published April 18, 2005, notes that more workers gained overtime protections than lost them under the new rules, citing recent surveys and consultations with employers to suggest that few employers reclassified any employees as exempt from overtime while many more employers gave overtime protection to some workers who did not have it before.

The few Federal courts that have considered the new rules have concluded that the duties tests are essentially the same as under the old rules and that the outcome of the cases would be the same as under the old rules.

#### CIVIL MONETARY PENALTIES FOR VIOLATIONS OF FLSA

*Question.* You are proposing legislation to increase penalties for violations of child labor and health and safety laws. How many additional resources do you estimate would be collected in fiscal year 2006 from these higher penalties?

*Answer.* The proposal, which would increase civil monetary penalties for violations of the Fair Labor Standards Act's youth employment provisions that result in the death or serious injury of a young worker, would provide ESA with stronger deterrents and more effective penalties to address the most serious of the youth employment violations.

The Department estimates it would receive no additional resources as a result of the increase in child labor civil monetary penalties. The proposal specifies that civil monetary penalties collected for youth employment violations are to be deposited in the general fund of the Treasury, as they are currently. The funds are not now, and will not be, returned to the Department as means to augment its enforcement efforts.

#### ASSOCIATION HEALTH PLAN LEGISLATION

*Question.* Is the Labor Department's fiscal year 2005 budget sufficient to effectively administer Association Health Plan (AHP) legislation, or would additional resources be necessary?

*Answer.* The Department's fiscal year 2005 budget that has already been enacted does not include resources specifically allocated for AHP administration. This is due to the fact that the legislation has not been finalized, and we do not know the extent of the Department's jurisdiction, authority, or workload.

The Department will make determinations about any additional funding and staff requirements when the legislation becomes law.

#### H-1B SKILLS TRAINING GRANTS

*Question.* Madame Secretary, while the Department of Labor's budget request identifies a number of proposed competitive grant programs, such as Prisoner Re-Entry and Community College/Community-based Training grant programs. The Department's fiscal year 2006 budget request does not identify the H-1B skills training program, which is financed through employer paid H-1B fees, as one of those competitive grant programs.

With roughly \$125 million available in fiscal year 2006 for these H-1B skills training grants, can I have your assurance that these grants will continue to be awarded on a competitive basis, as they have been in previous iterations of the H-1B grant program, and coordinated through the workforce investment boards?

*Answer.* The implementation plan for the new H-1B job training grant program is currently under development. As you know, the new grant program and the fees on employers submitting H-1B applications that will be the source of funding for the grants were authorized by amendments to the Immigration and Nationality Act

that were contained in the fiscal year 2005 Consolidated Appropriations Act enacted last December. ETA anticipates that the vast majority of investments of new H-1B job training grants will be awarded on a competitive basis. The competitive investments will be strategic partnerships that develop solutions-based approaches to workforce challenges identified by industry. ETA will look to fund mature partnerships between the workforce investment system, education, and employers to implement activities, including job training. These services and activities are designed to prepare workers, unemployed and employed, to take advantage of new and increasing job opportunities in high-growth/high-demand and economically vital industries and sectors in the American economy.

#### OVERHEAD

*Question.* Madame Secretary, the President's budget request states that the President's job training reforms would increase the number of workers trained in large part by eliminating unnecessary overhead. The fiscal year 2006 budget builds on the President's April 2004 proposal for job training reform that sought to "double the number of workers trained." Please define precisely what the Department means when it uses the term "overhead".

*Answer.* Part of the problem lies in the lack of an appropriate statutory definition in WIA of overhead or administrative costs. As a result, too many WIA dollars are spent on overhead and non-training services, such as management studies, travel, and other infrastructure costs. In Program Year 2003, the largest share, or 30 percent of WIA funds, was spent on "Infrastructure." Nineteen percent of funds were spent on employment placement activities while 23 percent was spent on core and intensive services and 28 percent was spent on training. Many of the infrastructure activities are necessary and appropriate, but it is difficult to justify spending more WIA funds on infrastructure activities than on training.

Part of the solution is to more accurately define administrative costs. Through WIA reauthorization, the Administration proposes to specifically define administrative costs, while emphasizing the relative importance of training. The new definition would clarify that administrative cost limits apply to subrecipients and vendors just as they do to primary grant recipients.

More broadly, the consolidation of four separate programs proposed by the Administration will reduce overhead costs by eliminating duplication in the provision of services, taking advantage of gains in economies of scale, and promoting a more effective and efficient use of Federal dollars. Continuation of the four programs—the WIA Adult program, the WIA Dislocated Worker program, the WIA Youth program, and the Wagner-Peyser Employment Service program—promotes "silos" of duplicative government systems providing identical services such as job search assistance and career counseling. By continuing duplicative service delivery systems, taxpayers pay more for administrative costs, overhead, and government bureaucracy, and receive fewer services. Furthermore, States that opt for WIA Plus State Consolidated Grants will be able to eliminate even more duplication.

#### NATIONAL FARMWORKER JOBS PROGRAM

*Question.* Madame Secretary, the Department has once again proposed to eliminate the Migrant and Seasonal Farmworker Program, rating it "ineffective" in an Office of Management and Budget PART assessment. The OMB materials go on to note the program's poor performance accountability. However, the Department's own budget materials indicate that the Program Year 2003 goal was achieved—84 percent of program participants were employed at program exit; 80 percent were still employed 6 months after initial entry into unsubsidized employment and average earnings gains for those employed was over \$4,300. Importantly, 84 percent of farmworkers who participated in education or training under the program received an education or occupational credential or certificate, enhancing their ability to compete for better jobs.

*Answer.* The performance results for the National Farmworkers Jobs Program (NFJP) appear high, but these performance levels only reflect how successful the program is for those participants who receive employment and training services. The majority of the approximately 20,000 farmworkers served through the NFJP—about two out of three—receives related assistance services only (such as emergency assistance, transportation or child care) and do not receive any employment and training services. Therefore, NFJP is providing employment and training services to a very small proportion of the estimated 2 to 3 million farmworkers, and it is difficult to justify the program's overall impact on improving the economic opportunities of farmworkers.



In addition, the PART review found that the NFJP was duplicative of other programs and services available through the WIA Title I programs and that farmworkers would be served better by accessing those services through the One-Stop system. Many NFJP grantees are already partners in the One-Stop delivery system at the State level. Yet, many localities rely on NFJP grantees almost exclusively to serve farmworkers outside the better-suited One-Stop delivery system.

QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

ODEP MOU WITH SBA

*Question.* I was very pleased to see that the Department of Labor (DOL) recently signed a Memorandum of Understanding (MOU) with the Small Business Administration on the development of programs and policies to encourage self-employment for people with disabilities. Unfortunately, no DOL funds have yet been committed to this MOU, and the 2006 budget proposes to drastically reduce funding for the Office of the Disability Employment Policy (ODEP). Part of this proposed savings is to come from the elimination of \$16 million worth of grants to enhance employment opportunities for Americans with disabilities. Please provide a list of the \$16 million worth of grants and a justification for why you believe they have outlived their usefulness. In addition, I'd like to know how much of the proposed million in the budget will be allocated toward programs associated with this MOU.

*Answer.* In fiscal year 2006, ODEP will continue, with the Small Business Administration (SBA), to implement the Memorandum of Understanding through the allocation of staff resources (Full Time Equivalents) in order to develop specific activities related to Small Business Development. This includes providing information, technical assistance, and policy guidance to the workforce development and small business development systems, to increase participation of people with disabilities in entrepreneurship training, financing, accessing needed capital, and increasing capital for individuals with disabilities who desire to start their own businesses. ODEP is working with SBA, DOL agencies, and business associations to develop the capacity of small businesses to recruit, hire, retain, and promote people with disabilities by documenting and disseminating effective practices to the small business community.

In addition, the fiscal year 2006 Budget will enable ODEP to continue its core mission of policy analysis, technical assistance and dissemination of effective practices to increase the employment opportunities for people with disabilities. ODEP plans to refocus its research emphasis from a reliance on using externally-grant funded public and private organizations, to a stronger internal emphasis on policy development, analysis, and dissemination.

NATIONAL AGRICULTURAL WORKERS STUDY (NAWS)

*Question.* The President's budget for 2006 proposes a \$13 million increase in the Bureau of Labor Statistics and yet a stop work order went out in January on the \$2 million National Agricultural Workers Study (NAWS). This study determines the distribution of more than \$1.3 billion in government spending. Departmental statements in the past have been that the study was cancelled in an effort to get other Federal agencies to fund the contract. Can you provide a record of DOL attempts to ask other agencies to fund the contract prior to terminating it? What is the status of the contract right now? Have other agencies stepped forward and if not, what are DOL plans with respect to this study?

*Answer.* Let me begin by clarifying that the Department of Labor has not cancelled the NAWS. The Department and this Administration recognize that, although the wages, income, and working conditions for migrant and seasonal farm workers have improved in recent years, these important workers face unique challenges as they continue contributing to the success of the agricultural industry.

As part of the Department's ongoing effort to improve programs that benefit both workers and employers, we have been consulting with other Federal agencies that use the data collected by the NAWS to determine the most suitable host agency for this survey. The Department issued a partial stop-work order to the NAWS contractor on January 12, 2005, but that stop-work order has been lifted and the NAWS contractor is again collecting data and will continue to do so periodically in the future. During the stop-work order, the contractor was instructed to cease survey work but to continue three NAWS-related task orders, one each for the Department's Employment and Training Administration (ETA), the Environmental Protection Agency (EPA), and the Centers for Disease Control and Prevention, National Institute for Occupational Safety and Health (CDC NIOSH). Under these task or-

ders, the contractor is analyzing data, writing reports, testing new questions, and providing special data sets.

The Department continues to evaluate survey options for the future. We recently produced the ninth NAWS Report, which is based on information collected in fiscal years 2001–2002. We are in the process of analyzing NAWS data from fiscal years 2003–2004, which will be presented in a future report.

#### SANITARY FACILITIES AND FEMALE EDUCATION

*Question.* Madam Secretary, research has repeatedly shown that the health and survival of children improve in direct proportion to the mother's level of education. The education of girls leads to major benefits: higher incomes and smaller families for the girls themselves and more productive economies in the countries that support the education of girls. Despite these statistics, UNICEF has found that girls represent 70 percent of children ages 6–11 who are not attending school worldwide. There are many reasons for this but one simple intervention is making a big difference—girls are more likely to be kept out of school if there are no sanitation facilities. When we put girls' bathrooms in schools, parents are more likely to send their daughters to school rather than to work.

This is why grants have been made from the Basic Education program in the International Labor Affairs Bureau to organizations that build girls bathrooms in schools, primarily in Africa. However, I have recently become aware of reports that the Department of Labor is warning these organizations that for some administrative reason, they cannot leave the toilets in the school after the grants have expired.

If this is true, it is just ridiculous. The whole purpose of the funding was to put the bathrooms in the schools so that generations of girls would get educated and improve their families and their countries—why would we spend additional dollars to take them out after 3 years or 5 years, or whatever the length of the grant?

If the Department is indeed requiring the organizations to remove the equipment, can you please provide the rationale behind this requirement to the committee along with your plan for how you intend to fix this situation?

*Answer.* The Department of Labor (DOL) believes that projects which expand access to quality educational opportunities are a vital tool in combating child labor. Moreover, we strongly agree that the construction of latrines and other sanitary facilities as part of such projects is an effective means of encouraging parents to send their children, especially girls, to school, rather than to work in often exploitive forms of labor. To date, DOL has not directed any grantee to remove latrines from schools, and it is not our intention or desire to do so. However, Federal grant regulations governing the acquisition and use of items of property may require the removal of these sanitary facilities upon the conclusion of the grant, in such cases we are obligated to advise the Bureau of International Labor Affairs (ILAB) grantees of their responsibilities regarding property acquired with Federal grant funds.

You can be confident that the Department will work very closely with its grantees to assist them in retaining any sanitary facilities even after direct grant funding ends, by encouraging them to continue to use the property to support the grant's goals of improving educational opportunities and decreasing exploitive child labor. We believe that such uses of the property will allow indefinite retention of the sanitary facilities under the Federal grant regulations, and we are committed to ensuring the sustainability of these critical projects. Given the nature and value of latrines being funded by ILAB, we believe Federal property regulations would require removal of the facilities or compensation to the United States for the facilities' value only in the rare circumstance that the educational project closes down, or the project seeks to sell or dispose of the facilities.

#### NATIONAL EMERGENCY GRANTS

*Question.* Secretary Chao, at your last appearance before us, you and I spoke about the National Emergency Grant program. I am very concerned that this remains a problem. A majority of States in a recent GAO report stated that they had to delay or deny services to workers as a direct result of the backlog in NEG applications at the Department of Labor. Is it as a direct result of the backlog in NEG applications at the Department of Labor? Is it true that your Department now plans to stop counting the number of days elapsed if there is a problem with an application? If so, will that include routine clerical errors or must there be a significant lack of information for the application to stop being counted?

*Answer.* The Department of Labor is committed to reviewing National Emergency Grant (NEG) applications as quickly as possible, and we have made significant progress in resolving any backlog. When the issue was raised initially, we imposed a goal on ourselves of making award decisions within 30 working days of receiving

a completed application. Further, we have taken steps to simplify and automate the application process through an electronic application system. The GAO study you refer to was based on data from a couple of years ago, prior to these actions.

Phase 1 of the e-application system was operational on July 1, 2004. We are already enhancing this system for State use with a Phase 2 system that will be fully implemented on July 1, 2005. Preliminary testing of Phase 2 with State users received a uniformly positive reception. Additional design enhancements will be developed and implemented next year.

The new NEG e-application system ensures that all necessary information is provided and eliminates the possibility that applications could be rejected purely for clerical errors.

Since the introduction of the e-application system, the Department has seen a reduction in the amount of time required for review and approval of NEG applications, and we expect to improve upon this response time in the future. We have been within our self-imposed timeframe of 30 working days. Further, we will continue to track the application award period. States have not been complaining about NEG timeliness in the past year due to our proactive reform of the program.

Finally, the Department believes that States and localities have sufficient funds to initiate services to workers who may subsequently be served under a National Emergency Grant. Services should not be denied or delayed while awaiting a decision on a NEG award. States carried in almost \$550 million in unexpended Dislocated Worker formula funds—roughly two times the amount available for NEGs.

#### NATIONAL LABOR MARKET INFORMATION

*Question.* The National Labor Market Information programs provide State-by-State information on employment, unemployment, earnings, occupational information, skills trends by industry, worker displacement, and job openings. Policy makers, including those of us in Congress, utilize this information to make decisions on allocation of Federal funds, program planning and evaluation as well as labor market dynamics. Why does the President's budget propose to eliminate the national labor market information programs? What measures will you put in place to ensure that State information is reported in a consistent, timely, and accurate manner?

*Answer.* It is important to clarify that the funding for workforce and labor market information within DOL occurs in two different agencies. The Bureau of Labor Statistics (BLS) funds States to collect a wide array of information, including the information mentioned in the question. That information is available on a State by State basis and is also used as the foundation for national labor market statistics.

The Employment and Training Administration (ETA) provides funding to States to develop workforce information as a service to businesses and job seekers. The data and statistical information that States collect on behalf of BLS is an important foundation for the workforce information funded by ETA. However, supplemental workforce information may come from many other sources including census data, State economic development data, educational data, data collected by industry trade associations, and information received from direct contact with the business community. The goal of ETA's investments is to transform these BLS and supplemental data sources into workforce intelligence through analysis and the development of user-friendly tools and products.

The U.S. Department of Labor fiscal year 2006 budget proposal for ETA does not eliminate the national labor market information programs. As part of the proposed WIA Plus State Consolidated Grants, \$39,680,000, which was previously provided to States in a stand alone grant, would be moved from the One-Stop Career Center/Labor Market Information line item into the consolidated grants to support State development and dissemination of workforce information. The consolidation of the workforce information funding into the WIA Plus Consolidated Grants will serve as an additional catalyst for transforming the silo system of the past into a demand-driven workforce information system that provides more and better information products and services that consumers will need in making strategic and tactical workforce investment and critical career decisions.

The consolidation proposal does not affect funding for BLS or the Census Bureau, where much of the information used in the national allocation of Federal funds, program planning, and evaluation, as well as labor market dynamics information is provided.

#### JOB CORPS

*Question.* Madam Secretary, this Subcommittee has demonstrated a long-standing support for the Job Corps program. That support has been based on proven results working with disadvantaged youth. Despite the fact that 74 percent of Job Corps

enrollees are high school drop outs and 32 percent come from families on public assistance, 90 percent of Job Corps graduates are placed in full-time employment. The average hourly wage for Job Corps graduates at 6 months after initial placement is \$8.95 per hour. This is a real opportunity for kids who are headed down a tough road.

In the current economy, however, this figure does not adequately reflect the benefit of Job Corps to graduates because it does not address the health and pension benefits. Please submit data to the Committee on the availability of health and pension benefits to Job Corps graduates 6 months after initial placement, the estimated value of those benefits, and other significant benefits such as the opportunity for continuing education or ongoing training. Madam Secretary, these benefits are getting more valuable by the day and I strongly urge you to incorporate this question in your 6 and 12 month follow-up surveys.

Answer. Both the 6-month and 12-month follow-up surveys ask initially-placed graduates (who indicate that they were employed during the week prior to the survey) whether any benefits are available to them through their job. Specifically, the survey asks whether the employer offers a health insurance plan, paid sick leave, paid vacation, childcare assistance, or a retirement or pension plan. The 6-month and 12-month surveys do not collect information in regard to the value of these benefits.

The table below depicts the percentage of graduates, employed at 6 months and/ or 12 months during PY 2003, who responded to the survey that their employer offers one or more of the listed benefits.

Benefits offered by employer	Percent of employed graduates offered benefits	
	at 6 Months	at 12 Months
Health Insurance Plan .....	62.0	61.7
Paid Sick Leave .....	49.2	51.2
Paid Vacation .....	61.0	61.0
Childcare Assistance .....	15.5	17.2
Retirement or Pension Plan .....	42.2	45.6

Not included in these data are the over 1,581 Job Corps students placed in the military during PY 2003, all of whom, as service members, receive benefits such as medical, dental, 30 days paid vacation, an automatic \$32,000 Montgomery GI Bill, and 100 percent tuition assistance for college education.

*Question.* In addition, while I am a strong supporter of the benefits of online learning for rural areas and I am certainly always appreciative of budget savings, I am concerned about the suggestion in your budget documents that you want to move toward relying more heavily on online learning in Job Corps Centers. The kids in these programs are difficult to reach and Job Corps does a fantastic job of turning them around. At the heart of the program is the personal connection that highly qualified instructors make with these kids, cheering them on and giving them a real sense of accomplishment. Can you provide a 5 year plan for Job Corps curriculum? Please include information on the manner in which online learning will be utilized to deliver services to Job Corps participants.

Answer. Since 2002, Job Corps centers have increasingly provided online and server-based courses to students to enable them to complete their high school programs and receive diplomas. These programs are particularly beneficial in situations where the Job Corps centers are in rural locations and/or cannot make arrangements with local high schools to allow students to attend classes.

In Job Corps classrooms with online learning opportunities, an instructor circulates among the students to answer questions and provide one-on-one assistance. Group instruction and written materials are often incorporated with the delivery of online courses. Currently Job Corps centers do not use a single online curriculum. Operators of multiple centers tend to have contracts with online course and software providers to enable cost-effective delivery to several centers.

In PY 2005, however, the Job Corps National Office plans to undertake a major effort to establish standards and curriculum for foundation courses in reading, math, and writing and to establish core standards for high school programs with recommended curricula. These efforts will follow the development of strategic education and instructional technology plans. Therefore, Job Corps does not currently have a 5-year curriculum plan in place. While the specific approaches to incorporating online and other curricula will be based on the planning process, Job Corps

intends to build on best instructional practices and courses to create a “blended learning” approach involving a mix of face-to-face and online instruction. This approach has been proven effective in engaging students with diverse learning styles and abilities and enabling them to work closely with qualified instructors. The use of online learning will also allow students to have equal access to Job Corps’ newly developed core curricula, based on rigorous standards in both academic foundation skills and high school programs.

#### HIGH GROWTH JOB TRAINING INITIATIVE

*Question.* As a Member of both your Appropriations and Authorizing Committees, I was very interested to read in your testimony about a new program that is not authorized under the Workforce Investment Act (WIA) called the High Growth Job Training Initiative. You cite the fact that you have spent \$164.8 million for 88 grants since 2002. I have a series of questions related to the expenditure of these dollars.

How many of these grants were awarded on a competitive basis?

*Answer.* The High Growth Job Training Initiative was initiated to model new and innovative strategies to create a demand-driven workforce investment system. In carrying out this mission, the Department awarded grants to model programs using discretionary funding for this activity as is authorized under title I of the Workforce Investment Act. Through unsolicited grants, which are not awarded on a competitive basis, the Department has been able to strategically invest in innovative models that address the key issues industry identified and to do so in the context of different sectors for each industry. Unsolicited grants also have allowed the Department to spark transformation of the workforce investment system to a system that is more demand-driven—that is, more responsive to the skill needs of businesses and industry. This innovative approach to workforce investment features partnerships that include the workforce investment system, business and industry, education and training providers, and economic development working collaboratively to develop solutions to workforce challenges. The 88 grants cited, and a subsequent grant awarded on June 3 to the Pennsylvania Workforce Investment Board for a comprehensive statewide strategy for addressing the workforce needs of Pennsylvania’s plastics manufacturing sector, were awarded as non-competitive grants. All of these grants were subject to review and approval by the Department’s Procurement Review Board.

It has been the Department’s intent from the beginning to move to competitive opportunities following the first round of strategic investments by industry. In June 2005, the Department announced 12 grants, in the health care and biotechnology industries, which were competitively awarded in accordance with a Solicitation for Grant Applications. Moving forward, the majority of future investments will be made on a competitive basis.

*Question.* How many of these grants were awarded directly to private sector companies?

*Answer.* Of the 88 grants cited, three were awarded to private sector companies in partnership with non-profit associations, workforce investment boards, and other public sector entities, which was a requirement. These grants were awarded to:

- Catalyst Learning*, in partnership with Anne Arundel Community College
- Hospital Corporation of America (HCA)*, in partnership with Broward County Community College, Dade County Community College, and Palm Beach County Community College
- Management & Training Corporation*, in partnership with City Colleges of Chicago, Cincinnati State Technical and Community College, Sinclair Community College, Luzerne County Community College, Lehigh/Carbon County Community College, the Metropolitan Chicago Healthcare Council, the Paul Simon Chicago Job Corps Center, the Cincinnati Job Corps Center, the Dayton Job Corps Center, and the Keystone Job Corps Center

Two subsequent grants were competitively awarded in accordance with a Solicitation for Grant Applications to private sector companies. They are:

- CVS Regional Learning Center*, in partnership with Detroit Workforce Development Department, ORC Macro, Wayne County Community College District, Goodwill Industries of Greater Detroit, New Galilee Missionary Baptist Church, Perfecting Church, and Little Rock Baptist Church
- United Regional Health Care System*, in partnership with North Central Texas Healthcare Consortium, United Regional Healthcare System, Wilbarger General Hospital, Electra Memorial Hospital, Seymour Hospital, Vernon College, Midwestern State University, Texas Christian University, North Texas Tech Prep Consortium, Partners-in-Education, and Region 9 Education Service Center

*Question.* Can you provide the Appropriations Committee with a complete list of all of the grants awarded under this program and their geographic locations?

*Answer.* Yes. Through the High Growth Job Training Initiative, the Department has made 101 investments in 12 high growth industries. The details on each award follows:

*Grant Recipient and Location:* Henderson-Henderson County Chamber of Commerce/Kentucky

*Partner(s) and Location(s):* Henderson, Union, and Webster County WIBS; Henderson Community College; the Kentucky Community and Technical College System; Employer representatives from targeted industries; County economic development councils; city and county municipal governments and county high school technology centers/KY

*Funding Amount:* \$2,991,840

*Purpose of the Award:* This pilot will design and deliver demand-driven training and placement services in the following industries: industrial technology, engineering technology, manufacturing, hydraulics, pneumatics and IT. We anticipate that this demonstration will train and place 1,265 workers. It is anticipated that at least 63 percent will be placed within four weeks and 71 percent of dislocated workers will be placed.

*Grant Recipient and Location:* Automotive Youth Educational Systems/Michigan  
*Partner(s) and Location(s):* Automotive manufacturers and dealers' associations; local high schools/national

*Funding Amount:* \$600,000

*Purpose of the Award:* The grantee will demonstrate a demand-driven automotive technician curriculum and training process that uses a new blended training delivery model (including on-line features). This new approach to learning, paired with work-based applications in dealerships across the country, will offer access to expanded learning opportunities in urban and rural communities. This pilot project is projected to train 6,250 new participants in year 1, 7,700 in year 2, and 8,600 in year 3.

*Grant Recipient and Location:* Council for Adult and Experiential Learning/Pennsylvania

*Partner(s) and Location(s):* WIBs in local sites; Community colleges in local sites; hospitals at local sites; Department of Labor Office of Apprenticeship/IL, MD, SD, TX, WA, GA, VA, DE, WI

*Funding Amount:* \$2,174,450

*Purpose of the Award:* This pilot is designed to increase the number of CNAs, LPNs, and RNs by building upon a pre-existing career ladder model and adding an apprenticeship component for CNAs and LPNs. It is anticipated that the demonstration will train approximately 300 students per site at 5 sites for a total of 1,500 students served during the pilot.

*Grant Recipient and Location:* Computing Technology Industry Association (CompTIA)/Illinois

*Partner(s) and Location(s):* Northern Virginia Community College; NFL Films; Okidata; Hill International, Keyport Division; Naval Undersea Warfare Center; Henkels & McCoy; Exodux IT Services; Cosmopolitan Chamber of Commerce/national

*Funding Amount:* \$2,818,795

*Purpose of the Award:* This demonstration will support the development and implementation of a National Information Technology Apprenticeship System (NITAS), a competency-based apprenticeship methodology that supports consistent and flexible credentialing for the career development and advancement of IT workers. It is anticipated that through this demonstration approximately 384,000 IT workers will become registered apprentices and approximately 6,700 employers will register as on-the-job learning providers. The seven-track NITAS career matrix allows workers to progress through all or part of the apprenticeship program using a combination of classroom instruction and on-the-job training. Standardized, industry-recognized certifications are earned as each apprenticeship tier is completed and the certifications are transferable from employer to employer.

*Grant Recipient and Location:* The National Retail Federation Foundation (NRFF)/Washington, D.C.

*Partner(s) and Location(s):* Local WIBs involved in multiple project sites; local community colleges involved in multiple locations; Toys "R" Us; Saks, Inc.; CVS/pharmacy; the Home Depot; seven major shopping center developers; hundreds of large and small retail employers and businesses; NRFF's State and Local Affiliate Network; State and Government Agencies; Community-based organizations/DC

*Funding Amount:* \$2,250,000

*Purpose of the Award:* Grantee will demonstrate a model for creating a comprehensive cross-industry career ladder from sales associate through senior level management. For each level in the career ladder, a core competency and training curriculum model will be developed for distribution throughout the industry and the public workforce system. In addition, the demonstration will train a significant number of incumbent and new workers in the retail sector in partnership with employers and the public workforce system. The curriculum will be disseminated broadly to retail employers across the country through the public workforce system.

*Grant Recipient and Location:* The National Retail Federation Foundation/Washington, D.C.

*Partner(s) and Location(s):* Local WIBs involved in multiple project sites; seven major shopping center developers and hundreds of large and small retail employers and businesses; Montgomery College; NRFF's State and Local Affiliate Network; State and Local Government Agencies; and community-based organizations/national

*Funding Amount:* \$2,815,000

*Purpose of the Award:* This Project will demonstrate the use of retail skills centers' at eight sites that provide retail and customer service education and training services for mall employees and area job seekers. Located in shopping centers, these "skills centers" help retail employers recruit, retain, and advance workers through a range of training options, from language and employability skills classes to customized seminars. This pilot project is projected to train and place over 3,000 individuals in the retail sector.

*Grant Recipient and Location:* National Restaurant Association Educational Foundation/Illinois

*Partner(s) and Location(s):* State Restaurant Associations in each State; International School Licensing Corporation's America's Schools Program/national

*Funding Amount:* \$1,765,000

*Purpose of the Award:* NRAEF will demonstrate the value of creating a national system of State hospitality partnerships through the HBA/ProStart project. These partnerships, in 19 States across the country, are dedicated to the establishment of 900 high school hospitality School-to-Career programs and industry mentoring programs that lead to an industry-recognized national certificate. The goal of the project is to offer work-based learning opportunities for 6,700 students at approximately 6,000 work sites. By increasing student worksite experience and increasing industry involvement in workforce issues through this project, NRAEF will have the ability to cultivate new sources of talent and thus strengthen the hospitality industry by attracting, supporting, guiding, training, and teaching current and future workers.

*Grant Recipient and Location:* National Institute for Metalworking Skills (NIMS)/Virginia

*Partner(s) and Location(s):* Employer partners are mentioned but not specifically named/national

*Funding Amount:* \$1,965,700

*Purpose of the Award:* This demonstration is designed to create a more economical, rational, effective and efficient competency-based apprenticeship model that builds on the time-tested NIMS skill standards credentialing system. Under this demonstration, NIMS will develop a competency web for metalworking occupations consistent with NIMS skill standards.

This includes developing apprenticeship programs and curriculum development for the six competency-based apprenticeship programs with portable, nationally-recognized credentials for these occupations complete with a curriculum guide and implementation guide. It is anticipated that this demonstration will train ATELS staff and industry partners on the apprenticeship programs to better serve the over 500 apprenticeships under way at any one time by employers and associations.

*Grant Recipient and Location:* Community Learning Center, Inc. (CLC)/Texas (two grants)

*Partner(s) and Location(s):* Tarrant County Workforce Development Board; Tarrant County College; Lockheed Martin-Aero; Bell Helicopter-TEXTRON; Interconnect Wiring and Southwest Airlines/TX

*Funding Amount:* \$4,028,400

*Purpose of the Award:* This demonstration project will continue the Aerospace Industry Training Project (AITP) for preparing and placing dislocated workers in aircraft assembly and will provide incumbent workers with advanced training. It is anticipated that 1,024 dislocated workers will receive training and wage increases and that 802 workers will be placed in unsubsidized employment.

*Grant Recipient and Location:* Downriver Community Conference—AutoAlliance International/Michigan

*Partner(s) and Location(s):* Michigan Works Association; Monroe County Community College; Henry Ford Community College; Wayne County Community College; Davenport University; Baker College; AutoAlliance International (joint venture of Ford and Mazda); UAW; Downriver Career Technical Consortium; Flat Rock secondary schools/MI

*Funding Amount:* \$5,000,000

*Purpose of the Award:* It is anticipated that the grantee will demonstrate methods for training and preparing automotive workers for new advanced manufacturing production processes. Grantee will map, track, and analyze transferable manufacturing skills sets and competencies required for the new positions and provide training, assessment and employment for 1,400 worker

*Grant Recipient and Location:* Alameda County Workforce Investment Board/California

*Partner(s) and Location(s):* San Mateo County WIB; Skyline Community College; Ohlone Community College; Genetech; Alza; Baxter; Chiron; Adecco; Gruber and Pereira Associates; Opportunities Industrialization Center West/CA

*Funding Amount:* \$2,000,000

*Purpose of the Award:* Under this pilot, it is anticipated that the grantee will develop career pathways in bio-tech manufacturing, facilities management, quality control, and product engineering. Additionally, the program will work with area community-based organizations to create a "bridge" program to prepare lower skilled individuals for entry-level employment. This pilot project is expected to train up to 150 workers and place them in employment at wages of \$35,000–\$40,000 per year. In addition the grantee is expected to train 40 dislocated engineers and place them in employment at wages of \$50,000–\$80,000 per year.

*Grant Recipient and Location:* Forsyth Technical Community College/North Carolina

*Partner(s) and Location(s):* Forsyth Tech has a local JobLink One-Stop Career Center on campus; grantee is Community College; Syngenta, Targacept, Orthofix and Wake Forest University School of Medicine (WFUSM); North Carolina Biotechnology Center; Wake Forest University; Winston-Salem State University; University of North Carolina-Greensboro; Winston-Salem Chamber of Commerce; Winston-Salem/Forsyth County Schools/NC

*Funding Amount:* \$754,146

*Purpose of the Award:* Forsyth Tech will demonstrate a program designed to implement a biotechnology associate degree training program for the region's dislocated manufacturing workers. Forsyth Tech will retrain workers who have been dislocated from declining industries so that they are qualified for employment in the emerging biotechnology field. The Forsyth Tech curriculum will focus on training laboratory technicians in biotechnology and related pharmaceutical occupations and can be broadly replicated in community colleges across the country.

*Grant Recipient and Location:* Indian Hills Community College/Iowa

*Partner(s) and Location(s):* Iowa Workforce Development; Des Moines Area Community College; Biotechnology Association; Iowa Renewable Fuels Association; Cargill, Inc.; Genencor; Pioneer Hybrid International; Garst Seed; Phytodyne; Kemin Industries; Iowa Biotechnology Association; Iowa Renewable Fuels Association/IA

*Funding Amount:* \$996,250

*Purpose of the Award:* Under this demonstration project, the grantee will establish a comprehensive State-wide approach to growing the biotech industry as a part of the Iowa economic base; Create a skilled workforce through community colleges and workforce investment system partnerships; Educate middle and high-schoolers about biotech career options and skills needed. The grantee anticipates they will train 100 high school teachers and counselors, 100 unemployed and underemployed biotech workers, 600 incumbent biotech workers and provide career awareness training activities to over 6,000 students during the life of the grant.

*Grant Recipient and Location:* Lakeland Community College/Ohio

*Partner(s) and Location(s):* STERIS Corp.; Athersys, Inc.; Lakeland's BioTech Council and its employer members; school systems in Mentor, Ashtabula, and Mayfield, Ohio; Tech Prep Consortium; Ricerca Biosciences; BioEnterprise; Association for the Advancement of Medial Instrumentation; NeoBio; Lakeland Community Learning; Lakeland Center for Quality and Productivity/OH

*Funding Amount:* \$333,485

*Purpose of the Award:* The grantee will develop demonstration training programs that are designed to recruit new workers, beginning at the high-school level and up through a Master's Degree level in northeast Ohio. The grantee will partner with industry to create training and curriculum; develop a BioCenter and a national biotechnology career coaching model. This curriculum will be deseminated broadly ex-



panding the availability of industry-based curriculum and articulating career ladders and competency models designed to industry standards. It is expected that the grantee, as part of their activities, will expand internship and training opportunities through the pilot Bio Center.

*Grant Recipient and Location:* Pittsburgh Life Sciences Greenhouse/Pennsylvania  
*Partner(s) and Location(s):* Three Rivers Workforce Investment Board; Community College of Allegheny County; Renal Solutions, Inc. and six additional employers in the area; the Pittsburgh Technology Council; The Allegheny County Job Link/PA

*Funding Amount:* \$2,433,160

*Purpose of the Award:* In this pilot project, the grantee will match trained workers with local area biotechnology companies with the goal of rapidly deploying professionals into biotechnology employment through customized training programs and biotechnology curriculum. The grantee anticipates that they will train and place 200–400 workers in biotech business jobs. As a part of its efforts to support the growth of greater Pittsburgh life sciences employers, the project will provide training for new entrants into biotech as well as retraining for workers affected by declining industries.

*Grant Recipient and Location:* The Workforce Alliance, Inc./Florida

*Partner(s) and Location(s):* the Workforce Alliance; Treasure Coast Workforce Development Board; Indian River Community College; Workforce Florida, Inc.; Palm Beach County Business Development Board and Economic Development Council; Regional Biotechnology Employers; Florida Atlantic University; Office of the Governor; Scripps Research Institute; Palm Beach County's Government; school boards; the Agency for Workforce Innovation; Business Development Board; Economic Development Council/FL

*Funding Amount:* \$2,325,303

*Purpose of the Award:* This demonstration project is designed to retrain employed and unemployed workers to build careers in biotech in the Palm Beach County, Florida area. Through this demonstration project, the grantee anticipates enrolling 110 workers. The grantee estimates that 80 percent of employed and 65 percent of unemployed participants will complete their training with a certification or degree. FAU's Biotech Training Program will establish a biotech career ladder and develop curriculum as well as a program for participants to obtain a postgraduate level certificate in Biotechnology and Bioinformatics. The learning's from this program will be disseminated broadly for replication.

*Grant Recipient and Location:* American College of the Building Arts/South Carolina

*Funding Amount:* \$2,750,000

*Purpose of the Award:* The grantee will demonstrate the development and testing of an innovative, industry-driven curriculum that focuses on the traditional building arts, such as carpentry, ironwork, masonry, timber framing, plasterwork, and stone carving through the first of its kind school, the American College of Building Arts (ACBA). ACBA also will establish partnerships with industry organizations for future internship programs based on this piloted curriculum. The inaugural class of 100 students will be recruited from across the nation to attend this unique restoration training college and will return to local communities for work-based learning opportunities and employment.

*Grant Recipient and Location:* SkillsUSA-VICA/Virginia

*Funding Amount:* \$142,000

*Purpose of the Award:* Grantee will demonstrate methods for increasing the pipeline of skilled trade workers by building advanced competency models and career ladders and provide secondary students interested in the skilled trades with more post-secondary training alternatives, such as the opportunity to continue their skills development in advanced community college programs.

*Grant Recipient and Location:* Oklahoma Department of Career and Technology Education/High Plains Technology Center/Oklahoma

*Partner(s) and Location(s):* Northwest Workforce Development Council; Workforce Oklahoma; Marathon Oil Company; Mid-Continental Oil; Mid-Continental Oil and Gas Association of Oklahoma; Unit Drilling; Patterson-UTI Drilling; BP America Production Company/OK

*Funding Amount:* \$1,546,463

*Purpose of the Award:* In this demonstration project, the grantee will develop a bilingual training curriculum in gas and energy based on the skills needs of local employers. The grantee estimates they will train approximately 500 workers, including 125 workers new and 325 incumbent workers. As part of the demonstration, the grantee will develop and provide training for new and incumbent workers in the oil and gas industry and better integrate the industry with existing workforce development resources in Northwest OK, Southwest KS and the TX Panhandle. This model

will be disseminated to the public workforce system for replication across the country in areas in need of a skilled energy workforce.

*Grant Recipient and Location:* San Juan College Regional Training Center/New Mexico

*Partner(s) and Location(s):* Farmington WIB; local One-Stops in other participant recruitment States (CO, NM, UT, WY); Key Energy Services; Navajo Nation; Church of Jesus Christ of Latter-Day Saints/NM

*Funding Amount:* \$2,113,127

*Purpose of the Award:* This pilot project is designed to develop a regional energy training center with initial recruitment and screening conducted at one-stop centers to provide training to three targeted groups: minorities, predominately Spanish-speaking and Native Americans, underemployed and dislocated worker populations and underemployed incumbent workers. The grantee anticipates training 50 workers to complete applied basic education to attain required literacy level and training 400 workers in a certificate-based training program. The grantee anticipates that 320 candidates will complete the training, with 300 projected placements. In addition, the grantee anticipates that 240 will be retained after 30 days and 210 after 180 days of employment. In addition, the grantee will design a skills-based, competency model curriculum by mapping key occupational skills and benchmarking against the skills of current incumbent workers. This curriculum will be used as the basis for safety training certifications. To support efforts to reach under represented populations, the grantee will also develop video assessment tools, training videos with supportive curriculum written in Navajo and Spanish language. These recruitment tools will be made available to the public workforce system for use in providing career guidance to workers.

*Grant Recipient and Location:* University of Southern Mississippi (USM)—Geospatial Development Center/Mississippi

*Partner(s) and Location(s):* Local WIBs and One-Stop Career Centers; Mississippi Gulf Coast Community College; Pearl River Community College/MS

*Funding Amount:* \$1,565,227

*Purpose of the Award:* In this demonstration project, the grantee will develop a registered apprenticeship program in Geospatial Technology based on a competency model that will be designed as part of the pilot. The grantee anticipates that as part of the project, 30 apprentices will be trained. In addition, training materials, tests for related classroom instruction, and assessments for structured OJT will be developed. Some curriculum modules will be made available through web-based distance learning tools to allow for easy replication by the workforce system in partnership with employers in the Geospatial sector.

*Grant Recipient and Location:* American Health Care Association Foundation/Washington, D.C.

*Partner(s) and Location(s):* George Washington University's Center for Health Services Research and Policy and Wertlieb Educational Institute for Long Term Care Management/DC

*Funding Amount:* \$113,296

*Purpose of the Award:* This research and demonstration project is designed to support the workforce challenges faced by the over 16,000 long-term care facilities across the country. In this project, the grantee will develop an infrastructure of "Best Practice" models to build partnerships for combating the nursing shortage in long-term care that can be expanded, evaluated, replicated, and transported to other areas of the country. This project is designed to support addressing the nursing shortage in long-term care and offer a model designed to be replicable by workforce systems across the country, meeting this critical workforce shortage.

*Grant Recipient and Location:* Berger Health System/Ohio

*Partner(s) and Location(s):* Ohio University/OH

*Funding Amount:* \$200,000

*Purpose of the Award:* This demonstration project is designed to meet the needs of the rural community hospital by holding all classes and clinical rotations at the Berger Hospital facilities for the 3-year, university-based Associate Degree nursing program. The grantee anticipates that through this project, 30 incumbent employees and non-traditional students will enroll in credentialed programs. This project will serve as a model for replication in rural communities across the country, offering employee and opportunity to grow in their careers while remaining in their rural community.

*Grant Recipient and Location:* Capital IDEA/Texas

*Partner(s) and Location(s):* Worksource-Greater Austin Area Workforce Development Board; Austin Community College; in Austin: Seaton Healthcare Network; St. David's Healthcare Partnership; Austin Heart; in San Marcos: Central Texas Medical Center/TX

*Funding Amount:* \$224,088

*Purpose of the Award:* This demonstration project is designed to enable students and lower-skill hospital employees to advance to career training courses by providing tutoring in a key pre-requisite anatomy and physiology course. Tutoring begins the first week of class in order to: (a) increase the success rate of students, thereby reducing the extra expense of tuition, counseling, child care, and time associated with students repeating the course; (b) accelerate graduations; and (c) increase the success rate of disadvantaged students. Rather than take remedial action after students fall behind, the tutoring will raise their chances of enrolling in training for and successfully completing a nursing or allied health occupation.

*Grant Recipient and Location:* Catalyst Learning/Kentucky

*Partner(s) and Location(s):* Anne Arundel Community College/FL, IL, IN, KT, MD, MI, MO, NC, OH, PA, TN, TX, VA

*Funding Amount:* \$3,176,000

*Purpose of the Award:* Make basic skills and work-related education more accessible to adults in low-wage jobs and more feasible for employers by combining interactive television broadcasts in the workplace with additional coursework through printed materials and interactive online exercises.

*Grant Recipient and Location:* Columbia Gorge Community College/Oregon

*Partner(s) and Location(s):* Region 9 Workforce Investment Board; Columbia Gorge Community College; eight area hospitals and health care providers; K-12 school districts; Oregon Health and Science University; and city and county governments/OR, WA

*Funding Amount:* \$1,250,000

*Purpose of the Award:* This pilot project is designed to create a Health Occupations Career Ladder Nursing Program to train 200 new workers and expand CGCC's offerings and opportunities for an Associate Degree in Nursing and a distance learning option for a Bachelor Degree of Nursing Program. The grantee anticipates they will train 200 new healthcare workers. It is expected that forty nurses of 200 total trainees will have the opportunity to earn a BSN through Columbia Gorge's dual admission agreement with Oregon Health and Science University. In addition, the grantee will expand Certified Nursing Assistant/Certified Medication Aide training to fill vacancies created from the pilot project. The grantee anticipates they will offer 7-9 classes per year to train an additional 60 students and to develop opportunities for training including 10-20 CMAs per year.

*Grant Recipient and Location:* Excelsior College/New York

*Partner(s) and Location(s):* Excelsior College; fourteen hospices in New York State, along with one each in Montana, North Carolina, Rhode Island, South Carolina, and Texas; WINs demonstration project in various local areas/MT, NY, NC, RI, SC, TX

*Funding Amount:* \$516,154

*Purpose of the Award:* In this pilot project the grantee is expected to expand the number of registered nurses and create a stable, highly skilled RN workforce for hospices by developing a Hospice and Palliative Care Online Certificate Program (HPCC) that includes a period of practical experience and training supervised by an expert or specialist. The grantee is expected to development of a recruitment strategy designed to attract nurses to end-of-life care. Emphasis will be placed on the recruitment of RNs who are no longer employed in nursing but are interested in re-entering the field, nurses planning to leave the acute care arena, and new graduates. As part of the career awareness, the grantee will establish a website that will give hospices across the nation free access to discuss best practices, announce job openings, and publicize trainings and conferences. The grantee will also develop a 12-month end-of-life nursing training program that will be disseminated broadly to employers and community colleges for replication. The grantee anticipates serving 60 interns and approximately 30 preceptors affecting the quality of care of over 17,000 patients from its 212 hospice partners.

*Grant Recipient and Location:* Florida International University School of Nursing/Florida

*Partner(s) and Location(s):* Florida International University School of Nursing; Hospital Corporation of America/FL, TX

*Funding Amount:* \$1,421,639

*Purpose of the Award:* This innovative demonstration is designed to train 100 baccalaureate-prepared nurses from a pool of foreign educated physicians who are currently unemployed or underemployed, offering a new model for addressing the critical shortage of nurses in this country. As part of the demonstration, the grantee will pilot test a synchronous distance education component utilizing interactive television, offering an opportunity and method of replication for other areas of the country.

*Grant Recipient and Location:* Hospital Corporation of America (HCA)/Tennessee  
*Partner(s) and Location(s):* Broward County Community College; Dade County  
Community College; Palm Beach County Community College/FL, TX

*Funding Amount:* \$4,000,000

*Purpose of the Award:* Under this demonstration, the grantee will address the lack of experienced nurses and set standards that can be replicated across the country by creating a distance learning model and a fellowship program that will create an intensive, hands-on, accelerated learning setting similar to a medical residency. The grantee anticipates that 100 students will enroll in the critical care core program during the first year of the grant. During the second year of the grant, these 100 students will specialize in either critical care specialties or emergency department specialty and an additional 100 students will enroll in the critical care core. In addition to this training, the grantee anticipates that at least 30 students annually will receive sponsored scholarships. This demonstration will also allow for the development of a competency based Basic Arrhythmia challenge examination for experienced nurses as well as various forms of blended e-learning curriculum modules for additional topics in the critical care core curriculum. The project is designed to enhance the basic critical care core on-line curriculum with e-learning course content and didactic and laboratory activities. The model will develop critical care clinic courses for new nursing graduates and experienced med-surg and telemetry nurses and includes a teaching manual that provides course outlines, course syllabi, and clinical assessment instruments.

*Grant Recipient and Location:* States of Georgia, Colorado, Texas, and Florida

*Partner(s) and Location(s):* WIBs in all local areas, HCA, Inc.; community colleges in local sites

*Funding Amount:* \$4,541,205

*Purpose of the Award:* Grantee will demonstrate a program designed to assist workers dislocated since 9/11 by providing training scholarships for employment in high-growth nursing careers, LPN, radiology technologists, surgical technicians and certified nursing assistants. Over 875 individuals along the healthcare career ladder will receive scholarships.

*Grant Recipient and Location:* Johns Hopkins Health System/Maryland

*Partner(s) and Location(s):* Baltimore City WIB; Baltimore City Community College, Community College of Baltimore County (CCBC)/MD

*Funding Amount:* \$3,000,000

*Purpose of the Award:* In this demonstration, the grantee will develop and execute an Incumbent Worker Career Acceleration Program, including five components: (1) an initiative for addressing retention and growth of at-risk workers; (2) a GED and diploma preparation program; (3) an initiative for retraining of employees in declining jobs for emerging jobs; (4) a high-potential worker assessment and skills training program; and (5) an initiative to upgrade training of incumbent workers into critical skills shortage positions. The grantee anticipated that they will have an 80 percent retention rate for 100–150 employees participating in the Retention and Growth of At-Risk Workers Initiative as well as a 70 percent retention rate among 50 incumbent workers receiving a GED or diploma through the initiative; they expect that at least 25 of these individuals will go on to further skills training and higher-skilled positions. They anticipate that 75 participants to receive skills assessment, career counseling, and skills-based training and that 200 incumbent workers will receive assessment and training leading to the staffing of more critical skilled positions.

*Grant Recipient and Location:* Management & Training Corporation/Utah

*Partner(s) and Location(s):* In Illinois: City Colleges of Chicago; the Metropolitan Chicago Healthcare Council; in Ohio: Cincinnati State Technical and Community College and Sinclair Community College; In Pennsylvania: Luzerne County Community College and Lehigh/Carbon County Community College. Also, the Paul Simon Chicago Job Corps Center, the Cincinnati Job Corps Center, the Dayton Job Corps Center, and the Keystone Job Corps Center in Drums, Pa./IL, OH, PA

*Funding Amount:* \$1,500,000

*Purpose of the Award:* The focus of the grant is to unite the efforts of Job Corps Centers with community colleges to address the health care workforce challenges in Illinois, Ohio, and Pennsylvania. This demonstration is expected to train 210 youth over a 2-year period span at three different Job Corps Centers. The grantee is expected to measure retention and completion rates, percent of students who complete training in the project and become employed in the healthcare industry (job-training match), average wage of students employed, long-term attachment to the workforce, and promotions or lateral moves in the healthcare fields. As part of their activities, the grantee will develop outreach materials that are designed to attract low income,

out of school youth between the ages of 16–24 targeting out-of-school youth and Hispanic worker populations.

*Grant Recipient and Location:* Maryland Department of Labor, Licensing, and Regulation and Governor's Workforce Investment Board/Maryland

*Partner(s) and Location(s):* WIB is the grantee; a MOU will be developed among the community college system, the university system and the health care industry/MD

*Funding Amount:* \$1,500,000

*Purpose of the Award:* This demonstration is designed to address the faculty capacity problem by implementing a scholarship program for nurses who pursue credentials to teach nursing and allied healthcare professions. The grantee anticipates offering forty \$10,000 scholarships to nurses selected to obtain teaching credentials in healthcare. In addition, the grantee will offer forty \$10,000 scholarships will be provided to incumbent healthcare workers seeking to become Registered Nurses to replace those who have left to teach nursing. This model is designed to demonstrate partnerships that help backfill RN positions by implementing a scholarship program for Licensed Practical Nurses (LPNs) and other incumbent workers that are seeking their Registered Nurse (RN) credentials.

*Grant Recipient and Location:* North Carolina Department of Commerce Commission on Workforce Development/North Carolina

*Partner(s) and Location(s):* North Carolina WIBs; North Carolina Community College System; NC Hospital Association; University of North Carolina System; NC Department of Health and Human Services; NC Area Health Education Centers/NC

*Funding Amount:* \$1,500,000

*Purpose of the Award:* This demonstration is designed to address North Carolina's critical nursing and direct care worker shortages by targeting the State's pool of dislocated workers. The grantee anticipated training up to 450 displaced workers to enroll in Human Resource Development Plus pilot sites, 300 workers are expected to enroll in additional training with 200 placed in jobs including 120 as direct care workers. In this model, H.E.A.L.T.H. will work to enhance health career development and employability of dislocated workers and provide the needed support for an education and training institution for nursing. In addition, the grantee is building capacity to meet future training needs by training teachers and mentors, including adding MSN faculty with Master's Degrees in the Community College System, to meet on-going demand for healthcare workers.

*Grant Recipient and Location:* Paraprofessional Healthcare Institute/New York

*Partner(s) and Location(s):* Workforce Investment Board of Lancaster County, Pennsylvania; community colleges; Lehman College of New York; North Carolina Foundation for Advanced Health Programs/NY, PA, NC

*Funding Amount:* \$999,902

*Purpose of the Award:* The grantee will provide a range of technical assistance, training initiatives, and materials for the long-term care workforce. Emphasis will be placed on assisting Hispanic caregivers and supporting the nation's Workforce Investment Boards and community colleges in recruiting and training. As part of their activities, the grantee will create a coaching approach to supervision model for front-line supervisor with a curriculum designed specifically for employer-based community colleges and demonstrate the "Four Ps" problem solving training curriculum in partnership with Workforce Investment Board of Lancaster, PA. As part of this demonstration, the grantee will develop an apprenticeship career-lattice model based on work with home care agencies employing Hispanic and African-American workers as home health aides. To allow for replication of the model, the grantee will author a full series of guidebooks, curricula and teaching manuals-written in both Spanish and English-on a range of effective paraprofessional workforce development practices targeted to the home care workforce.

*Grant Recipient and Location:* Pueblo Community College/Colorado

*Partner(s) and Location(s):* Pueblo Work Link (One-Stop Career Center); Pueblo Community College; Trinidad State Junior College; Colorado Community College System; Parkview Episcopal Medical Center/CO

*Funding Amount:* \$715,402

*Purpose of the Award:* This demonstration is designed to bring healthcare training opportunities to outlying areas, and help volunteer medical personnel secure paid employment. As part of the grantee's activities they will create a multi-disciplinary curriculum based on competency models that is facilitated by Distance Learning modalities. As a result of their activities, the grantee expects to increase by 50 percent the efficiency of preparing under-represented minorities to take advantage of health career opportunities by developing a partnership between Pueblo Community College and Pueblo Work Link. The grantee expects that by the end of the grant, the project will increase the number of minority/disadvantaged EMT-I/Respiratory Care

training enrollees by 35 percent at Trinidad State Jr. College and 20 percent at Pueblo Community College.

*Grant Recipient and Location:* Rio Grande Valley Allied Health Training Alliance/Texas

*Partner(s) and Location(s):* Cameron County Workforce Development Board; Lower Rio Grande Valley Workforce Development Board; South Texas Community College; Texas State Technical College; Tech Prep of the Rio Grande Valley; Mission Hospital Harlingen Medical Center; Starr County Hospital; Brownsville Medical Center; Dolly V infant Memorial Hospital; Knapp Medical Center; Rio Grande Regional Hospital; South Texas Health System; Valley Interfaith; Valley Initiative for Development and Advancement/TX

*Funding Amount:* \$4,000,000

*Purpose of the Award:* It is expected as part of this demonstration that the grantee will assist area businesses and community leaders to develop, attract, and retain local talent by enrolling candidates, retaining them through tuition assistance, and developing a High School Concurrent Enrollment program and comprehensive Faculty Sharing Program while drawing from Alliance hospitals' supply of Masters of Science in Nursing. The grantee estimates that 135 participants enrolled in Post Licensure Specialties with a completion rate of 95 percent; 70 students annually prepared in academies; 90 high school juniors and seniors have the annual opportunity to take college classes; 360 participants receive comprehensive case management with 90 percent student retention rates. In this model demonstration, online coursework will be used as part of the Faculty Sharing Program for one allied health specialty and 400 students' clinical rotations coordinated via on-line, regional scheduling.

*Grant Recipient and Location:* State of Oregon/Oregon

*Funding Amount:* \$300,000

*Purpose of the Award:* This demonstration model will support the use of innovative technology to increase the capacity to train students for the health care industry by helping to purchase seven SimMan®, real-time interactive human patient simulators. The simulation technology will be integrated into health care curricula for use by well-prepared and networked faculty, available over the State's broadband Internet network, and affordable for all education and service groups in the State, increasing the capacity of the State to meet training needs for the industry. At least 90 instructors will receive training in using the patient simulators and will provide simulator-based training to at least 225 students.

*Grant Recipient and Location:* Tacoma/Pierce County Workforce Development Council/Washington

*Partner(s) and Location(s):* Bates Technical College; Clover Park Technical College; Tacoma Community College/WA

*Funding Amount:* \$762,659

*Purpose of the Award:* This demonstration is designed to improve and expand the pool of qualified professionals in high-demand health care jobs by training invasive cardiovascular technologists, creating a Comprehensive Career Coaching Program, establishing connections through a Healthcare Educator Network, and reaching out to minorities and youth. The grantee anticipates that 10 participants will complete the Health Unit Coordinator Pre-Apprenticeship Program and 50 healthcare workers will have access to the Comprehensive Career Coaching Program to access and complete high demand healthcare training programs. As part of the demonstration, the grantee will enroll 8 students in the Medical Rotation Program, implement a Health Summer Camp for 15 youths, and enter 15 students per year into a 2-year distance learning program. This grant will increase minority youth participation in job shadow and volunteer programs by 10 percent.

*Grant Recipient and Location:* Healthcare Workforce Network/Wisconsin

*Partner(s) and Location(s):* Northwest Wisconsin Workforce Investment Board, Ashland; Burnett Medical Center, Grantsburg; Flambeau Hospital, Park Falls; Memorial Health Center, Medford; Memorial Medical Center, Ashland/WI

*Funding Amount:* \$215,600

*Purpose of the Award:* This project will demonstrate the use of distance learning to train healthcare workers in rural areas and establish ongoing, collaborative relationships among rural health care providers and the One-Stop Career Center system. The grantee will pool financial, material, and human resources of small, remote hospitals and clinics for the purposes of increasing the supply and retention of health care professionals, and develop distance learning materials, including web-based training modules and satellite broadcasts. At least 300 incumbent workers will successfully complete at least one skills-upgrade module. The project will also increase the local pool of interested healthcare workers by 25 percent.

*Grant Recipient and Location:* The 1199 SEIU League Grant Corporation on behalf of the League 1199 SEIU Training and Upgrading Fund/New York

*Partner(s) and Location(s):* NYC Department of Education; the Consortium for Worker Education/NY

*Funding Amount:* \$192,500

*Purpose of the Award:* As part of this demonstration the grantee expects to expand the Contextualized Literacy Pre-LPN Program, which combines literacy and job training in preparation for LPN programs. This pre-LPN program has been designed for low-level health-care workers who have been out of school for a long period of time and have had difficulty passing entrance exams. The grantee expects to implement 10 pre-LPN classes of 25 students each (250 students) who will enroll in a 35-week contextualized course of study that will prepare them to pass the C-NET exam and lead to enrollment in an accredited LPN program. It is expected that 90 percent of the 250 workers pass the C-NET test and enroll in an LPN program, supporting meeting this critical workforce shortage. As part of the demonstration, the grantee will develop an easily replicable demonstration model of contextualized literacy for similar programs within the adult education and health care industries, allowing for replication throughout the workforce system in partnership with health care employers across the nation.

*Grant Recipient and Location:* The Evangelical Lutheran Good Samaritan Society/South Dakota

*Partner(s) and Location(s):* In South Dakota: Lake Area Technical Institute, Watertown; Sioux Valley Hospitals and Health System; University of South Dakota; South Dakota State University, Brookings; in Nebraska: Bellevue University, Bellevue; pullUin software/South Dakota Health Technology Innovations Inc./MN, SD, ND

*Funding Amount:* \$1,877,517

*Purpose of the Award:* In an effort to increase the pool of qualified workers, this demonstration is designed to raise public awareness of health care career opportunities by recruiting from high schools and non-traditional labor pools such as displaced workers. As part of the project, the grantee will produce a video/CD entitled "It's Happening in Healthcare!" that will be distributed to schools, the workforce investment system and other entities to promote healthcare careers with a specialized target of nontraditional workers. The grantee will also develop an online "virtual caregiver" that will provide a realistic view of career options in this field. The demonstration also is designed to increase healthcare worker retention by starting a mentor project to support entry-level workers and providing various support services. Finally, the grant will develop and pilot methods for providing supervisory and management training by delivering nursing programs through the Master's degree level, both online and through local community colleges. At least 110 participants will receive training under this grant.

*Grant Recipient and Location:* Delaware Valley Industrial Resource Center/Pennsylvania

*Partner(s) and Location(s):* Local WIBS; Delaware County Community College; Drexel University; Local Manufacturing Companies: AGF Manufacturing Co.; Kingsbury, Inc.; Philadelphia Coca Cola Bottling; PA's Industrial Resource Network/PA

*Funding Amount:* \$3,000,000

*Purpose of the Award:* This pilot project is designed as a model for helping the advanced manufacturing sector develop and recruit students for new technical education programs that will produce a steady and predictable supply of skilled and educated individuals for key technology-intensive industries. This project will train over 500 workers, serve over 300 companies and will establish a Regional Industrial Leadership Coalition to provide public policy leadership and outreach to better serve the manufacturing community. The goal of the grantee is to produce an annual pipeline that contains 1,000 skilled and educated individuals to support the region's advanced technology and manufacturing businesses over 3-5 years and to train 95 incumbent workers and 455 entry-level workers (100 percent placement) over the 2-year course of the grant.

*Grant Recipient and Location:* Greater Peninsula Workforce Investment Board/Virginia

*Partner(s) and Location(s):* Greater PA WIB; Thomas Nelson Community College; Northrop Grumman Newport News (NGNN); PA's regional Advanced Manufacturing Consortium; Consortium of Seven Cities and Counties; the PA Alliance for Economic Development; Pennsylvania Worklink; Virginia Employment Commission/VA

*Funding Amount:* \$1,965,000

*Purpose of the Award:* This demonstration will implement a 10-part program that will deliver a highly skilled workforce for a growing, high-performance manu-

facturing sector. The grantee estimates they will train over 5,000 workers for advanced manufacturing jobs covering a variety of industries in Southeast Virginia. The services are targeted to youth, incumbent workers, and career-transitioning individuals. As part of their activities, the grantee will develop or adapt education and training curricula to produce required skill sets for new, transitional, and incumbent workers. The grantee will offer opportunities for work-based experience will be developed as well. Instructors will have the option of expanding their skills through externships and a regional Advanced Manufacturing Instructor Training Institute. As part of the demonstration, the grantee will create detailed task analyses and training curriculum for more than 30 advanced manufacturing jobs and train 30 community college personnel to replicate the program and deliver curriculum content statewide. To support the recruitment of prospective employees, the grantee will develop realistic job action videos on locally-available jobs for posting on One-Stop Career Center computers and available.

*Grant Recipient and Location:* Illinois State University/NCIST/Illinois

*Partner(s) and Location(s):* Local WIBS; local community colleges; local/regional manufacturers and representatives from NAM/CWS local affiliate groups/IL, OH, PA, TX, WY, NC

*Funding Amount:* \$5,774,420

*Purpose of the Award:* The grantee will pilot a program curriculum to create an associate's degree in integrated systems technology, enhance the highly successful apprenticeship model, develop career awareness materials, and create a comprehensive career ladder and lattice standardizing the career competencies. This pilot will then be replicated in four additional States through the creation of regional centers of excellence to train more workers, new and incumbent, for careers in the advanced manufacturing sector. Approximately 420 workers will receive training under this demonstration grant.

*Grant Recipient and Location:* Lancaster County Workforce Investment Board/Pennsylvania

*Partner(s) and Location(s):* Lancaster County WIB; Stevens College of Technology; Viking Cabinetry Group; Lancaster County Career and Technology Center/PA

*Funding Amount:* \$1,354,585

*Purpose of the Award:* This demonstration is designed to address the issue of narrowing skill gaps in manufacturing through incumbent training. The Lumber & Wood Consortium, the Food Manufacturing Consortium, the Plastics Consortium, and the Powdered Metals Consortium want to develop curriculum and provide incumbent training. The grantee anticipates conducting 70 train-the-trainer sessions and placing 105–170 incumbent workers into training.

*Grant Recipient and Location:* Lower Rio Grande Workforce Development Board/Texas

*Partner(s) and Location(s):* Local WIBS; Texas State Technical College; Texas Southmost College; South Texas Community College; Texas Manufacturing Association (STMA); Brownsville Area Manufacturers Association; Harlingen Manufacturers Association; McAllen Economic Development Corporation; McAllen Independent School District; Valley Initiative for Development and Advancement/TX

*Funding Amount:* \$2,000,000

*Purpose of the Award:* This demonstration project will develop a curriculum and a 5-year Apprenticeship Strategic Plan with multiple programs for tool and die, industrial maintenance, and plastic process technicians. As part of their activities, the grantee expects to train 225 youth in advanced manufacturing trade skills; train 200 adults through the Skill Enhancement, Pre-Apprenticeship and Post Secondary Dual Credit Programs; train 213 adult apprentices over 2 years; and attain Journeyman Certification for 20 adult apprentices. The partnership will attain credentialing from NIMS for apprenticeship trainers. It will also develop program study guides and curriculum for Industrial Maintenance, Tool and Die and the Youth Apprenticeship Career Pathway.

*Grant Recipient and Location:* National Association of Manufacturers/Washington, D.C.

*Partner(s) and Location(s):* Undetermined/MO, TX and four other States

*Funding Amount:* \$498,520

*Purpose of the Award:* The grantee will pilot launch the national "Dream It, Do It" Career Campaign in Kansas City, Missouri, to increase career awareness for young people exposing them to high wage job opportunities in the manufacturing industry. The program will then be replicated throughout the county.

*Grant Recipient and Location:* National Center for Integrated Systems Technology (IL)/Illinois



*Partner(s) and Location(s):* Local WIBs in each of the 8 OH and IL sites; IL: Elgin, Moraine Valley, Richard J. Daley, Rock Valley; OH: Cuyahoga, North Central State, Owens, Sinclair; Caterpillar, Amatol, local manufacturers/IL

*Funding Amount:* \$9,142,496

*Purpose of the Award:* In this demonstration, the grantee will provide advanced manufacturing training in integrated systems technology for dislocated workers in 8 community colleges in Ohio & Illinois. The grantee anticipates training 288 dislocated workers in each State and placing 80 percent in full-time employment within six weeks of completion of training.

*Grant Recipient and Location:* National Institute for Metalworking Skills (NIMS)—2/Virginia

*Partner(s) and Location(s):* 25 pilot companies/national

*Funding Amount:* \$939,815

*Purpose of the Award:* As part of this pilot project the grantee will develop flexible yet structured training delivered “just-in-time” on the shop floor. Separate training models will be developed for, and piloted with, five targeted sub-sectors, including: machine tool builders, tool shops, contract stamping and mold making companies, Computer Numerical Control (CNC) job shops, and CNC high volume machining companies. The grantee anticipates piloting the project by training new and incumbent workers at 25 companies.

*Grant Recipient and Location:* Nebraska Central Community College/Nebraska

*Partner(s) and Location(s):* Six State community colleges; three Colleges/Universities; 10 core businesses and industry affiliates; 10 High Schools; Nebraska DOL; NE Department of Economic Development; Bureau of Apprenticeship and the NE Department of Education/NE

*Funding Amount:* \$1,639,403

*Purpose of the Award:* The demonstration will train 834 individuals with industrial training for high skill, high wage manufacturing jobs. The pilot will develop curriculum and competencies for mechatronics technicians and will include manufacturing seminars for 145 high school and college instructors annually. This curriculum will also be made available to community and technical colleges across the country to increase the number of workers trained as mechatronics technicians.

*Grant Recipient and Location:* Oregon Manufacturing Extension Partnership (MEP)/Oregon

*Partner(s) and Location(s):* The Northwest Food Processors Association; Oregon, Idaho, and Washington MEPs, not-for-profit teams of manufacturing professionals who help small-to-medium-sized manufacturers transform the way they do business/OR, WA, NV, ID

*Funding Amount:* \$3,199,709

*Purpose of the Award:* This pilot is designed to implement lean manufacturing training comprised of classroom and workplace-based activities during work hours, with a strong “English as a Second Language” (ESL) component. The grantee expects to train at least 2,026 workers at 48 companies in Oregon, Washington, Idaho, and Nevada. This model for implementing training for ESL students in a Lean environment will be promoted to the public workforce system as an effective model to pair ESL with high-growth jobs in the manufacturing sector.

*Grant Recipient and Location:* San Bernardino Community College District/California

*Partner(s) and Location(s):* WIBs; Business Alliance Partnerships; Regional Occupational Centers and Programs (ROOP, NACFAM, SMI, SMAC, OCBC, RCMIC, and IVMA); Manufacturing Skills Standards Council; and Centers for Applied Competitive Technologies (CACTs)/California

*Funding Amount:* \$1,618,334

*Purpose of the Award:* This demonstration will assess and train new and incumbent workers to MSSC skill standards, a nationwide industry-based skill standard, with assessment and certification system for all sectors of manufacturing. Workers’ skills will be documented and individuals certified for hire and promotion, allowing for new job opportunities and/or further training and education. Revised education and training for advanced manufacturing will also be incorporated into technical programs at high schools, WIBs, and community colleges throughout Southern California. The grantee expects to train 180 currently employed lower skill workers wishing to advance to a competency level of manufacturing certified by MSSC assessment. In addition, the grantee expects 80 job requisitions will be created and 100 clients identified who wish to pursue manufacturing careers at a certified skill level. To support efforts to reach under-served populations, the grantee will develop brochures, literature and CDs describing, in English and Spanish, the new jobs and career ladders in manufacturing. The grantee will also develop brochures, literature

and CDs describing the value of manufacturing careers and the process and qualifications needed to obtain certification.

*Grant Recipient and Location:* St. Louis WIB/Missouri

*Partner(s) and Location(s):* St. Louis City WIB; St. Louis Community College; Ford Motor Company; Daimler Chrysler Corporation; General Motors Corporation; UAW International—Region 5/MO

*Funding Amount:* \$1,499,998

*Purpose of the Award:* As part of this demonstration, automotive manufacturing workers will receive state-of-the-art training in: (1) integration of automated systems; (2) predictive maintenance for advanced manufacturing systems; (3) enhanced mechanical technology; and (4) enhanced electrical technology. This training will allow St. Louis area auto manufacturers to remain globally competitive while giving employees portable skills and job advancement opportunities. The grantee expects to train 430 workers.

*Grant Recipient and Location:* The Workplace, Inc./Connecticut

*Partner(s) and Location(s):* Connecticut WIB; Hurosatonic and Norwalk Community Colleges; ASML; Westport Precision; Jurman Metricas; Nerjan Development Co.; Nordex, Raym-Co.; Hurosatonic; State of CT Department of Education; State of CT Dept. of Economic and Community Development (DECD); The CT Employment and Training Commission (CETC)/CT

*Funding Amount:* \$2,000,000

*Purpose of the Award:* This demonstration is designed to address the training needs of small and medium-sized manufacturers of new and incumbent workers (mainly engineers and technicians) in the areas of innovation, soft skills and ESL. At a minimum, the grantee anticipates assessing and enrolling over 500 workers over the 3 year life of the grant. At least 75 percent of those enrolled will complete one or more training courses that will result in technical certification and a minimum of 90 percent of course completers will acquire technical skills that can advance them on a career ladder.

*Grant Recipient and Location:* Brevard Community College in partnership with American Technical Education Association/Florida

*Partner(s) and Location(s):* The Brevard Workforce Development Board; National Science Foundation's SpaceTEC, a national center for aerospace technical education; the Florida Space Authority; Florida Space Institute; and the U.S. Air Force 45th Space Wing/FL

*Funding Amount:* \$98,560

*Purpose of the Award:* The grantee will provide students the opportunity to assist in the operation of launch facilities and conduct six sub-orbital launches at Cape Canaveral Air Force Station, to demonstrate the usefulness of hands-on learning opportunities for students in developing technical aerospace skills and improving awareness of the skills required for aerospace careers.

*Grant Recipient and Location:* Edmonds Community College/Washington

*Partner(s) and Location(s):* Snohomish Workforce Development Council; Everett Community College; Manufacturing Industries; Boeing; Boeing Aerospace Suppliers; the Snohomish County Workforce Development Council; the Snohomish County Economic Development Council/WA

*Funding Amount:* \$1,475,045

*Purpose of the Award:* The grantee will train new and incumbent workers in a pilot implementation of advanced aerospace technician curriculum, develop career ladders, and demonstrate distance learning approaches to train workers for aerospace industry. The curriculum developed will be broadly disseminated for use by community and technical colleges resulting in an increased number of training workers, meeting the workforce demands of the aerospace industry.

*Grant Recipient and Location:* Florida Space Research Institute/Florida

*Partner(s) and Location(s):* Workforce Florida; NASA; the Civil Air Patrol; Florida School Districts/FL

*Funding Amount:* \$355,628

*Purpose of the Award:* The grantee will demonstrate the benefits to providing aerospace-industry training to school teachers as a means of improving aerospace career knowledge and awareness among youth. Specifically, aerospace mentors will work with 25 teachers in seven counties and provide externships for technology teachers to increase their industry knowledge and their ability to apply the learning's in the classroom. Approximately 5,000 students will be exposed to the Aerospace industry as a viable career path.

*Grant Recipient and Location:* The Houston-Galveston Area Council for the Gulf Coast Workforce Board/Texas

*Partner(s) and Location(s):* Gulf Coast Workforce Board and area One-Stop Career Centers; San Jacinto College; Aerospace Academy; 23 area aerospace employers including NASA Johnson Space Center/TX

*Funding Amount:* \$1,000,000

*Purpose of the Award:* This demonstration is designed to address the issue of narrowing skill gaps in high-tech manufacturing. This project includes piloting a training program in which people will be trained in high-tech automotive manufacturing and/or construction and building trades in addition to other training/curriculum that will be developed. The grantee expects to train an estimated 625 individuals in either aerospace (advanced IT) areas or advanced manufacturing. Nearly all will be incumbent workers. It is estimated that 90 percent of the enrollees will complete training and 90 percent of completers will receive a 3–5 percent wage increase. In addition, 90 percent of unemployed workers will receive job placements and 5 percent will receive a promotion.

*Grant Recipient and Location:* Automotive Retailing Today (ART)/Virginia

*Partner(s) and Location(s):* The National Automobile Dealership Association; National Automotive Technicians Education Foundation; other industry and business stakeholders; Automotive Youth Educational Systems/national

*Funding Amount:* \$150,000

*Purpose of the Award:* As part of this research project, ART and its partners will gather, validate, and deliver information and data about career opportunities in the automotive industry to career-related websites and portals and to workforce development professionals. This information will help promote the industry by describing viable and exciting career opportunities, connecting job seekers to training opportunities and job openings in the field, and dispelling negative presumptions that the general public may have about the industry. This information will be made available to the public workforce system to support their efforts of meeting the needs of local dealers across the country by educating job seekers on career opportunities in the automotive service sector.

*Grant Recipient and Location:* Automotive Youth Education Services/Michigan

*Partner(s) and Location(s):* Members of AYES' Board, including General Motors, DaimlerChrysler, Toyota, Volkswagen, Mercedes, Honda, BMW, Audi, Subaru, Nissan, Mitsubishi, Hyundai, and Kia Motors; Snap-On Tools; SkillsUSA; the National Automotive Technicians Education Foundation (NATEF); the National Institute for Automotive Service Excellence (ASE); Hudson Institute's Center for Economic Competitiveness/national

*Funding Amount:* \$600,000

*Purpose of the Award:* The grantee will demonstrate the expansion of a national automotive technician certification program through the use of on-line testing, which is linked to professional ASE certifications, in high schools. The grantee will also pilot the development of registered apprenticeship standards that can be applied across the nation in programs targeting high school students entering employment in the automotive service sector. The pilot project is expected to test 5,000 students for the credential, offering an industry-based credential to enter employment in the automotive service sector.

*Grant Recipient and Location:* Eastfield College/Texas

*Partner(s) and Location(s):* Workforce Investment Boards in Dallas, Fort Worth & East Texas; Tarrant County College of Fort Worth, TX; Toyota Motor Sales USA; Gulf States Toyota; 20 area Toyota and Lexus Dealers; Automotive Technology Advisory Committee/TX

*Funding Amount:* \$837,424

*Purpose of the Award:* The grantee will demonstrate methods for providing automotive services training to untapped labor pools by offering training to individuals, including support services, internship experiences, and an English as a Second Language component. The demonstration project is expected to train 100 workers to enter employment in the automotive service sector.

*Grant Recipient and Location:* Gateway Technical College/Wisconsin

*Partner(s) and Location(s):* Gateway (a community college); Snap-On Tools, Inc.; WI Automobile and Truck Dealers Association (WATDA); Melior Institute; National Coalition of Advanced Technology Centers (NCATC); Community-based organizations; Automotive Youth Educational Systems; the Workforce System/WI

*Funding Amount:* \$900,000

*Purpose of the Award:* The grantee will demonstrate the use of blended training delivery systems, including the use of on-line features, to provide training toward industry-driven certifications, as awarded by the National Automotive Technicians Education Foundation (NATEF). The grantee expects to train over 1,500 instructors for ASE certification, increasing the capacity of community colleges and career and

technical education institutions to train more students to industry standards for employment in the automotive service sector.

*Grant Recipient and Location:* Girl Scouts of the USA/New York

*Partner(s) and Location(s):* Automotive Insurance Companies; Dealerships; Associations including the Greater NY Automotive Dealership Association; Private Auto Repair Operations; Driving Schools; Girl Scout Local Councils; AAA Offices; High School Drivers' Education Departments/national

*Funding Amount:* \$200,000

*Purpose of the Award:* The grantee will demonstrate methods for reaching out to untapped labor pools (such as young women) to consider careers in non-traditional occupations, such as automotive services, by developing and distributing information geared toward young girls, educating them about automotive services as a career option and building their skills in car repair and maintenance. Girls will be placed in experiential learning programs such as an internship at a dealership or a tour of a training facility. This project is designed to expand the number of youth overall considering careers in automotive services, and particularly young women.

*Grant Recipient and Location:* National Institute for Automotive Service Excellence/Virginia

*Partner(s) and Location(s):* One-Stops; ACT, Inc.; The National Automobile Dealership Association; other industry and business stakeholders; National Automotive Technicians Education Foundation (NATEF); National Automobile Dealers Association/DC

*Funding Amount:* \$300,000

*Purpose of the Award:* The grantee will demonstrate new methods for training Spanish-speaking automotive service technicians by translating some of the most in-demand certification exams into Spanish and by having these exams administered throughout the country. Translation of these exams will allow for limited-English technicians to be industry certified and to enter in and move up the career ladder offering opportunity for greater wage gains in the automotive service sector. The grantee expects approximately 2,000 more Spanish-speaking technicians will take the test than took it in previous years.

*Grant Recipient and Location:* Pennsylvania Automotive Association/Pennsylvania

*Partner(s) and Location(s):* Harrisburg Area Community College; Harrisburg Career and Technology Academy; Snap-On Tools, Inc.; the PA Workforce System; Automotive Youth Educational Systems (AYES)/PA

*Funding Amount:* \$95,000

*Purpose of the Award:* This small grant will demonstrate a model for improving the capacity of local training institutions to provide industry-certified training in automotive services, as a means of increasing the industries ability to train a diverse workforce. To test this model, the grantee will develop a work-training opportunity, or on-the-job mentor/intern program, that strengthens business connections and provides career opportunities to five students facing social and economic barriers. This model will be made available to the public workforce system to partner with State dealer associations across the country to replicate, offering new career opportunities to underserved urban students.

*Grant Recipient and Location:* Shoreline Community College/Washington

*Partner(s) and Location(s):* Workforce Development Council of Seattle, and WorkSource-North Seattle; Toyota Motor Sales USA; General Motors Corporation; Daimler/Chrysler; American Honda; Puget Sound Auto Dealers Association; Hunter Engineering; Chevron Oil Company; Wagonmaster Corporation; Overall Laundry/WA

*Funding Amount:* \$1,496,680

*Purpose of the Award:* The grantee will demonstrate the use of curriculum based on a new set of industry-driven competency requirements by training hard to serve individuals for careers in the automotive service sector. The grant is targeted to train 50 out of school youth and dislocated workers. The curriculum developed will be broadly disseminated for use by community and technical colleges and high schools across the country to train more workers in the automotive service industry.

*Grant Recipient and Location:* U.S. Hispanic Chamber of Commerce Foundation/Washington, D.C.

*Partner(s) and Location(s):* BMW of North America; LLC; Snap-On Tools, Inc./CA, FL

*Funding Amount:* \$136,000

*Purpose of the Award:* This project will demonstrate successful methods for training Spanish-speaking individuals to become skilled automotive technicians while increasing employment opportunities for this untapped labor pool. This will be accomplished through the recruitment, training, and fostering of career paths for 20 His-

panic-Latino automotive technicians within Miami, Florida, and Los Angeles, California, leading to employment opportunities with dealerships in each city.

*Grant Recipient and Location:* Delaware Workforce Investment Board/Delaware  
*Partner(s) and Location(s):* Delaware WIB (State WIB); Delaware Technical and Community College; Agilent Technologies; Delaware Department of Education; Delaware Economic Development Office/DE

*Funding Amount:* \$250,000

*Purpose of the Award:* The grantee will demonstrate methods for engaging the workforce investment system and biotechnology business community in an effort to facilitate collaboration among teachers, school districts, the Department of Education, higher education, and the business community to improve student achievement in science. One key aspect being piloted is the development of mobile science vans that experienced instructors and mentors use to visit local schools. The objective of the mobile van is to transport science equipment for providing laboratory experiences to youth increasing their interest and exposure to Science, Technology, Engineering and Mathematics (STEM) careers in high growth, high demand industries. The project will train 30 mentors and is expected to offer 1,500 students hands-on experiences with the van.

*Grant Recipient and Location:* Forsyth Technical Community College/North Carolina (Partners: New Hampshire, Washington, Iowa, California)

*Partner(s) and Location(s):* Forsyth Tech has a local Job Link One-Stop Career Center on campus; Forsyth Technical Community College; New Hampshire Technical College; Indian Hills Community College; Bellevue Community College; Miracosta Community College; Caldwell Community College and Technical Institute; Catawba Valley Community College; Davidson C; Regional Employers/NH, IA, WA, CA, NC

*Funding Amount:* \$5,000,000

*Purpose of the Award:* The grantees, a group of five community colleges, will form Centers of Excellence in five different biotechnology sectors. They all come together as a National Center for the Biotechnology Workforce, which will: (a) allow workers to learn about the competencies and training availability for biotechnology careers, and (b) allow community colleges and the workforce investment system to access industry skill standards as well as training curricula and methods to implement in their location. Under this pilot, each college will implement various methods for providing biotechnology industry training to workers in this high growth industry. The training methods, skills standards, and curriculum developed from this demonstration project will be broadly disseminated for use by community and technical colleges resulting in an increased number of trained workers, meeting the workforce demands of the biotechnology industry.

*Grant Recipient and Location:* Massachusetts Biotechnology Education Foundation/Massachusetts

*Partner(s) and Location(s):* Massachusetts Workforce Board Association; Commonwealth Corporation; the Boston Private Industry Council (Boston PIC); the Metro Northwest Regional Employment Board; the Metro Southwest Regional Employment Board; Massachusetts Biotechnology Council; Boston University's School of Medicine; Henzyme; other local companies; the University of Massachusetts and the 5-campus Statewide system; local school systems in the urban and high-need areas/MA

*Funding Amount:* \$1,372,250

*Purpose of the Award:* The grantee will research the early-stage (high school) pipeline for biotechnology and health care industries by developing and launching a demonstration model of the BioCareer Lab in 25 urban and high-needs public schools to train and expose students to the emerging biotechnology industry. This pilot model is expected to train 100 science teachers and 2,000 students. The model will include new equipment, ongoing teacher training, a mobile biotech laboratory, access to curricula developed with National Science Foundation funds, and school to career pathways in partnership with workforce investment boards and colleges. This demonstration project will expose more young people to careers in the biotechnology sector.

*Grant Recipient and Location:* San Diego Workforce Partnership/California

*Partner(s) and Location(s):* San Diego Workforce Partnership is the local WIB; Miracosta Community College; BIOCUM/CA

*Funding Amount:* \$2,510,117

*Purpose of the Award:* This demonstration is designed to support the workforce system in meeting its growing needs for skilled workers in the biotechnology industry. The grantee will create a clearinghouse for local and national biotechnology labor market information and to coordinate student internships (from high-school to post-doctoral levels) and teacher externships for the regional biotechnology commu-

nity. The center will ultimately serve as a national clearinghouse for biotechnology industry labor market and occupational information; competency and skills requirement information; and training, internship, and research opportunities at all levels. As part of the grantee's activities, national and local labor market analyses will be performed; credit and non-credit classes that are flexible, short-term, and that will be recognized by multiple institutions will be developed; and local student internships and teacher externships at biotechnology companies will be provided.

*Grant Recipient and Location:* Associated General Contractors of America/Virginia

*Partner(s) and Location(s):* Chattanooga State Community College; San Antonio (TX) Chapter of AGC, AGC of East Tennessee; International Brotherhood of Electrical Workers Local 175; Laborers Local 846 (Chattanooga, TN); East Ridge High School; East Tennessee State University/national

*Funding Amount:* \$235,500

*Purpose of the Award:* The grantee will demonstrate the effectiveness of construction career academies by working with its partners to sustain existing construction career academies in Chattanooga and San Antonio, and to develop additional career academies in eight local communities. It is anticipated that the partnership will train 400–500 students to enter employment in the construction industry. Through the Construction Career Academy initiative, AGC will provide local academies with technical assistance in a number of areas, such as developing curriculum and forming partnerships between businesses and educational institutions. AGC also will provide students with materials and equipment and prepare instructors to teach in the academies.

*Grant Recipient and Location:* Chicago Women in Trades/Illinois

*Partner(s) and Location(s):* The Workforce Boards of Metropolitan Chicago; Illinois Community College Board; City Colleges of Chicago; The Builders Association; Construction Industry Service Corporation; Hispanic American Construction Industry Association; Mechanical Contractors Association of Chicago; Federation of Women Contractors; IL Departments of Labor, Employment Security, Transportation, and Commerce and Economic Opportunity; Mayor's Office of Workforce Development; Chicago Building Trades Council; Illinois Center for Professional Support Services/IL

*Funding Amount:* \$2,092,343

*Purpose of the Award:* The grantee expects that nine thousand two hundred women (9,200) will gain awareness of career opportunities in construction through orientations and career fairs. In addition, the grantee expects that seven hundred fifty (750) women will gain acceptance into apprenticeship programs offering an average wage of \$13 per hour during the grant period. Of those entering into an apprenticeship, 80 percent will be retained for a minimum of 90 days.

As part of this demonstration, CWIT will launch an outreach campaign to attract women into the construction industry. This campaign will include professional outreach and marketing materials that focus on women, as well as orientation sessions and job fairs that focus on construction industry careers. CWIT and its partners will help women address their barriers to employment through an array of education, training, and support services, such as career planning, placement, and mentoring by women currently working in the industry. Finally, CWIT and its partners will work with One-Stop Career Centers, apprenticeship information centers, and community colleges to enhance their capacity to serve women.

*Grant Recipient and Location:* Honolulu Community College/Hawaii

*Partner(s) and Location(s):* Oahu Workforce Investment Board; Kauai Community College; Hawaii Department of Education; Eight local high schools; Hawaii Carpenters Union Local No. 745; Sheet Metal Workers' International Association Local Union No. 293/HI

*Funding Amount:* \$1,400,000

*Purpose of the Award:* In this demonstration, HCC partners will create a Construction Academy for providing 500 high school students with an array of construction-specific courses and career opportunities in the construction industry. In addition, 300 students will enter apprenticeship programs, construction associate degree programs, or construction baccalaureate programs. HCC and its partners will also develop and demonstrate a standards-based curriculum that articulates with construction certificate and degree programs that will be utilized by Hawaii's community colleges, increasing the applicant pool for the construction trades in the State. The curriculum developed will be shared broadly with community and technical colleges across the country.

*Grant Recipient and Location:* St. Louis Carpenters Joint Apprenticeship Training Program (CJAP)/Missouri

*Partner(s) and Location(s):* Workforce Investment Board of Southeast Missouri; Workforce Investment Board of St. Louis City; Workforce Investment Board of St.

Louis County; Mineral Area College; St. Louis Community College; Jefferson Community College; Southeast Missouri Regional Industrial Training Group; Hazelwood and Affton School Districts/MO

*Funding Amount:* \$2,187,107

*Purpose of the Award:* As part of this demonstration, CJAP and its partners will train and license high school instructors in skill standard certifications so that they can teach and certify students in advanced manufacturing and construction skills. The grantee expects to train 130 entry-level and dislocated workers and 120 incumbent through the initiative. As a result of this training, the grantee expects that 750 youth will be trained to industry standards during the life of the grant. In addition, CJAP also will work with employers, community and faith-based organizations, and One-Stop Career Centers to identify incumbent workers with a strong interest in advancing their construction or advanced manufacturing careers and help them enhance their academic skills, access support services, and enroll in a maintenance mechanic program or other types of training. CJAP and its partners will also create an eight-week maintenance technician training program for dislocated workers and this curriculum, as well as the training model will be made available to community colleges across the country for possible replication.

*Grant Recipient and Location:* The Home Builders Institute (HBI)/Washington, D.C.

*Partner(s) and Location(s):* York Technical College (SC); community and technical colleges in (FL, KY); American Association of Community Colleges; Home Builders Association of Kentucky; Florida Home Builders Association; Home Builders Association of Charlotte (NC); Building Contractors Association of Wood River Valley (ID); Home Builders Association of South Carolina; Tidewater Builders Association/national

*Funding Amount:* \$4,268,454

*Purpose of the Award:* The grantee will demonstrate the creation of a systemic approach to construction industry workforce development that provides a continuum of recruitment, career exploration, education and training. The demonstration will increase the available applicant pool for the construction industry meeting their workforce shortages by training 2,500 individuals for the construction trade in construction academies in four States.

*Grant Recipient and Location:* Youthbuild USA/Massachusetts

*Partner(s) and Location(s):* local home builders associations; National Council of Churches; juvenile justice system; Home Depot/national

*Funding Amount:* \$12,202,600

*Purpose of the Award:* This demonstration is designed to build on the success of the Youthbuild USA, model, supporting the transition of adjudicated youth into high growth industries. The grantee will participate in an established training program that combines academic instruction with construction skill development and, ultimately, builds affordable housing in their communities. The grantee will develop a national demonstration project in which 325 adjudicated youth will participate full-time for 9–12 months in a YouthBuild education, job training, and service program. Skills training will occur primarily in the construction industry through the building of affordable housing or community facilities. Graduates will be helped in finding placements in post-secondary education or in jobs. The grantee expects that 60 percent of the 325 enrollees will complete the YouthBuild program; 85 percent will be placed in employment or post-secondary education; Program completers will have a recidivism rate of 15 percent or less; 34 percent will attain a GED or high school diploma; and 75 percent will be self sufficient over a 5-year period. Youthbuild USA includes significant support systems, such as mentoring that will continue for at least a year after the program; follow-up education, employment, and personal counseling services; and participation in community service and civic engagement. Youthbuild USA will work with local One-Stop Career Centers to place youth in employment upon completion of the program.

*Grant Recipient and Location:* Institute for GIS Studies (IGISS)/Tennessee

*Partner(s) and Location(s):* Charlotte-Mecklenburg Workforce Development Board; Central Piedmont Community College; Nashville State Community College; Motlow State Community College; Bank of America; Duke Energy; Smart Data Strategies; University of Southern Mississippi/TN, NC

*Funding Amount:* \$2,000,000

*Purpose of the Award:* IGISS will pilot the development of an industry-led, apprenticeship-based career advancement ladder for specialty certificates and degrees in land records management and utilities-based geospatial technical applications. The pilot is expected to train over 500 unemployed and underemployed workers in a variety of learning environments such as apprenticeship and associate degree programs in 13 different community colleges across Tennessee and North Carolina with

the goal of increasing the number of workers in the emerging geospatial technology sector.

*Grant Recipient and Location:* Kidz Online/Virginia

*Partner(s) and Location(s):* NAWB; Los Angeles Trade and Technical College, North Carolina State University; ESRI; American Institute of Aeronautics and Astronautics; Institute of Electrical and Electronic Engineers; Society of Women Engineers; National Council of Teachers of Mathematics; National Science Teach Association; Virginia Space Grant Consortium; Digital Quest; Environmental and Spatial Technology Initiative; National Institute of Technology and Policy Research; North Carolina 4-H; Hampton City Public Schools; Council of Great City Schools; NEC Found of America/VA, CA

*Funding Amount:* \$1,000,000

*Purpose of the Award:* Kidz Online will pilot the creation of a comprehensive youth and adult learner focused image building and career awareness effort by utilizing new distance learning methodologies. Specifically, grantee will deliver learning resources including video programming and live web casts, provide professional development services, and integrate geospatial concepts into existing programming and ETA's Career Voyages web site. Spanish language translation will be done for some content.

*Grant Recipient and Location:* Rancho Santiago Community College District/California

*Partner(s) and Location(s):* Rancho Santiago Community College; St. Louis Community College/CA

*Funding Amount:* \$187,939

*Purpose of the Award:* The pilot project will assess local geospatial workforce needs and use the findings to develop new and innovative curriculum and career ladder workforce development systems for a cross-section of industries. The grantee expects to train 20 community college faculty to teach the newly-developed geospatial curriculum as well as to host a training conference to train 75 teachers from across the country (from schools not directly associated with the grant) in using the new curriculum. As a result of these activities, the grantee expects to train 200 students using the newly-developed geospatial curriculum.

*Grant Recipient and Location:* W.F. Goodling Advanced Skills Center/Pennsylvania

*Partner(s) and Location(s):* South Central Workforce Investment Board; Penn State York; Harrisburg University; Harrisburg Area Community College; Manufacturers Association of South Central Pennsylvania; York County Board of Commissioners; Pennsylvania Department of Conservation and Natural Resources; Pennsylvania Office of Admin; Pennsylvania Department of Community and Economic Development; Pennsylvania Department of Labor and Industry; York County Community Foundation; Oork Counts Commission; York County/PA

*Funding Amount:* \$990,125

*Purpose of the Award:* The project will demonstrate the use of 2+2+2 articulation agreements with high schools, community colleges, and universities to produce imagery analysis technicians through a certificate program in imagery analysis in private and municipal applications. These 2+2+2 articulation agreements will provide over 100 students and/or workers with career and education advancement tracks, enabled by linked curriculum and levels of education, training and certifications at the high school, community college and university levels. The demonstration will also train 100 individuals in specific geospatial applications in homeland security, economic development, and land-use management.

*Grant Recipient and Location:* Geospatial Information and Technology Association (GITA)/Aurora, CO.

*Partner(s) and Location(s):* American Association of Geographers, National Association of Workforce Boards; National Association of State Workforce Agencies; Northrop Grumman, Lockheed Martin, Oracle, Intergraph, TeleAtlas/GDT, BAE Systems, ObjectFX, ESRI, NavTeq, Smart Data Strategies; The University of Southern Mississippi; Jefferson Community College; Lake Land College; City College of San Francisco; Jackson State Community College; Moraine Valley Community College; American Association of Community Colleges; the Philadelphia Community College System; Central Piedmont Community College; Fulton Montgomery Community College; Colorado Community College; Mississippi Community College; and the University of Pennsylvania's Wharton School of Business/national

*Funding Amount:* \$695,362

*Purpose of the Award:* GITA will (1) develop standard definitions for the geospatial industry, vet the definitions through industry leaders, and disseminate the results throughout the industry; (2) develop content for an on-line workforce information clearinghouse on industry jobs, education facilities, and program informa-



tion; (3) create a geospatial career awareness campaign; and (4) work with community colleges, employers, and workforce development organizations in a selected region to test the use of the Geospatial Industry Workforce Information System (an industry-developed and funded information network that houses industry jobs, educational facilities and programs) and career awareness materials to help local One-Stops and educators meet local geospatial industry needs.

*Grant Recipient and Location:* Lorain County Community College/Ohio

*Partner(s) and Location(s):* Lorain County Chamber of Commerce and its Small Business Development Center; The Workforce Institute of Lorain County Lorain County Commissioners and the Lorain County Development Office/OH

*Funding Amount:* \$2,599,979

*Purpose of the Award:* Grantee will demonstrate new methods for training workers in high growth careers, with a special emphasis on entrepreneurship, and for promoting the growth of existing businesses, especially small and medium business sector, as well as new business development—all within identified targeted industries. The first project objective is to develop a comprehensive education continuum and support system that provides a K–12 to master's degree pathway to prepare workers, at all levels, for high demand jobs. The second primary objective is to create a support system that combines economic and workforce development to collectively focus on providing easy access to resources that address the unique needs of existing businesses attempting to transition to the knowledge economy. The third primary objective is to grow and attract new high-growth businesses in the area to create jobs, and enhance objectives 1 and 2 through immersing entrepreneur education and support resources for both workers and businesses to create a pipeline of creative and innovative ideas. This pilot project is projected to train over 5,000 individuals in through a variety of learning opportunities including internships, certificate, and degree programs supporting small business growth in the community.

*Grant Recipient and Location:* City of Los Angeles, Community Development Department/California

*Partner(s) and Location(s):* City of Los Angeles Workforce Investment Board; Cedars-Sinai Medical Center/Kaiser Permanente Southern California Region/White Memorial Medical Center/East Los Angeles Doctors Hospital/Managed Career Solutions, Inc.; Valley Community College; City of Los Angeles Community Development Department; City of Los Angeles Health Care Career Ladder Training Program; Learn2excel/CA

*Funding Amount:* \$1,196,000

*Purpose of the Award:* This pilot project will fund six strategic interventions to provide education and training to out-of-school disadvantaged youth: (1) an Out-of-School to Career Program that creates an articulated pathway through the training process and provides supports to participants during the program; (2) a Health Care Career Mentoring Program in which mentors will assist youth throughout their education and training and into careers; (3) a Hosted Web-Based Portal that will function as an on-line learning community meeting place to facilitate networking, collaboration, and information sharing throughout the Los Angeles healthcare system; (4) a Healthcare Vocational Assessment Tool used to determine vocational interest and aptitudes for specific health occupations; (5) a Bilingual English/Spanish Fast Track Health Care Basics Curriculum that includes basic skills, medical terminology, and introductory health science courses; and (6) a Bilingual English/Spanish Marketing Outreach Program to attract minority, disadvantaged youth to healthcare occupations. As a result of this pilot project the grantee anticipates that 500 youth will go through pre-work and orientation for work experience; 200 youth will go through work experience at partner hospitals; 133 youth will attend medical fast track pre-requisite training; 117 youth will enter training; 80 placements leading up to healthcare tracks will be received; 112 will receive job placements or entry into higher level education at graduation of healthcare tracks; and approximately 4,635 individuals will enter the health care workforce pipeline annually.

*Grant Recipient and Location:* Miami-Dade College/Florida

*Partner(s) and Location(s):* South Florida Workforce; IVAX Corporation; MediVector; Onco-Venctor; BioFlorida; South Florida Biotechnology Consortium; Miami-Dade County Public Schools; Florida Atlantic University; South Florida Manufacturing Association; Greater Miami Chamber of Commerce/FL

*Funding Amount:* \$1,000,000

*Purpose of the Award:* As part of this demonstration, Miami-Dade College and its partners will pursue a number of strategies to build the region's skilled biotechnology workforce. The college will partner with industrial pharmaceutical manufacturing (IPM) experts to develop IPM curricula, train college faculty on the new curricula, and recruit industry experts to serve as adjunct faculty. These three strategies will address challenges related to educational capacity. All curricula developed

will address specialized skills sets in IPM and related specialty areas. Competency models, based on evolving industry standards, will support the mapping of biotechnology career ladders and cross-industry career lattices. Miami-Dade College will expand available labor pools through the recruitment of minority youth, low-income adult minorities, Limited English Proficient individuals, veterans, and individuals with disabilities. The grantee expects to train 800 incumbent and future IPM technicians and related workers.

*Grant Recipient and Location:* United Regional Health Care System/Texas

*Partner(s) and Location(s):* North Central Texas Healthcare Consortium (includes representatives from the workforce investment system, education and training providers, and hospital industry employers); United Regional Healthcare System; Wilbarger General Hospital; Electra Memorial Hospital; Seymour Hospital; Vernon College; Midwestern State University; Texas Christian University; North Texas Tech Prep Consortium; Partners-in-Education; Region 9 Education Service Center/TX

*Funding Amount:* \$846,325

*Purpose of the Award:* In this demonstration, the grantee will focus on recruiting, training, and capacity building in post-secondary institution nursing programs: (1) Recruiting—develop a pipeline of young workers for employment in the healthcare industry by recruiting from new and untapped, diverse labor pools; (2) Training—train 35 new and 85 incumbent workers for hospital positions such as patient care associates/medical assistants, nurses, health information technicians, Spanish language hospital interpreters, and surgical technicians; and (3) Capacity Building—increase the pipeline of available workers by training faculty from partner organizations as advanced practice nurses and nurse educators to gain qualification needed to teach in professional nursing programs.

*Grant Recipient and Location:* Claflin University/South Carolina

*Partner(s) and Location(s):* Lower Savannah Workforce Development Board; Zeus Corporation, Albemarle Corporation; SuperSod; Regional Medical Center of Orangeburg and Calhoun Counties; Orangeburg-Calhoun Technical College; South Carolina Department of Education; Orangeburg-Calhoun Tech Prep Consortium; Orangeburg County Economic Development Board/SC

*Funding Amount:* \$750,000

*Purpose of the Award:* As part of this demonstration, Claflin, a historically black college in rural Orangeburg, SC, and its partners will develop a pipeline of skilled biotechnology workers for all rungs of the biotechnology career ladder (high school diploma to Master's degree level). The grantee estimates that they will train 100 students in biotechnology certificates and degrees. In addition, the university will also develop curricula for each ladder of the biotechnology career ladder. As part of its efforts to stimulate youth enrollment in biotechnology training programs, Claflin will implement a comprehensive career development process for high school students, incumbent workers, and dislocated workers, and will also train local K-12 and secondary faculty to co-teach biotechnology modules with industry partners. This model of increasing the pool of minorities into high grow careers in biotechnology will be offered for broad dissemination to community colleges across the country for replication with partner 4-year institutions.

*Grant Recipient and Location:* Orange County Workforce Investment Board/California

*Partner(s) and Location(s):* Life Science Industry Council; Beckman-Coulter Inc.; Edwards Lifesciences Inc.; Allergan Inc.; Saint Joseph Health System; Coast Community College District; University of California-Irvine; Orange County Department of Education; Orange County Business Council; local One-Stop Career Centers; Central Labor Council—Local 441/CA

*Funding Amount:* \$1,000,000

*Purpose of the Award:* The project will implement a regional skills development collaborative that will leverage workforce investment system resources to meet the demands of the biotechnology industry and its related occupations in healthcare sectors. This project will train and advance 75 incumbent workers in allied health occupations such as hospital technicians and technologists in radiology, surgical, ultrasound, and x-ray. Additionally, 75 workers dislocated from declining industries and 75 entry-level workers will receive training for high-growth occupations such as medical equipment repairers, inspectors and testers; pharmacy technicians; medical assistance; biological technicians; and others. The Orange County Workforce Investment Board will target services to minority trainees and economically-disadvantaged residents. The partnership will also work to standardize skill requirements, define biotechnology career ladders, and develop effective strategies for engaging and developing youth interested in biotechnology careers.

*Grant Recipient and Location:* The University of Utah/Utah

*Partner(s) and Location(s):* Utah Department of Workforce Services; Intermountain Health Care; University of Utah Hospitals and Clinics; Veterans Affairs Medical Center/UT

*Funding Amount:* \$871,707

*Purpose of the Award:* In this demonstration project, The University's Clinical Faculty Associate model seeks to address the severe nursing faculty shortage through a number of connected methodologies. The purpose of the project is to promote career advancement for Registered Nurses (RNs) working in clinical settings through a collaborative clinical teaching model and education program that enhances retention and acquisition of the skills needed to teach nursing. Practicing RNs will augment their existing clinical skills and knowledge by acquiring formal education resulting in a Master's degree, post-Master's certificate, or specific coursework related to teaching nursing, clinical instruction, and nursing education. These RNs will then function as Clinical Faculty Associates under the mentorship of university master teachers. By upgrading RNs to Clinical Faculty Associate positions increased numbers of baccalaureate nursing students will be admitted into the program. The grantee expects to enroll 13 Clinical Faculty Associates in the University of Utah's Teaching Nursing Program and enroll 32 students in the Baccalaureate Nursing program. Projected number of students supervised by CFAs is 336 at the end of the second project year.

*Grant Recipient and Location:* Orange County Workforce Investment Board/New York

*Partner(s) and Location(s):* 7 local workforce investment boards in middle Hudson Valley; Orange County Health Care Cluster; Hudson Valley Health Care Consortium; Healthcare Workforce Training Consortium, including NorMet (Northern Metropolitan Hospital Association); Pace University School of Nursing; Dyson College of Arts and Sciences/NY

*Funding Amount:* \$1,048,300

*Purpose of the Award:* This demonstration project will fund a market-driven system trading educational credits for instructor hours. It will provide incentives for health care providers in the region to provide staff holding master's degrees to serve on the faculties of educational institutions in exchange for credits to meet providers' future training needs. As a result of this demonstration, the grantee project is to have 1,000 additional students admitted to healthcare education and training programs in 2 years as a result of the increased capacity of providers. Fifty clinical nurses will be trained as instructors in 2 years and 100 clinical nurses will be trained as preceptors in 2 years. The capacity of educational institutions to provide nurse training will increase with the addition of 70 adjunct instructors and 70 preceptors, offering a unique model for replication by the health care industry.

*Grant Recipient and Location:* CVS Regional Learning Center/Michigan

*Partner(s) and Location(s):* Detroit Workforce Development Department; ORC Macro; Wayne County Community College District; Goodwill Industries of Greater Detroit; New Galilee Missionary Baptist Church; Perfecting Church; Little Rock Baptist Church/MI

*Funding Amount:* \$1,757,981

*Purpose of the Award:* The major components of this pilot project include: a community education and outreach campaign designed to build awareness and interest in pharmaceutical careers; recruitment, screening, and training of 80 candidates to receive training in an apprenticeship program to first become a Pharmacy Service Associate and then a Pharmacy Technician; a peer support group; provision of "wrap-around" services, such as child support and transportation; identification and support of 130 incumbent CVS Pharmacy Service Associates faced with career advancement barriers to become Pharmacy Technicians through occupational English as a Second Language and customer service skill development instruction; and opportunities for both apprentices and incumbent workers to advance their pharmaceutical careers through 2-year or 4-year academic programs.

*Grant Recipient and Location:* State of Wisconsin/Wisconsin

*Partner(s) and Location(s):* Wisconsin workforce investment boards; Wisconsin Department of Workforce Development; private sector health care associations, including the Wisconsin Nursing Redesign Consortium; Wisconsin Technical College System/WI

*Funding Amount:* \$1,365,101

*Purpose of the Award:* In this demonstration, the grantee proposes a two-part strategy to fast-track nurse educators to prepare the next generation of Registered Nurses (RNs) for the State of Wisconsin, including accelerated graduate study programs and a partner-based model for identification, recruitment and preparation of health professionals for nurse educator careers. The grantee will create an accelerated curriculum option and career ladder to facilitate movement of Associate's De-

gree nurses to the Master's degree level. This training model will decrease the time-to-degree by 18–24 months without diluting the quality of the graduate education programs. These efforts will result in fast-track preparation of 70 new and diverse nurse educators in Wisconsin by 2007 as replacement and expansion nurse faculty for all Wisconsin nursing programs, with an additional 50 Associate's degree nurses (ADNs) prepared to enroll in Master's programs Statewide by 2007. Contracts between partnering employers and program participants will result in their contractual commitment as nurse faculty in a Wisconsin nursing school and as clinical care providers in sponsoring health facilities upon their graduation (2–3 years depending on course of study). Recruitment will focus on identifying underrepresented populations in nursing, including racial and ethnic minorities, men, and people with disabilities. The project will produce two major replicable innovations: a streamlined curriculum for rapid progression to the Master's degree along various career ladders and from various start points, and a Statewide partnership model for developing health care solutions.

*Grant Recipient and Location:* Temple College/Texas

*Partner(s) and Location(s):* Central Texas Workforce Investment Board and affiliated Workforce Centers; Scott & White Clinical Laboratory Science Program; Scott & White Hospital Clinics; Central Texas Veterans Health Care System; Cancer Research Institute; Cardiovascular Research Institute; Temple Health and Bioscience District; Temple Independent School District; Central Texas Tech Prep Consortium; Tarleton State University of Central Texas; Texas A&M University College of Medicine; Temple Economic Development Corporation/TX

*Funding Amount:* \$920,495

*Purpose of the Award:* In this demonstration, the grantee will develop a pipeline of skilled biotechnology technician and research workers for all rungs of the biotechnology career ladder (high school diploma to Bachelor's degree level). Working with area tech prep schools, the project will establish an Advanced Technical Middle College for high school students to assist them in preparing for biotechnology careers, and will develop community college curriculum to advance the area's available biotechnology career lattice. This program will be piloted with at least 20 students receiving job placements. The grantee will also work with its industry partners to launch innovative, mentored, on-the-job and apprenticeship opportunities for students. Specific occupations to be targeted include medical laboratory technician, research technician, and genomic technician.

*Grant Recipient and Location:* Indianapolis Private Industry Council, Inc./Indiana

*Partner(s) and Location(s):* Indiana Department of Workforce Development; Wishard; St. Vincent's and St. Francis hospitals; Indiana Health Industry Forum; Roche Diagnostics; Dow Agro-Sciences; Eli Lilly and Company; Baxter Pharmaceutical; Ivy Tech State College; Indiana University School of Medicine; City of Indianapolis/IN

*Funding Amount:* \$1,000,000

*Purpose of the Award:* Under this pilot project the grantee will execute four primary strategies First, work with Ivy Tech, the State community college, to expand the number of seats in the school's programs that prepare persons to become radiological technicians, registered nurses and respiratory therapists. The goal is to graduate and certify 80 people for the three positions. Second, work with Indiana University to develop an accelerated Master's of Science program for registered nurses. Third, expand or create on-site training opportunities for entry level workers at all hospitals, including basic skills training, job readiness and GED prep and testing. At least 120 workers will access these services. Fourth, create state-of-the-art outreach and recruitment material to reach 14,000 area residents over a 2-year period. These materials will provide information about career opportunities in medical manufacturing and biotechnology.

*Grant Recipient and Location:* JobPath, Inc./Arizona

*Partner(s) and Location(s):* BIO5; TGEN; BIOSA; Pima County College; Pima County Superintendent of Schools; University of Arizona; Pima County One-Stop; La Paloma Family Services; Arizona Biosciences Association/AZ

*Funding Amount:* \$276,393

*Purpose of the Award:* This demonstration program will build a pipeline of youth interested in pursuing careers in biotechnology through the development of an Introduction to Biotechnology course taught by community college faculty to high school students in a biotechnology summer institute. The grantee expects to train 50 graduates of Biotechnology Summer Institute; 40 community college students will complete introductory classes and advance to biotechnology prerequisites; 60 graduates of the biotechnology college program will move on to employment or higher education; and 30 graduates from paid internships with bioscience employers. Paid internships with local bioscience employers will be offered to students upon

completion of the program. The program will also recruit and support participants from untapped labor pools enrolled in biotechnology courses and certificate programs at the local community college.

*Grant Recipient and Location:* The Pennsylvania Workforce Investment Board/Pennsylvania

*Partner(s) and Location(s):* Pennsylvania's local workforce investment boards; Ben Franklin Technology Partners; Industrial Resource Centers; Penn State University; Pennsylvania College of Technology/PA

*Funding Amount:* \$3,750,000

*Purpose of the Award:* This demonstration project will develop a Statewide network that supports multiple facets of the plastics industry's development. Specifically, ETA will fund: Incumbent Worker Training, Curriculum Transfer, Occupational Forecasting; Supply Chain Analysis; a Plastics Occupations Toolkit; Internships/Co-ops; Scholarships; and Research & Development Symposiums. The grantee anticipates training over 1,200 incumbent workers in the plastics industry, including machine operators, machine set-up technicians, process engineers and production supervisors. The Pennsylvania Workforce Investment Board will play an oversight role and serve as the clearinghouse for documenting the overall impact of the initiative. Penn State will be involved in technology transfer and Research & Development. Local workforce investment boards will be able to meet employers' needs and provide key support for developing Centers of Excellence. This model will be promoted for replication to the public workforce system.

*Grant Recipient and Location:* RISE Business/Virginia

*Partner(s) and Location(s):* Center for Women's Business Research; Council of Growing Companies, Inc. Business Resources; Kauffman Center for Entrepreneurial Leadership; Edward Lowe Foundation; National Foundation for Teaching Entrepreneurship; National Minority Business Council; National Small Business United/national

*Funding Amount:* \$150,000

*Purpose of the Award:* In this research project conducted by RISEbusiness, RISEbusiness will act as an intermediary between the public workforce system and small business by researching and publicizing the key issues affecting small and emerging businesses. RISEbusiness aims to research the following topics in order to increase small business' support for, access to, and utility of the workforce system: review existing literature; define and refine research questions; launch a research effort; refine the research methodology; collect and analyze qualitative and quantitative data; and disseminate the findings and implications. A final report will be distributed to the State and local workforce system to further support their access to services provided by the public workforce system.

*Grant Recipient and Location:* Jobs for the Future—Workforce Innovations Networks (WINS)/Massachusetts

*Partner(s) and Location(s):* Great Lakes Innovation and Development Enterprise (GLIDE); the Enterprise Ohio Skills MAX Center; Mid-Ohio Securities; KS Associates; Ross Environmental Services; Beckett LogiSync; the Braye Group; JD Munch Integrated Solutions; Cash Strategies; CyStorm; Banyan Technology; Accurate Processing; Catalyst Strategies; Hot Dog Heaven; National Association of Manufacturers- Center for Workforce Success; U.S. Chamber of Commerce, Center for Workforce Preparation/national

*Funding Amount:* \$5,121,777

*Purpose of the Award:* The Workforce Innovations Network—WINS—is a collaboration of the Center for Workforce Preparation of the U.S. Chamber of Commerce, the Center for Workforce Success/Manufacturing Institute of the National Association of Manufacturerers, and Jobs for the Future to accelerate, expand, and broaden employer engagement strategies. The first module provided a comprehensive analysis of employer engagement strategies, and identified approaches and models for the system to replicate for better engagement and involvement of employers. The WINS Module II Project demonstrated three primary strategy objectives: (1) that locally business-based organizations (e.g., Chambers of Commerce, employer's organizations) could effectively serve as "intermediary" agents to establish and strengthen relationships between local businesses and local Workforce Investment Boards and service offices; (2) that these intermediary organizations could work with local businesses and WIBs to develop "talent" supply chains to bring skilled workers to businesses; and (3) that intermediaries could contribute to improved governance of public workforce investment systems. WINS II established 12 local demonstration sites and three State-level sites where the objectives were validated. Among the sites hundreds of businesses have been connected to WIB services and in a few sites the WIB depends upon the intermediary for the majority of business connections. Local demonstration sites have received additional WIB grants to continue and/or extend

the projects thereby leveraging the WINs II grant funds. Beyond the additional WIB funding, the sites have acquired more than \$5 million from State and private funding sources.

*Grant Recipient and Location:* U.S. Chamber of Commerce, Center for Workforce Preparation/Washington, D.C.

*Partner(s) and Location(s):* Lehigh Carbon Community College in Schnecksville, Pennsylvania; National Association of Workforce Boards; American Association of Community Colleges; Chicagoland Chamber of Commerce; Greater Seattle Chamber of Commerce; Greater New Orleans/national

*Funding Amount:* \$1,502,700

*Purpose of the Award:* The Business Coalition for Workforce Development Project will demonstrate the employer benefits of accessing the public workforce system by improving services and relationships between employers and the public workforce system. This will include research identifying areas of successful business engagement with the workforce system, identifying specific issues to retaining and engaging business partnerships, and documenting insight and advice on how systems and services can be improved to support improved outcomes for workers.

*Question.* Since the program has been up and running for 3 years, what performance data from these grants can you share with this Committee?

*Answer.* In an effort to model innovative strategies for investment, the projects funded under the High Growth Job Training Initiative have included both training and curricula development activities. A significant number of these investments are in their first year of performance. As such, we have limited performance outcome data at this time. However, performance data is available for grants that have concluded their activities. The outcomes from these grants are detailed below. Active grantees are in the process of submitting quarterly reports. These reports are presently being analyzed by the Department. In addition, the Department is working to complete an analysis and conduct an evaluation of the grants awarded to date, as well as to refine performance standards for future investments.

OUTCOMES OF GRANTS IN THE PRESIDENT'S HIGH GROWTH JOB TRAINING INITIATIVE

[Expiring by June 1, 2005]

Grantee	Expected outcome	Actual outcome
National Center for Integrated Systems Technology (Illinois and Ohio)—Dislocated Worker Integrated Systems Technology Training Project.	Illinois—Train 288 dislocated workers. Place 80 percent (230) of all participants in jobs with 75 percent (216) placed in small or mid-sized companies. Ohio—Train 288 dislocated workers. Place 80 percent (230) of all participants in jobs with 75 percent (216) placed in small or mid-sized companies.	Illinois—Grant completed. 302 workers were enrolled with 262 completers and 74 percent placed in jobs. Ohio—Grant ongoing. To date, 249 participants have enrolled, 121 completed training, and 95 have received job placements.
National Restaurant Association Educational Foundation.	(1) Increase student worksite experience to 6,000 ..... (2) Add states to the program ..... (3) Increase number of ProStart school to 900 ..... (4) Increase industry involvement in project .....	(1) 9,444 students received experience. (2) 43 States added to program. (3) Increased to 1,075 schools with enrollment of nearly 44,000 students. (4) No increase reported.
Community Learning Center, Inc.	(1) 1,024 dislocated workers will receive training ..... (2) Place 802 workers in unsubsidized employment .....	(1) 1,028 workers served (2) 914 workers placed in unsubsidized jobs.
U.S. Chamber of Commerce—Center for Workforce Preparation.	(1) Develop a research report documenting business needs, providing training services in One-Stop Centers, and developing successful promising practices in these areas. (2) Disseminate grant information through business conferences and development of grant-related promotional materials.	Report and promotional materials developed and delivered to ETA.
RISEBusiness .....	Develop a research report to increase understanding of the workforce needs of small and emerging businesses..	Research report developed and delivered to ETA

OUTCOMES OF GRANTS IN THE PRESIDENT'S HIGH GROWTH JOB TRAINING INITIATIVE—Continued

[Expiring by June 1, 2005]

Grantee	Expected outcome	Actual outcome
Workforce Innovation Net-works—Jobs for the Future Partnership (1)Develop a re-search report that: (1) Identifies obstacles to employer use of the work-force investment system and proposes solutions. (2) Documents the WINs demonstration projects at nine sites.	Research report developed and delivered to ETA..	

*Question.* Do these grantees perform better or worse than grantees who received awards through a competitive process?

*Answer.* A significant number of these investments are in their first year of performance. As such, we have limited performance outcome data at this time. However, both solicited and unsolicited grants are integral to the goals of the Department in providing services to individuals and to employers, as well as in transforming the workforce investment system. The initial sole source investments under the High Growth Job Training Initiative were made in order to demonstrate and model new approaches to workforce education and investment and are providing learning opportunities that are informing investments as we move forward on a primarily competitive basis. Models and demonstrations, by their nature, are intended to try new approaches, not all of which will be successful. The Department is currently in the process of evaluating the initial High Growth grants and to develop an ongoing strategy for evaluating performance and outcomes for competitive grants as we move forward.

The learning from these initial grants has already provided critical information for the development of criteria for future investments, which will improve the outcomes of these investments.

QUESTIONS SUBMITTED BY SENATOR DANIEL K. INOUE

NURSING SHORTAGE IN RURAL AREAS

*Question.* Please provide a report on the Department's progress in addressing the nursing shortage, specifically within rural communities and ethnic minority populations, such as Native Hawaiians.

What initiatives, such as summer employment opportunities for students, have the Department utilized to foster continued growth of the nursing profession?

*Answer.* We share your interest regarding the training of nurses. The Department of Labor has invested over \$4.3 million through the President's High Growth Job Training Initiative to support projects in rural areas that develop and implement innovative solutions to address shortages in nursing and other health professions. Each of these projects will increase the number of nurses and other health professionals trained, hired, and retained in rural communities throughout the nation, including in Hawaii. Further, it is the Department's vision that rural communities across the country will benefit from these investments for many years to come through replication of the models.

We are aware that Maui Community College is interested in such initiatives, and there have been a number of Congressional earmarks for Maui in the areas of rural development and rural job training, as well as pending proposals. With respect to fiscal year 2004 earmarks, we are near completion of our review of a proposal from the University of Maui for training and employment of Hawaiians living in rural areas. That award should be made shortly. In addition, the Department of Labor's fiscal year 2005 Appropriation includes \$1,500,000 for Maui Community College for the Remote Rural Hawaii Job Training Program. We are working closely with Maui Community College to ensure that they will be able to implement an exemplary project.

It also is worth noting that the Department of Health and Human Services, through the Health Resources and Services Administration, currently invests \$150

million in nursing workforce development activities, including \$31 million for the Nursing Education Loan Repayment and Scholarship Program.

*Question.* Education and job training services programs have provided employment opportunities for Native Hawaiians. How does the Department plan to continue supporting these programs and further develop programs already in existence?

*Answer.* The Department of Labor's fiscal year 2005 Appropriation includes \$1,500,000 for Maui Community College for the Remote Rural Hawaii Job Training Program. We are working closely with Maui Community College to ensure that they will be able to implement an exemplary project.

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QUESTIONS SUBMITTED BY SENATOR PATTY MURRAY

H-2A ENFORCEMENT

*Question.* I am concerned about the lack of enforcement of H-2A program requirements by the Wage and Hour division of DOL for migrant and seasonal farm workers. A large farm labor contracting company, Global Horizons recruited and employed Thai nationals in central Washington fruit production under the H-2A guest worker program in 2004 and is planning on doing so again this year.

A number of my constituents have raised serious concerns with respect to Global's compliance with H-2A laws and regulations. I know you agree it is imperative that the DOL fully enforce these requirements to protect both U.S. workers and guest workers who enter our country under the H-2A program. In fact, while the H-2A program has not been used extensively in Washington State, there have been problems with enforcement of program requirements for many years.

It appears that Global routinely violated State and Federal employment laws by:

- Refusing employment to qualified U.S. workers under the Federal H-2A guest worker program,
- Failing to provide the work promised in the employment contract,
- Failing to pay the wage rate required by the H-2A program and contract; and
- Providing substandard, unlicensed housing, with workers sleeping on the floor or two to a bed, with no cooking or washing facilities and no drinking water.

Washington State's Department of Labor and Industry has denied Global's application for renewal of its State farm labor contractor's license. I also understand that there are outstanding complaints to the DOL from my State alleging various H-2A program violations by Global.

Can you please provide a status report on DOL's investigation of these complaints?

*Answer.* On February 10, 2005, the Wage and Hour Division of the Employment Standards Administration issued a notice of determination to Global Horizons under the H-2A program assessing civil money penalties totaling \$154,700, and back wages totaling \$131,267 for alleged violations occurring in Hawaii from September, 2002 through March 2003. These determinations have been appealed to the Department of Labor Office of Administrative Law Judges for a de novo hearing. Additional investigations involving other locations and periods of time are ongoing. However, because of their continuing nature we can not comment about those investigations at this time.

In addition, on February 25, 2005, ETA issued a letter debaring Global Horizons from the H-2A program for a 3-year period based on Global Horizon's failure to fulfill requirements of its H-2A certifications and the Wage and Hour Division's prior findings of violations. Global Horizons requested a de novo hearing on debarment before an ALJ, and that has been consolidated with a Wage and Hour Division case against Global Horizon. The notice of determination for back wages and civil money penalties and the debarment proceeding have been consolidated and the hearing is presently scheduled for next year.

While debarment is pending, ETA continues to process individual Global Horizon H-2A applications and to reach determinations on the merits of each. ETA continues to examine all applications for compliance with H-2A requirements and has rejected some of Global Horizons applications while certifying others. As one example, in January 2005, ETA denied Global Horizon's application for a new H-2A certificate for Eastern Washington based on the fact that Global Horizon at that time did not have a State-issued farm labor contract certificate, which is required by the State of Washington. Global Horizon appealed, and an ALJ upheld the denial on February 25, 2005.

Washington State is taking its own actions involving Global Horizons. While the State had denied Global Horizon's application for renewal of its State farm labor contractor's license, we understand that the State has now extended that license



until September 30, 2005. However, the State is also taking action to discontinue State provision of services to Global Horizons under the Wagner-Peyser Act, which includes such services as recruitment of local workers and placement of job orders in interstate clearance.

*Question.* Please also inform me as to whether DOL is taking any action with respect to Global's Farm Labor Contractor registration under Federal law.

*Answer.* Global is registered as a farm labor contractor under the Migrant and Seasonal Agricultural Worker Protection Act (MSPA). DOL has not initiated action to revoke this registration, but has pursued debarment action under H-2A. The Wage and Hour Division has an open investigation of Global. As with all such investigations, the Division will consider appropriate action at the conclusion of the investigation.

*Question.* Are you willing to work with me to closely examine whether increased enforcement efforts are needed, including the imposition of penalties real deterrence?

I know you agree with me that those who benefit from the H-2A program should do their part to make sure that the program operates lawfully. I also hope you will commit to work with me to educate growers who hire farm labor contractors for recruitment under the H-2A program to ensure that those growers monitor the contractor's compliance with the law.

*Answer.* The Department of Labor is charged with two essential duties with respect to the enforcement of the H-2A program. First, the Department of Labor ensures that employers follow established rules and regulations for bringing foreign workers into the United States. Second, the Department of Labor vigorously enforces applicable labor standards. Guest worker programs cannot succeed without strict adherence to these responsibilities, and the Department takes them very seriously. In addition, the Department has an active H-2A compliance assistance program, which is designed to educate employers and employees of their responsibilities and rights under the law. The Department works with all interested parties to ensure that participants of the H-2A program are in full compliance with the law.

PBGC

*Question.* I commend you for tackling in the budget proposal the difficult issue of shoring up the Pension Benefit Guarantee Corporation. The PBGC insures the pensions of about 44 million American workers and is in danger of defaulting on those promises. Reforming this grossly under-funded insurance plan is long overdue. I am concerned, however, about the feasibility of some of your suggestions. For example:

- You propose to increase fees on the corporations at the very time they are less likely to be able to pay them—once they are preparing to file for bankruptcy.
- Your proposal would impose restrictions on pension benefits for rank-and-file workers, without restricting the pensions of executives.
- The American Benefits Council (a group representing some of the country's largest corporations on their employee benefits program) predicts the Administration's plan could have the effect of encouraging companies to dump their defined benefit plans.

Could you please explain why the plan discriminates against companies already in trouble and against rank-and-file workers?

*Answer.* We appreciate your support for restoring the solvency of the PBGC. The Administration is committed to strengthening the pension insurance program and keeping defined benefit plans as a viable option for employers and employees. This requires a careful balancing of interests and inevitably will require trade-offs among various stakeholder interests. The Administration proposal strikes a necessary balance that will best protect the pension benefits earned by workers and retirees and alleviate the possibility that taxpayers will be called upon to rescue the insurance program.

As you stated, the insurance program is grossly underfunded. Reform of the plan funding rules, by itself, will not eliminate PBGC's \$23 billion deficit. Premiums must be increased. The Administration's proposal is reasonable. It would increase the flat-rate premium for wage inflation since the last increase in 1991, and require a risk-based premium for all pension underfunding. We believe that the Administration's proposal equitably distributes the cost among employers and does not put too great a burden on financially weak companies.

With respect to your question about benefit restrictions, the proposal is based on the principle that employers should pay for what they promise and not make promises to their workers and retirees that cannot be funded. Employers with severely

underfunded plans would not be allowed to divert funds from rank-and-file pensions to deferred compensation plans for executives. If a financially weak employer has a severely underfunded plan, the employer would be prohibited from funding any nonqualified deferred compensation for executives. In addition, funding would be prohibited for executive compensation at any time within 6 months before or 6 months after the termination of an underfunded plan.

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QUESTIONS SUBMITTED BY SENATOR RICHARD J. DURBIN

WORKER OVERTIME PROTECTION

*Question.* An amendment to the bankruptcy bill that was on the Senate floor last week that would have marginally increased the minimum wage, but would have also eliminated the 40 hour work week and the overtime benefits of thousands of workers.

This scheme would create an 80 hour, two week work period that would allow employees to work up to 50 hours one week and 30 hours the next week without receiving one dime of overtime pay.

The amendment's sponsors said the plan is voluntary, but how voluntary is it when your boss threatens to hire someone else who will agree to his 50 hour/30 hour week schedule? This is an assault on workers, and it comes on top of the administration's elimination of 6 million workers from overtime pay eligibility last year.

Can you provide the Administration's perspective on such proposals to weaken overtime protection?

*Answer.* The Administration has not taken a formal position on this specific legislation. However, the President has called on Congress to pass legislation to help working families juggle the demands of work and home through comp-time and flex-time and give private-sector workers the same flexible scheduling options that Federal employees now enjoy. Providing choices like whether to receive overtime pay as cash or as paid time off would allow workers to balance the demands of the workplace and the needs of their families.

The minimum wage amendment to the bankruptcy bill would have doubled the scope of so-called small businesses that would be exempt from paying the minimum wage, but by doing this, he would also be stripping workers in those companies from other Federal protections, like equal pay, overtime pay and child labor safeguards under the Fair Labor Standards Act.

The amendment would end individual worker protections under the FLSA, and expand the size of businesses that need not apply the Act from those grossing \$500,000 annually to those grossing \$1 million annually. This would exempt about 700,000 businesses from providing worker protections, and cover a total of about 10 million fewer workers than we do today.

*Question.* In light of the work that has been done in this country to ensure that children are not working and that women are paid the same as men for the same work, why would we want to rollback these protections?

*Answer.* The Administration has not taken a formal position on this specific legislation. However, the President has indicated that he is willing to work with Congress on a sensible proposal to increase the minimum wage in a way that does not price people out of jobs or hurt small businesses. In addition, the President has called on Congress to pass legislation to help working families juggle the demands of work and home through comp-time and flex-time and give private-sector workers the same flexible scheduling options that Federal employees now enjoy. Providing choices like whether to receive overtime pay as cash or as paid time off would allow workers to balance the demands of the workplace and the needs of their families.

PERSONAL REEMPLOYMENT ACCOUNTS

*Question.* You talked about the Administration's proposal to consolidate four programs authorized by the Workforce Investment Act (WIA) into a single \$4 billion block grant. You suggest this is done for flexibility, but even with the community colleges funding, the Department's job training funding is more than \$300 million short of current year funding.

The House Committee approved a WIA reauthorization bill that creates a nationwide pilot program to give unemployed workers considered at risk for long-term unemployment a \$3,000 voucher they can spend on training. There is no specific budget request for this, but the Labor Department has already diverted funds from other discretionary programs to initiate a seven-State pilot. I understand we have no results yet from the Department's pilot program.

How do you reconcile the House plan for expanding these untested personal accounts nationwide before your Department has completed its pilot study?

Answer. The current seven-State Personal Reemployment Account (PRA) demonstration project builds upon the positive findings of earlier demonstrations by offering reemployment bonuses, targeting them using the Worker Profiling Reemployment System (WPRS), and increasing consumer choice through flexible worker accounts. PRAs are similar to current practice under the Workforce Investment Act, where workers can choose their training through Individual Training Accounts. PRAs give workers more opportunities and choices.

Mathematica Policy Research Inc., a firm with wide experience in employment and training program evaluation, including the evaluation of the reemployment bonuses and individual training account experiments, is the evaluation contractor for the PRA demonstration. Although results from the demonstration are not yet available (accounts were first made available in March 2005), States are reporting some initial successes in implementing PRAs. For example, Minnesota has offered accounts to 301 individuals, and so far 188 individuals have accepted.

*Question.* The Economic Policy Institute has said that the accounts are “too small to purchase meaningful training but just large enough to discourage workers from pursuing cost-effective short-term services that could help them get back to work more quickly.” To get the \$3,000 accounts workers would have to forfeit about \$10,000 in other worker training programs. What kind of training and education does the Department anticipate an unemployed worker “purchasing” with a \$3,000 training voucher.

Answer. First, this question assumes that all workers can access \$10,000 in training when, in fact, most cannot. The estimated WIA unit cost for all types of services an individual would receive (in Program Year 2005) is \$3,200 for dislocated workers and \$2,064 for adults; no where near \$10,000. Further, information in a recent GAO report, based on a survey of local workforce investment boards across the country, indicates that the average amount spent on training for adults and dislocated workers was slightly less than \$2,300.

Second, as you know, the community college system has and continues to be an important provider of training to our system, and the \$3,000 account level is based upon the average cost of 2 years of instruction at a community college. We believe that Personal Reemployment Accounts will provide individuals with opportunities to connect more directly with meaningful training at a community college or from another training provider.

*Question.* With less money available, no data yet on a seven-State pilot, and a \$7,000 reduction in investment per worker, it’s hard for me to see how we are helping move people back into the workplace. Can you explain how we will gain \$7,000 in “administrative efficiencies” per worker? Or how \$330 million in funding cuts will not lead to less opportunity for unemployed workers?

Answer. As described earlier, the worker’s forfeiture of \$7,000 is not correct, as the average cost of 2 years at a community college is \$3,000 and the unit costs for the WIA Adult and Dislocated Worker programs are \$2,064 and \$3,200, respectively. (Additionally, ITAs under WIA offer more limited choices in training, with no opportunity for a reemployment bonus). The Department of Labor anticipates that evaluation data will show that:

- PRAs are significantly less staff-intensive than traditional forms of service delivery (reducing program overhead costs by directing resources directly into the hands of workers);
- The time spent collecting Unemployment Insurance will likely decrease; and
- The nature of placement into and retention of good jobs will remain constant or even increase as a result of more consumer choice and the ability to manage and customize one’s plan for employment.

#### PROPOSED CHANGE TO CES SURVEY

*Question.* The Bureau of Labor Statistics recently announced a decision to stop collecting data on women who work from its Current Employment Statistics program, claiming it is trying to reduce the paperwork burden on employers. By the agency’s own admission, this survey takes only seven minutes to fill out.

This data on women in the workforce is invaluable to researchers and policy-makers in their efforts to understand gender inequality. At a time when women’s employment may be changing in fundamental ways due to the economy, we should be expanding our ability to understand the evolving role of women in the labor force, not reducing it.

I sent a letter, along with Senator Kennedy, to the Department about this issue on February 9. In your response, which I just received, you acknowledged that the

Current Employment Statistics program is superior to the Department's other data collections programs for analyzing month-to-month trends. Help me understand why the Department would agree to eliminate a program that serves a valuable policy purpose and that experts agree is working?

Answer. The BLS believes that its proposal to discontinue the Current Employment Statistics (CES) series on women workers is in the best interest of public policy. The discontinuation of the women workers series is part of a larger set of changes that the BLS has proposed for the CES survey. The BLS' decision to discontinue the women workers series is based on three factors: (1) the availability of extensive information on women's employment from the CPS, (2) the public's lack of use of the CES data, and (3) a desire to reduce respondent burden for a voluntary survey.

Data on women's employment, occupations, earnings, and other labor force statistics will continue to be available from the Current Population Survey (CPS), a monthly survey of about 60,000 households. From the CPS, users have access to a rich source of data on women's employment, unemployment, and earnings by industry, occupation, education, age, marital status, and other characteristics. These data are used extensively in the study of women in the labor force.

The BLS recognizes that one of the main concerns expressed about the proposed discontinuation of the women worker series is that the CES is superior to the CPS for analyzing month-to-month trends. However, the agency believes that such short-term measures are not appropriate for most assessments of the changing status of women (or any demographic group) in the labor market. When examining longer term trends, the advantage the CES has in sample size declines in importance. The two surveys have displayed similar trends for women's employment growth over the past several years.

CPS data are used extensively in the study of women in the labor force. By contrast, CES women workers series are little used. In an effort to gauge the impact of the proposal to terminate the women workers series, the BLS undertook an analysis of the extent to which this data series is used by researchers and the general public. The BLS found that, while there was an average of 130,000 requests per month for CES national estimates through the BLS public use website, only about one-half of one percent of those requests were for the women worker employment series. Additionally, an informal literature search by BLS found almost no usage of CES women worker series. Articles that addressed women's employment and earnings issues nearly all used data from the CPS as their source.

In addition, although the data it produces are used but rarely, the series imposes a significant reporting burden on some survey respondents because payroll records do not typically include gender identification. It is important to consider the context in which the women worker data is collected. The BLS relies upon the voluntary cooperation of approximately 155,000 businesses each month (representing about 400,000 individual worksites) in providing information from their payroll records on the employment, hours, and earnings of their workers. In an increasingly difficult data-collection environment, survey response burden is a crucial factor in survey design. We must minimize this burden to ensure the continued accuracy and integrity of the payroll data on which we rely to produce the Employment Situation, which is a principal Federal economic indicator and represents some of the nations most closely watched economic data. The individuals who complete the CES report often have indicated that gender information is not present on their standard payroll records and that they do not have ready access to the data. As an example of this burden, although 100 percent of employers who respond provide their total employment count, approximately one out of every six declines to provide data on female employment. In addition, the BLS proposal stems from a view that it is poor public policy to continue burdening several hundred thousand respondents each month to produce a data series with only a small handful of users.

The BLS' proposed elimination of the women worker series in the CES survey is a part of a larger agency effort to improve the survey's relevance to the needs of data users and its value as input to other key economic statistics. For example, in mid-2005, the CES is changing its current policy of collecting data only for production and non-supervisory employees and will begin collecting data for two new series: hours and regular earnings of all employees, and a total earning series (including both regular and irregular pay) for all employees. These changes are designed to make the survey more responsive to the needs of data users and increase its value in relation to other key economic statistics. For example, the Bureau of Economic Analysis has long sought more timely data on all-employee earnings in its construction of national income statistics. The new all employee hours and earnings series will provide more comprehensive information than the present series for analyzing economic trends. They also will provide improved input for other major eco-

conomic indicators, including series on non-farm productivity, as well as eliminate a potential source of bias in BLS estimates of the productivity growth rate.

The Department believes that accurate data on women's employment are crucial to understanding the economic opportunities that are available to women today. As we have indicated, the BLS will continue to collect timely and accurate data on women workers through the CPS, which is an overall richer source of data for women workers than the CES.

#### FEWER WORKERS TRAINED

*Question.* Page 41 of your Budget Justification Material states that, with the Fiscal 2005 appropriation, you expect to serve 870,000 participants in the Dislocated Worker Programs; 475,200 participants in the Adult Block Grant program; and 329,000 participants in the Youth Block Grant program. Yet you estimate that only 400,000 persons will be trained when these programs are consolidated as you are requesting for 2006. Why is it that the current level of more than 1.6 million participants will only lead to 400,000 trainees next year?

*Answer.* The estimated participant levels for fiscal year 2005 for the Adult and Dislocated Worker programs reflect the number of individuals receiving all types of employment assistance—not just those receiving job training. Also, the figure of 870,000 for the Dislocated Worker program was included in error—the correct participant level is 368,700.

The Employment and Training Administration's fiscal year 2006 Budget request emphasizes the Administration's commitment to increasing employment and training opportunities by funding new Consolidated State Grants that merge the WIA Adult, Dislocated Worker, and Youth programs and the Wagner-Peyser Employment Service program into a single base grant. The fiscal year 2006 Budget estimates that between 18,535,700 and 18,960,000 participants will be served through the consolidated grants.

The President's proposal for job training reform would double the number of workers receiving job training through major WIA grant programs, from approximately 200,000 to 400,000 annually. By eliminating unnecessary overhead costs and simplifying administration through the consolidation of duplicative employment and training bureaucratic structures, we project an overall savings of at least \$300 million, which can be used by States for training an additional 100,000 workers annually. In addition, the President has requested \$250 million for Community Based-Job Training Grants for fiscal year 2006. This new initiative, which will begin July 1, 2005, will utilize our nation's successful community colleges to train 100,000 more workers annually.

#### SUBCOMMITTEE RECESS

Senator HARKIN. Thank you very much, Madam Secretary.

The subcommittee will stand in recess to reconvene at 10:30 a.m. on Wednesday, March 16, in room SD-138. At that time we will hear testimony from the Honorable Michael O. Leavitt, Secretary, Department of Health and Human Services.

[Whereupon, at 11:37 a.m., Tuesday, March 15, the subcommittee was recessed to reconvene at 10:30 a.m., Wednesday, March 16.]



**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION, AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

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**WEDNESDAY, MARCH 16, 2005**

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

The subcommittee met at 10:42 a.m., in room SD-138, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Craig, DeWine, Harkin, Kohl, Murray, and Durbin.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF THE SECRETARY

STATEMENT OF HON. MICHAEL O. LEAVITT, SECRETARY

ACCOMPANIED BY:

KERRY WEEMS, ACTING ASSISTANT SECRETARY FOR BUDGET,  
TECHNOLOGY, AND FINANCE

JENNIFER YOUNG, ASSISTANT SECRETARY FOR LEGISLATION

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning. The Subcommittee on Labor, Health and Human Services, Education, and Related Agencies will now proceed. We have established a record for starting these hearings on time so that we do not keep busy people waiting or people who are not busy waiting. But as I had said a moment or two ago, the floor manager had scheduled my amendment for increasing the budget of the subcommittee by \$2 billion, \$1.5 billion for the National Institutes of Health, and \$500 million for Education. We just concluded the argument and came right over here and have had a very brief discussion with the distinguished Secretary.

We do welcome you here, Mr. Secretary. You come to this office with a very, very distinguished record with the governorship of Utah and Administrator of the Environmental Protection Agency, and a very distinguished record before public service. We look forward to working with you.

My full statement will be made a part of the record and in view of our late arrival I will make only a very few introductory remarks. As I had commented to the Secretary when we moved the hearing from 9:30 to 10:30, that has compressed my schedule, and

I've asked Senator DeWine to be here to take over the chairmanship here at 11.

But the only introductory comments that I will make are the daunting tasks which we all have. We have a budget for the subcommittee which is several billion dollars under what it was last year. We have a 3.5 percent cut for the Department of Labor. We have a \$500 million cut for Education. There is a proposed budget for your Department, Mr. Secretary, for \$62.4 billion, which is a reduction of almost \$1.3 billion, and that's not calculating the inflation rate. So that means it's another \$2 billion on top of a billion, probably \$3.5 billion.

PREPARED STATEMENT

But you come to this job with a great reputation for being a wonder worker, so we will watch your work and we will work with you. Now I yield to my distinguished colleague, the seamless Senator Harkin.

[The statement follows:]

PREPARED STATEMENT OF SENATOR ARLEN SPECTER

This morning, the subcommittee on Labor, Health and Human Services, Education, and Related Agencies will discuss the President's \$62.4 billion 2006 budget request for the Department of Health and Human Services, which is \$1.3 billion below the fiscal year 2005 level. We are Delighted to have before us the distinguished Secretary of Health and Human Services, the honorable Michael O. Leavitt.

This subcommittee is pleased to see several shared priorities funded in the fiscal year 2006 budget, including \$303 million over the fiscal year 2005 level for Community Health Centers and \$203 million over the fiscal year 2005 level for the Strategic National Stockpile to protect our Nation against bioterrorism.

However, this subcommittee is concerned by the small 0.5 percent increase in Biomedical Research Funding at the National Institutes of Health—which is a cut in real terms. Also of concern are the large cuts in funding of many HHS programs, including the complete elimination of 35 programs.

Mr. Secretary, I know that you can appreciate the difficult tradeoffs that this subcommittee will need to negotiate in the coming months as we balance the competing pressures of biomedical research, worker protection programs and continued investment in our Nation's youth. Mr. Secretary, I look forward to working with you as we craft an appropriations bill that maintains our commitment to fiscal restraint while preserving funding for high priority programs.

OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Thank you very much, Mr. Chairman. I will follow your lead and not make a full opening statement. Again, thank you, Mr. Chairman, for your leadership on the floor, on NIH, to get that funding back up. It just—at a time when we're making so many great breakthroughs, when we've finished mapping the human gene, when we've gotten a lot of young people now more interested in basic research because of the doubling of NIH, now it seems like, well, we did that and now we don't have to do anything more.

But that was just catch-up ball. We were just playing catch-up ball. Now we've caught up, now all of a sudden we're moving back again. So I just want to compliment my friend and my chairman for taking the lead on the floor on this.

Just a couple—three things, Mr. Secretary. Again, welcome you to your first appearance before our subcommittee. Congratulations on your new position. Like the chairman, we have met personally



and I've just heard a lot of good things about you, and your reputation is sterling, I can say that.

I just—a couple of comments on the budget, eliminating services for some 25,000 kids on Head Start. That's very bothersome. The community services block grant program. Now, you might say, well, we're continuing some of the things like LIHEAP and Head Start, things like that, but if you don't have the people that do it, how does it get done? Community services block grants being zeroed out is just—I don't know what we—what could be behind that.

There's one other thing, the systems change grant. Your predecessor was very strong and the President was, the President spoke about this in the past, better check the record on the system change grants. This has to do with the court case—what am I thinking about—Olmstead case. The Supreme Court decision said that people with disabilities must live in the least restricted environment.

Well, we've built up a system of nursing homes in this country that are still needed for some obviously. But for a lot of people with disabilities who can get to the community, they need these system change grants. Your predecessor and the President has spoken strongly about this and something called money follows the person, but there's nothing in this budget for it.

So, again, just a few of those things I wanted to point to, but lest you think I think everything's bad in this budget, I compliment you for the increase in the community health centers. This is one thing that serves—the \$300 million proposed increase is welcome, it's needed. They do a great job I'm sure in your State, mine, all over the country. So that is one right spot in this budget that will have our full support, you can be assured.

Thank you, Mr. Secretary. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Harkin. We welcome you again, Mr. Secretary, and the floor is yours. We look forward to your testimony. Your full statement will be made a part of the record and our practice is to ask you to summarize to the extent you can, leaving the maximum amount of time for questions and answers. We have a very good attendance for the subcommittee today.

#### SUMMARY STATEMENT OF HON. MICHAEL O. LEAVITT

Secretary LEAVITT. Thank you, Mr. Chairman, and Senator Harkin. I will in the spirit of efficiency summarize quickly. As you indicated, the budget—the overall budget is \$642 billion. That's a 10 percent increase over last year. Much of that will be in the Medicare Modernization Act and its implementation.

#### MEDICAID

This subcommittee, as you pointed out, is \$62.4 billion, and it's a lot of money, and we're here to do our best to defend how in fact we will do it efficiently. I hope we have a chance today to talk about Medicaid. Forty six million Americans are served by it. It's rigidly inflexible. The Governors are desperate to have some change so they can maintain coverage for people who have it and hopefully provide coverage for some who don't.

I hope we have a chance to talk some about the implementation of the Medicare Modernization Act. That's the main event for 2005 in my opinion for HHS, and we're working hard to make certain that it's done well. We all have a substantial stake in its implementation.

Community health centers is a favorite of mine to talk about too, Senator Harkin, and I'm hopeful that we'll get a chance to talk more about that.

Homeland defense has been very much on my mind, as I suspect it is everyone else's, \$4.3 billion to continue our work there, \$600 million of it into strategic stockpiles. Our goal is to have needed medications within 12 hours of every man, woman, and child in the United States.

NIH, a subject I know that's very important to you, Senator, and to others, \$28.8 billion, \$1.8 billion of that again in biodefense. The flu has become an area of major concern to me, particularly the—as we begin to see the avian flu become more prominent in Asia. I hope we have a chance to talk about our preparation there.

The President has emphasized faith-based initiatives also, his hope that reauthorization of the Welfare Act of 1996 could be accomplished this year. This budget will support the administration's belief in both faith-based and also in abstinence education. The budget does support Head Start with \$6.9 billion.

#### PREPARED STATEMENT

A subject I hope we get a chance to talk about is Health IT. That's an issue that I intend to take on personally.

It's what I believe to be a lean but strong and fiscally responsible budget, and I'm looking forward to more conversation.

[The statement follows:]

#### PREPARED STATEMENT OF HON. MICHAEL O. LEAVITT

Good morning Mr. Chairman, Ranking Member Harkin, and members of the Subcommittee. I am honored to be here today to present to you the President's fiscal year 2006 Budget for the Department of Health and Human Services (HHS). The President and I share an aggressive agenda for the upcoming fiscal year, in which HHS advances a healthier, stronger America while upholding fiscal responsibility and good stewardship of the People's money.

In his February 2nd State of the Union Address, the President underscored the need to restrain spending in order to sustain our economic prosperity. As part of this restraint, it is important that total discretionary and non-security spending be held to levels proposed in the President's fiscal year 2006 Budget. The budget savings and reforms in the President's Budget are important components of achieving the President's goal of cutting the budget deficit in half by 2009 and we urge the Congress to support these reforms. The President's fiscal year 2006 Budget includes more than 150 reductions, reforms, and terminations in non-defense discretionary programs, 19 of which affect HHS programs. The Department wants to work with the Congress to achieve these savings.

The President's health agenda leads us towards a Nation of healthier Americans, where health insurance is within the reach of every American, where American workers have a comparative advantage in the global economy because they are healthy and productive, and where health technology allows for a better health care system that produces fewer mistakes and better outcomes at lower costs. The fiscal year 2006 HHS budget advances this agenda.

The fiscal year 2006 HHS budget funds the transition towards a health care system where informed consumers will own their personal health records, health savings accounts, and health insurance. It enables seniors and people with disabilities to choose where they receive long-term care and from whom they receive it. Equally important, it builds on the Department's Strategic Plan and enables HHS to foster

strong, sustained advances in the sciences underlying medicine, in public health, and in social services.

To support our goals, President Bush proposes outlays of \$642 billion for HHS, a 10 percent increase over fiscal year 2005 spending, and more than a 50 percent increase over fiscal year 2001 spending. The proposed fiscal year 2006 HHS budget increase accounts for almost two-thirds of the entire proposed federal budget increase in fiscal year 2006. The overall discretionary portion of the President's HHS budget totals \$67 billion in budget authority and \$71 billion in program level funding. The discretionary portion of programs covered by this subcommittee totals \$62.4 billion in budget authority and \$65.3 billion in program level funding.

The Department will direct its resources and efforts in fiscal year 2006 towards:

- Providing access to quality health care;
- Enhancing public health and protecting America;
- Supporting a compassionate society; and
- Improving HHS management.

The President and the Department considered a number of factors in constructing the fiscal year 2006 budget, including the need for spending discipline and program effectiveness to help cut the deficit in half over four years. Specifically, the budget decreases funding for lower-priority programs and one-time projects, consolidates or eliminates programs with duplicative missions, reduces administrative costs, and makes government more efficient. For example, the budget requests no funding for the Community Services Block Grant that was unable to demonstrate results in Program Assessment Rating Tool evaluation. Instead, the Administration proposes to focus economic and community development activities through a more targeted and unified program to be administered by the Department of Commerce. It is due to this scrutiny that I am certain the proposed increases in spending will enable the Department to continue to provide for the health, safety, and well-being of our People.

Americans enjoy the finest health care in the world. This year's budget provides opportunities to make quality health care more affordable and accessible to millions more Americans. Our challenge is to ensure that everyone has access to health insurance.

#### PROVIDING ACCESS TO QUALITY HEALTH CARE

##### *MMA Implementation*

The next important step toward meeting this challenge is the implementation of the Medicare Modernization Act (MMA), including the Medicare Prescription Drug Benefit and the new Medicare Advantage regional health plans. The Centers for Medicare and Medicaid Services (CMS) administrative budget request of \$3.2 billion includes \$560 million for implementing the new voluntary drug benefit that begins January 1, 2006, enhanced health plan choices in Medicare Advantage, as well as numerous other MMA provisions. The new prescription drug benefit will cost \$58.9 billion in 2006 and will be financed through beneficiary premiums and general revenue. The President's Budget also proposes \$75 million for program integrity efforts to combat fraud and abuse in the new Part D and Medicare Advantage programs.

February 15, 2004 was the final date for plans to submit Medicare Advantage 2005 applications to provide coordinated care plans, including local preferred provider organizations (PPOs). The deadline for stand-alone prescription drug plans, new Medicare Advantage contractors, and regional PPOs to submit their "Notice of Intent to Apply" was February 18, 2005. CMS has received significant initial interest from potential prescription drug plan sponsors to offer the Medicare drug benefit throughout the Nation. In addition, insurance plans have expressed interest in significantly expanding Medicare Advantage service areas providing more options to Medicare beneficiaries.

##### *Medicaid*

The President and I are also committed to improving Medicaid. Medicaid provides health insurance for more than 46 million Americans, but as you are all aware, States still complain about overly burdensome rules and regulations, and the state-federal financing system remains prone to abuse.

This year, for the first time ever, States spent more on Medicaid than they spent on education. Over the next ten years, American taxpayers will spend nearly \$5 trillion on Medicaid in combined state and federal spending. The Department plans to make sure tax dollars are used more efficiently by building on the success of the State Children's Health Insurance Program (SCHIP) and waiver programs that allow states the flexibility to construct targeted benefit packages, coordinate with private insurance, and extend coverage to higher income and non-traditional Med-

icaid populations. Additionally, we estimate that proposals included in the President's Budget to strengthen program integrity and ensure that Medicaid doesn't overpay for drugs will create \$60 billion in new savings over a ten-year period.

The President plans to expand coverage for the key populations served in Medicaid and SCHIP by spending \$15.5 billion on targeted activities over ten years. The President's Budget includes several proposals to provide coverage, including the Cover the Kids campaign to enroll more eligible uninsured children in Medicaid and SCHIP. In addition, the extension of the Qualified Individual and transitional medical assistance programs will ensure coverage is available to continue full payment (subject to a spending limit) of Medicare Part B premiums for qualified individuals, and provide coverage for families that lose eligibility for Medicaid due to earnings from employment. The Department projects that over 50 million individuals will be covered by Medicaid and SCHIP in fiscal year 2006, at a federal cost of \$198 billion.

#### *Community Health Centers*

In addition to expanding access through Medicaid and SCHIP, the President's Budget builds on the Department's aggressive efforts to help those who are uninsured or underinsured by expanding the good work of community health centers. These centers provide quality, compassionate care to the patients who need our help the most, regardless of their ability to pay.

The President's Budget requests \$2 billion, a \$304 million increase from fiscal year 2005, to fund community health centers. This request completes the President's commitment to create 1,200 new or expanded sites to serve an additional 6.1 million people by 2006. By the end of fiscal year 2006, the Health Centers program will deliver high quality, affordable health care to over 16 million patients at more than 4,000 sites across the country. Health centers are effectively targeted to eliminate health disparities and provide a range of essential services. In 2006, health centers will serve an estimated 16 percent of the Nation's population who are at or below 200 percent of the federal poverty level. Almost forty percent of Health Center patients have no health insurance and 64 percent are racial or ethnic minorities. In addition, the President has set a new goal to help every poor county in America that lacks a community health center by establishing a community health center in counties that can support one, or a rural health center. The President's Budget includes \$26 million to fund 40 new health centers in high poverty counties.

#### *Ryan White/HIV*

Our request also includes approximately \$18 billion for domestic AIDS care, treatment, research, and prevention. We are committed to the reauthorization of the Ryan White CARE Act treatment programs, consistent with the President's reauthorization principles of prioritizing lifesaving services including HIV/AIDS medications and care; providing more flexibility to target resources; and ensuring accountability by measuring progress. The President's Budget requests a total of \$2.1 billion for Ryan White activities, including \$798 million for lifesaving medications through the AIDS Drug Assistance Program.

#### *Providing Access to Quality Health Care: The Administration's Comprehensive Plan*

These projects and reforms, as well as those at other Departments, cooperate to extend health care and insurance to millions of people. For instance, the President proposes to spend more than \$125.7 billion over ten years to expand insurance coverage to millions of Americans through tax credits, purchasing pools, and Health Savings Accounts. The proposed Traditional Health Insurance Tax Credit would pay for 90 percent of the cost of the premium of standard coverage, up to a maximum of \$1,000 for an individual, and \$3,000 for a family of four. The proposed Health Insurance Tax Credit for those with Health Savings Accounts (HSAs) would allow individuals to use a portion of the credit to purchase a high-deductible health plan while putting the remaining portion of the credit in an HSA. The Administration also proposes legislation that would allow small employers, civic groups, and community organizations to band together and leverage purchasing power to negotiate lower-priced coverage for their employees, members, and their families through Association Health Plans (AHPs). As opposed to previous proposals that limited AHPs to small businesses, this proposal also applies to private, non-profit, and multi-state entities outside the workplace.

Thanks to the comprehensive nature of this vision, workers are already investing money tax-free for medical expenses through Health Savings Accounts, Americans have increasing flexibility to accumulate savings and to change jobs when they wish, and more Americans are accessing high-quality health care. We estimate that 12 to 14 million additional people will gain health insurance over the next ten years.

*Bioterrorism Preparedness*

Since 2001, your support for HHS's bioterrorism efforts has been unwavering. As a result we have made tremendous strides in protecting our Nation from various threats. The HHS fiscal year 2006 budget builds upon these achievements to strengthen our ability to minimize the number of casualties that would occur as a result of a bioterrorist attack, or other attack with weapons of mass destruction. From 2001 to 2005, HHS invested nearly \$15 billion to prepare our Nation's health systems. The fiscal year 2006 budget requests \$4.3 billion to continue this work, a 1,500 percent increase from the 2001, pre-9/11 level.

The fiscal year 2006 request places the highest priority on those programs that address readiness issues for which there is a unique federal role. These include the new mass casualty initiative, the Strategic National Stockpile (SNS), and National Institutes of Health (NIH) research on next-generation countermeasures.

HHS has a responsibility to lead public health and medical services during major disasters and emergencies. Toward this end, the President's Budget would invest \$70 million in a new effort to develop federal mass casualty treatment capacity that can be rapidly deployed and staffed to supplement the surge capacity being developed at the state and local level. Of this amount, \$50 million, financed through the SNS, will be used to procure and manage the mass casualty treatment units. The Medical Reserve Corps will be expanded by \$12.5 million to support the enrollment, training, and credentialing of volunteers that could be deployed in the event of a national emergency. A new \$7.5 million effort will fund the development of a secure database that can consolidate healthcare provider credentialing information from federal, state, and non-government sources for quick retrieval in a major emergency. This activity will be fully coordinated with the state-based Emergency System for Advance Registration of Volunteer Healthcare Personnel that the Health Services and Resources Administration (HRSA) sponsors.

The Strategic National Stockpile's goal is to provide state and local governments the pharmaceuticals and supplies they would need to minimize casualties from a bioterrorist attack or other major public health emergency within 12 hours. The budget requests a total of \$600 million for the SNS, an increase of \$203 million above the fiscal year 2005 enacted level (including the \$50 million for mass casualty treatment units discussed earlier). The Administration has continued to reassess the stocks that are needed to best protect the American population. As a result, by the end of fiscal year 2006, the SNS will have sufficient antibiotics to provide prophylaxis to up to 60 million Americans exposed to the anthrax organism. The SNS will set up the highly specialized cold storage capacity needed for the IND vaccines procured through BioShield. Substantial funds will also be used to replace medications that are losing potency, and to maintain the capacity needed to deploy assets to any part of the Nation within hours of the detection of an event.

Our Nation's ability to detect and counter bioterrorism ultimately depends on the state of biomedical science, and NIH will continue to ensure full coordination of research activities with other federal agencies in this battle. The President's Budget includes \$1.8 billion for NIH biodefense research efforts, a net increase of \$56 million. When this is adjusted for non-recurring extramural construction in fiscal year 2005, NIH biodefense research activities grow by \$175 million, or 11 percent, over fiscal year 2005. Included in this total is a \$50 million initiative budgeted in the Public Health and Social Services Emergency Fund to develop new medical countermeasures against chemicals that could be used as weapons of mass destruction.

HHS continues to have a strong commitment to preparing States and local public health departments and hospitals to prepare against public health emergencies and acts of bioterrorism. From fiscal year 2002 to fiscal year 2005, \$5.4 billion has been invested in this work through the Centers for Disease Control (CDC) and HRSA's ongoing state and local preparedness programs. The fiscal year 2006 budget includes \$1.3 billion more for this work, increasing the cumulative total to \$6.7 billion.

*Influenza*

Since the H5N1 strain of avian influenza first appeared in 1997, public health officials have grown increasingly concerned about the possibility that a pandemic strain will emerge that could cause an additional 90,000 to 300,000+ deaths in the United States. Avian influenza has reappeared in Southeast Asia again this year, indicating that the virus has become endemic. The fiscal year 2006 budget continues to expand HHS's efforts to be prepared in the event this or another deadly influenza strain changes in a way that makes it easily communicable from person to person.

Since fiscal year 2001, HHS has increased its direct expenditures related to influenza vaccine from \$42 million to \$439 million in fiscal year 2006, in addition to in-

insurance reimbursement payments through Medicare. The fiscal year 2006 budget includes targeted efforts to ensure a stable supply of annual influenza vaccine, to improve access to influenza vaccine for children and Medicare beneficiaries, to develop the surge capacity that would be needed in a pandemic, and to improve the response to emerging infectious diseases before they reach the United States.

Increasing the use of annual influenza vaccinations will both reduce annual morbidity/mortality, and make the Nation better prepared in the event of a pandemic. CDC estimates that 185 million people should receive annual immunizations but fewer than half of that number have ever been immunized in a given year. The President's Budget seeks to increase annual immunization rates by both making sure an ample supply is manufactured each year and working to ensure it is used. The President's Budget includes several initiatives within CDC's two immunization programs to expand the production of bulk monovalent and finished influenza vaccine for the 2006/7 influenza season. CDC will invest \$70 million in new resources to build vaccine stockpiles. First, CDC will set aside \$40 million in new mandatory Vaccines for Children (VFC) budget authority for a stockpile of finished pediatric influenza vaccine that can be used in the event of a late-season surge in demand; the first ever stockpile was purchased for the winter of 2004/5. Second, CDC's discretionary Section 317 program will invest \$30 million in contracts to get manufacturers to make additional bulk monovalent vaccine over and above the amounts the companies expect to use for the 2006/7 season. This added bulk vaccine will be available to be turned into finished vaccine if other producers experience problems, or if an unusually high demand for vaccine is anticipated. Bulk vaccine not used for the 2006/7 season will be kept for potential use the following year. Commonly, one or two of the strains in the trivalent influenza vaccine remain the same from one year to the next.

HHS is also continuing its efforts to expand annual influenza immunizations. The Section 317 program will also use increased funding of \$20 million over fiscal year 2005 to purchase an estimated two million doses of influenza vaccine for the 2006/7 influenza season to help states expand vaccination for children. Centers for Medicare and Medicaid Services has taken steps to ensure that physicians have appropriate incentives to improve vaccination rates. Since 2002, the Medicare reimbursement rate for the administration of influenza vaccine has increased more than four times, from an average of \$3.98 in 2002 to \$18.57 in 2005. The reimbursement rate for the vaccine product also increased, from \$8.02 to \$10.10.

To ensure sufficient vaccine can be made quickly in a pandemic, the Nation needs to develop the ability to surge domestic vaccine production as soon as scientists determine that a pandemic strain has emerged. The President's Budget increases the Department's investment in pandemic preparedness efforts by \$21 million, for a total of \$120 million in fiscal year 2006. This increase will be used to develop the year-round domestic surge vaccine production capacity that would be needed in a pandemic; this added surge capacity could also be used to respond to unexpected problems in the production of annual vaccines. It will finance contracts with vaccine manufacturers to develop and license influenza vaccines using new production techniques and establishing a domestic manufacturing capability. HHS will continue to ensure a year-round supply of specialized eggs needed for domestic production of currently licensed vaccines. Manufacturers will be encouraged to license and implement new processing and other technologies to improve vaccine yields from both new cell culture vaccines and existing egg-based vaccines. In addition, HHS will sponsor the development and licensing of antigen-sparing strategies that would increase the number of individuals who could be vaccinated from a given amount of bulk vaccine product. Finally, the President's Budget maintains the flexibility to redirect these funds to initiate pandemic vaccine production at any time a pandemic appears imminent.

To improve our Nation's long-term preparedness and enhance the annual vaccine supply, NIH will invest approximately \$120 million in influenza-related research nearly six times the fiscal year 2001 level. Research areas include new cell culture techniques for flu vaccine production, which complements the advanced development; vaccines for potential pandemic strains, including H5N1; next-generation antiviral drugs; rapid, ultra-sensitive diagnostic devices to detect influenza virus infection; and ways to make flu vaccine more effective among the elderly.

These research and advanced development efforts will be complemented by expanding funding for CDC's Global Disease Detection initiatives by \$12 million, from \$22 million to \$34 million in fiscal year 2006, to improve our ability to prevent and control outbreaks before they reach the United States.

*Childhood Immunization*

The President's Budget includes proposed legislation in the mandatory VFC program to improve low-income children's access to routine immunizations that I believe members of this committee should strongly support. This proposed legislation would ensure that all children have access to all routinely recommended vaccines regardless of cost such as the newly-approved meningococcal conjugate vaccine. This legislation would enable any child who is currently entitled to receive VFC vaccines to receive them at state and local public health clinics. There are hundreds of thousands of underinsured children who are entitled to VFC vaccines, but can receive them only at HRSA-funded health centers and other Federally Qualified Health Centers. When these children go to a state or local public health clinic, they are unable to receive vaccines through the VFC program and the State may decide not to use scarce discretionary dollars to provide newer, more expensive vaccines. This legislation will expand access to routine immunizations by eliminating this barrier to coverage and will help States meet the rising costs of new and better vaccines. As modern technology and research has generated new and better vaccines, that cost has risen dramatically. For example, when the pneumococcal conjugate vaccine became available, it increased the cost of vaccines to fully-immunize a child by approximately 80 percent. A new meningococcal vaccine has recently been approved that will further raise the cost to fully immunize a child making this legislation even more important.

*Focus on the Future—Health Information Technology and NIH*

Our fiscal year 2006 budget was also constructed with the knowledge that health information technology will improve the practice of medicine and make it more efficient. For example, the rapid implementation of secure and interoperable electronic health records will significantly improve the safety, quality, and cost-effectiveness of health care. To implement this vision, we are requesting an investment of \$125 million. The Office of the National Coordinator for Health Information Technology would spend \$75 million to provide strategic direction for development of a national interoperable health care system, and to address barriers to the widespread adoption of electronic health records. The Agency for Health Care Quality and Research continues to direct \$50 million to accelerate the development, adoption, and diffusion of interoperable information technology in a range of health care settings.

Equally important, major advances in knowledge about life sciences, especially the sequencing of the human genome, are opening dramatic new opportunities for biomedical research. Heretofore un-imagined prospects for more precisely predicting individual susceptibility to disease and responses to medication are now close at hand, as are new approaches to diagnosing, preventing, and treating disease and disability. These advances have been driven by the investments in research made by the National Institutes of Health (NIH), the world's largest and most distinguished organization dedicated to medical science.

The fiscal year 2006 budget request for NIH of \$28.8 billion seeks to capitalize on the opportunities these investments have created to further improve the health of the Nation. The NIH budget is built upon and reflects the tremendous growth in biomedical research spending in recent years. In fiscal year 2006, over \$24 billion of the \$28.8 billion requested for NIH will flow out to the extramural community, which supports work by more than 200,000 research personnel affiliated with approximately 3,000 university, hospital, and other research facilities across our great Nation. These funds will support nearly 39,000 investigator-initiated research project grants in fiscal year 2006, including an estimated 9,463 new and competing awards. NIH will also fund close to 1,400 research centers, over 17,400 research trainees, and much more.

In fiscal year 2006, NIH will also continue to implement the Roadmap for Medical Research by spending a total of \$333 million, an increase of \$98 million over fiscal year 2005, on initiatives to target research gaps and opportunities that no single NIH institute could solve alone. The budget request also emphasizes efforts to enhance collaborations for multidisciplinary neuroscience research and accelerate efforts to develop and evaluate vaccines against HIV/AIDS. Within this total, NIH will also increase funding to address critical requirements in biodefense, including a targeted \$50 million research effort to develop new medical countermeasures for chemicals that can be used as weapons of mass destruction.

## SUPPORTING A COMPASSIONATE SOCIETY

*Faith-Based and Community Organizations*

As part of the Administration's Faith-Based and Community Initiative, the HHS fiscal year 2006 budget maintains a commitment to strengthen the capacity of faith-

based and community organizations, including the Access to Recovery program, the Compassion Capital Fund, the Mentoring Children of Prisoners program, and Maternity Group Homes.

The toll of drug abuse on the individual, family, and community is both significant and cumulative. Abuse may lead to lost productivity and educational opportunity, lost lives, and to costly social and public health problems, including HIV/AIDS, domestic violence, child abuse, and crime. Through the Access to Recovery program, HHS will assist States in expanding access to clinical treatment and recovery support services and allow individuals to exercise choice among qualified community provider organizations, including those that are faith-based. This program recognizes that there are many pathways of recovery from addiction. Through Access to Recovery individuals are assessed, given a voucher for appropriate services, and provided with a list of providers from which they can choose. Fourteen States and one tribal organization were awarded Access to Recovery funding in fiscal year 2004, the first year of funding for the initiative. The funded entities have identified target populations that include youth, individuals involved with the criminal justice system, women, individuals with co-occurring disorders, and homeless individuals. The President's Budget increases support for the Access to Recovery initiative by 50 percent, for a total of \$150 million, and will support a total of 22 States participating.

The Compassion Capital Fund advances the efforts of community and charitable organizations, including faith-based organizations, to increase their effectiveness and enhance their ability to provide social services where they are needed. The President's Budget includes \$100 million, an increase of \$45 million in support of the Compassion Capital Fund.

Within this program, the President has proposed a new focus on young Americans that will include support for programs that help youth overcome the specific risk of gang influence and involvement. This three-year, \$150-million initiative will provide grants to faith-based and community organizations targeting youth ages 8–17, and will help some of America's communities that are most in need. These organizations will provide a positive model for youth one that respects women and rejects violence.

#### *Abstinence*

Expanding abstinence education programs are also part of a comprehensive and continuing effort of the Administration, because they help adolescents avoid behaviors that could jeopardize their futures. Last year, HHS integrated abstinence education activities with positive youth development efforts at the Administration for Children and Families (ACF), by transferring the Community-Based Abstinence Education program and the Abstinence Education Grants to States to ACF. The HHS fiscal year 2006 budget expands activities to educate adolescents and parents about the health risks associated with early sexual activity and provide them with the tools needed to help adolescents make healthy choices. The programs focus on educating adolescents ages 12 through 18, and create a positive environment within communities to support adolescents' decisions to postpone sexual activity. Where appropriate, the programs also offer mentoring, counseling, and adult supervision to promote abstinence with a focus on those groups which are most likely to bear children out of wedlock. A total of \$206 million, an increase of \$39 million, is requested for these activities.

#### *Head Start*

The Head Start program helps ensure that children, primarily in low-income families, are ready to succeed in school by supporting their social and cognitive development. Head Start programs also engage parents in their child's preschool experience by helping them achieve their own educational, literacy, and employment goals. The HHS fiscal year 2006 budget of \$6.9 billion will provide comprehensive child development services to 919,000 children. This level includes an increase of \$45 million to support the President's initiative to improve Head Start by funding nine state pilot projects to coordinate state preschool, child care, and Head Start in a comprehensive system of early childhood programs for low-income children.

#### *Temporary Assistance for Needy Families*

It has been three years since President Bush first proposed his strategy for reauthorizing TANF and the other critical programs included in welfare reform. During this time, the issues have been debated thoroughly but the work has not been completed and States have been left to wonder how they should proceed. We believe it is important to finish this work as soon as possible and set a strong, positive course for helping America's families. The proposal is guided by four critical goals that will transform the lives of low-income families: strengthen work, promote healthy families, give States greater flexibility, and demonstrate compassion to those in need.



*Administration on Aging*

The President's Budget requests a total of \$1.4 billion in the Administration on Aging for programs that serve the most vulnerable elderly Americans, who otherwise lack access to healthy meals, preventive care, and other supports that enable them to remain in their home communities and out of nursing facilities. It also continues investments in program innovations to test new models of home and community-based care.

## IMPROVING HHS MANAGEMENT

The President's Management Agenda (PMA) provides a framework to improve the management and performance of HHS. HHS has taken significant steps to institutionalize its focus on results and achieve improved program performance that is important to the HHS mission and the American taxpayer.

Budget and Performance Integration (BPI) aims to improve program performance and results by ensuring that performance information is used to inform funding and management decisions. For fiscal year 2006, HHS operating divisions produced their first "performance budgets" which combine budget and performance information in a single document. With this new format the Department moved from the traditional approach of presenting separate budget justifications and performance plans to the use of one integrated document to present both budget and performance information. This move also enhanced the availability and use of program and performance information to inform the budget process.

HHS has made significant steps in its implementation of the President's five government-wide management initiatives. The Program Assessment Rating Tool (PART) is an important component of the Budget and Performance Integration initiative and is used to assess program performance and improve the quality of performance information. Sixty-five HHS programs were reviewed in the PART process between fiscal year 2004 and fiscal year 2006. HHS consolidated 40 personnel offices into four Human Resources Centers, which became operational in January 2004, and is planning several upcoming projects to support Human Capital strategic management. Since the start of the competitive sourcing initiative, HHS has competed almost 25 percent of its commercial activities, resulting in increased efficiencies and savings for the American taxpayer. For example, HHS anticipates gross savings of \$55 million from studies completed in fiscal year 2004, which will be redirected to mission critical activities at HHS. This year, HHS will focus on structuring competitions to maximize efficiencies and savings, as well as implement a savings validation plan. HHS also implemented several processes to improve the financial performance of the Department, such as streamlining and accelerating the annual financial reporting process and combining annual audited financial statements with program performance information in the Department's Performance and Accountability Report. HHS is also continuing to implement the Unified Financial Management System throughout the Department. More than 95 percent of HHS' information systems have certified and accredited security plans. Finally, HHS has been working to achieve a more mature Enterprise Architecture that links performance to strategic, capital planning, and budget processes.

Over the past four years, the Administration has worked diligently with the Department to make America and the world healthier. I am proud to build on the HHS record of achievements. For the upcoming fiscal year, the President and I share an aggressive agenda for HHS that advances a healthier, stronger America while upholding fiscal responsibility and good stewardship of the People's money. I look forward to working with Congress as we move forward in this direction. I am happy to answer any questions you may have.

## MEDICAID PROTECTION

Senator SPECTER. Well, thank you very much, Mr. Secretary, for many things, most recently brevity.

Mr. Secretary, I begin with a question on the Medicaid. It has been a topic among Senators. It serves people who are desperately in need of medical attention. There is a projected reduction which is represented at 1 percent, but in the out-years it grows exponentially. You come with three terms as Governor of Utah, so you've been in the Governor's role. The Governors are very concerned about Medicaid.

Senator Smith of Oregon has offered an alternative proposal to take a closer look at it on a commission, not satisfied with the review which has been made so far, which has—could have more depth. We can always study more. Of course it involves some delay. But how will the recipients of Medicaid at the present time be protected with the proposal which you have backed?

Secretary LEAVITT. Senator, that's the right question in my mind. How do we protect the coverage of people who are currently being served, and how in fact can we expand the reach of Medicaid? It's currently serving some 46 million Americans. But some of them are in jeopardy because the program has such rigid inflexibility that States are by the nature of that inflexibility being forced to look at diminishing the coverage substantially or eliminating the coverage of many optional groups.

A couple of points. One is, if there is any perception that Medicaid is being cut, I would like to suggest that is not correct. The Medicaid budget will grow by in excess of 7 percent over the next 10 years. We'll see almost \$5 trillion spent at the end of that 10 years. We'll see \$900 billion more from the Federal side be put into Medicaid. It is a rapidly growing program.

What the budget does reflect is a desire to see it increase at a slightly slower rate. The Governors I believe are, as I've spoken with them, some—I think I've had conversations now with 38 of them about this subject in direct and personal ways. There are a series of reforms that they're anxious to see that provide flexibilities that will allow them to continue the coverage of many who they believe are imperiled.

The reforms are quite common sense in my mind. One is to reduce the amount that's paid for prescription drugs, not to reduce the number of people served by them or to reduce the number of drugs they can receive, but to change the way in which they are paid for. Medicaid would be widely known as the best payer in the business. They pay higher costs for prescription drugs than Medicare or for that matter most private plans. This would propose a statute change that would allow them to essentially pay the same rate as Medicare Part B will pay.

The second reform is caring for what's known as an asset spend-down where people have learned to give their assets to their children so that the State can pay for their Medicaid, and Governors would like to see that changed.

The third is in being able to provide a series of co-pays among those who are in higher income brackets served by Medicaid. Governors are interested to see Medicaid recipients become cost-conscious consumers in the same way that others are required.

The fourth would be really a celebration of SCHIP, to use SCHIP more broadly to provide more flexibility in constructing benefit plans of again mostly mothers and children in higher income brackets that would provide the ability to serve more.

The last is an important reform, and that is as the number of elderly served by Medicaid increases and will clearly increase in the future, there's a desire to in essence liberate Medicaid from exclusive use of nursing homes. We'd like to be able to have people served in their homes and in communities. It's more efficient, and frankly that's where they want to be served.

So, Senator, those are the reforms that are on the table. They are reflected in the budget as a budget reduction, but only because they provide flexibility that in my judgement almost all the States will be using in health care in different ways to preserve the coverage of those who might lose it otherwise.

Senator SPECTER. Mr. Secretary, let me compliment you on finishing your answer within 2 seconds of the allotted time which I have. That plus your opening statement on brevity gets you off to a very, very good start with this subcommittee.

Secretary LEAVITT. Thank you.

Senator SPECTER. I'm now going to turn the gavel over to my distinguished colleague, Senator DeWine, to relieve me on the chairmanship. Thank you very much.

Secretary LEAVITT. Thank you, Senator.

Senator DEWINE [presiding]. Senator Harkin.

#### IOWA ARMY AMMUNITION PLANT

Senator HARKIN. Thank you very much, Mr. Chairman. Mr. Secretary, we visited earlier. We talked about briefly, a month or so ago, I forget when it was, about the situation at the Iowa Army ammunition plant that had to do with workers who had worked there for years in a nuclear weapons facility there.

A little background. Several years ago a worker had contacted me there because of all the cancers that had been happening to people, asked me to look into this. I contacted the Department of the Army who informed me that they had never assembled nuclear weapons there, and so I went out on a limb and told this guy that he must be mistaken, and he never gave up, Mr. Anderson never gave up. He came back and we finally found out that in fact they had been assembling nuclear weapons there for many, many years, and many of the workers there were exposed to high levels of radiation, had no knowledge of this. They were sworn to secrecy. Many of them never talked to doctors, never talked to anyone, because of this oath of secrecy they had taken.

Well, this has all gone through a lot of hearings and processes and stuff. Senator Bond and I have managed to win four votes on this. But basically the NIOSH Advisory Board on Radiation and Worker Health voted seven-yes, seven to nothing, to provide automatic compensation for former nuclear weapons workers at the Iowa Army ammunition plant.

Now, under the law they are then to notify you by letter of their decision. Under the law you then have 30 days whether to approve or disapprove of this, and then of course Congress then can step in depending upon what the decision is. Have you received any—that notification yet?

Secretary LEAVITT. No.

Senator HARKIN. Well, this may be an unfair question, but I'll ask it. Do you have any explanation as to why you have not received an official notification?

Secretary LEAVITT. I don't. I've read accounts that the vote took place as you have indicated. I'm aware that—but I can't reconcile why they haven't. When I do receive it, we'll obviously act in a way that's timely.

Senator HARKIN. Well, Mr. Secretary, I—well, I wrote them a letter yesterday along with others to Mr. Howard, director of NIOSH, and Mr. Paul Ziemer, chairman of the Advisory Board on Radiation and Worker Health, because I didn't know, I really didn't know if they had transmitted or not. So I wrote them a letter saying, if you haven't, please do it. So I hope that we can find out why it is that they have not forwarded this, because these workers have been waiting a long time. It was a—wasn't even a—as I said, wasn't even a close vote, seven to nothing. So I'm hopeful we can move ahead on that.

The other thing I wanted to talk about just for the record, Mr. Secretary, it was reported yesterday that the White House disagrees with the GAO opinion that prepackaged video news releases prepared and distributed by Federal agencies or their public relations firms that do not disclose, that this would not constitute illegal covert propaganda.

One of the videos reviewed by GAO was funded by one of your agencies, CMS. Now, again, I don't expect you to have these numbers at your fingertips, but if your staff could take note of this, as the appropriations subcommittee here, could you provide this subcommittee with your anticipated budget for fiscal year 2006 for public relations activities, including any contracts with public relations firms, media buys, et cetera, if you could provide that for the committee.

Secretary LEAVITT. Indeed we will.

[The information follows:]

## National Medicare &amp; You Education Program Budget

Activity	FY 2005 Appropriation	FY 2006 Estimate	Description of Activity in FY 2006
Beneficiary Materials	\$47.9 M  (\$13.0M UF) (\$15.0M PM) (\$19.9M MMA)	\$43.5 M  (\$14.0M UF) (\$13.0M PM) (\$16.5M MMA)	National handbook with comparative information in English and Spanish (national & monthly mailing); <i>targeted materials only to the extent that funding is available after payment of the handbook.</i>
1-800 MEDICARE (toll-free line)	\$181.6 M  (\$61.0M PM) (\$120.6M MMA)	\$173.3 M  (\$43.8M PM) (\$41.8M UF) (\$87.7M MMA)	Full call center and print fulfillment services with 24 hours a day, 7 days a week access to customer service representatives for 12 months
Internet	\$22.7 M  (\$9.1M PM) (\$3.0M QIO) (\$10.6M MMA)	\$15.2 M  (\$9.0M PM) (\$3.0M QIO) (\$3.2M MMA)	Maintenance, updates and enhancements to existing interactive databases and web sites; software licenses.
Community- Based Outreach	\$48.8 M  (\$16.0M PM) (\$32.8M MMA)	\$45.1 M  (\$13.2M PM) (\$31.9M MMA)	SHIP grants; REACH; and HORIZONS
Program Support Services	\$39.45 M  (\$19.3M PM) (\$12.25M QIO) (\$7.9M MMA)	\$41.15 M  (\$13.9M PM) (\$12.25M QIO) (\$15.0M MMA)	Ad Campaign at \$22.9M; \$12.25M for CAHPS; \$6.0M for evaluation & assessment, formative research, and consumer testing
<b>Total</b>	\$340.45 M  (\$120.4 M PM) (\$13.0 M UF) (\$15.25 M QIO) (\$191.8M MMA)	\$318.2 M  (\$92.9M PM) (\$55.8M UF) (\$15.25M QIO) (\$154.25M MMA)	PM - Program Management UF - User Fees QIO - Quality Improvement Organizations MMA - Medicare Modernization Act

Senator HARKIN. I appreciate that.

MEDICARE MODERNIZATION—PART D

Secretary LEAVITT. Senator, I might just comment—

Senator HARKIN. Sure.

Secretary LEAVITT [continuing]. Make one statement that we will obviously follow the guidance of our legal counsel on this matter and make certain that we are acting within the scope of the rules. We have a very demanding challenge in front of us collectively as a government during the next 15 months, and it's the rollout of Medicare Modernization, the Part D for prescription drugs.

One of the—at the base of this conflict was the question of what tools we should deploy and use to provide people with information about their options under Part D. I mention that simply to put some perspective on the dilemma we're facing, reaching people, educating them. We enlist the help of the Senate, and at the risk of eliminating the good reputation I formed with Senator Specter on stopping when that red light goes on, I'll quit there.

Senator HARKIN. Well, Mr. Secretary, just summing up, we send out letters and information to our constituents all the time, but we sign our names to it, you know, and I'm certain those who in my State who disagree with me dismiss it because I've said it, and you know how that goes. But at least they know where it comes from.

Secretary LEAVITT. Right.

Senator HARKIN. Do you think that any information provided by HHS should be attributed to HHS? I mean, I realize you're going to get information out, but at least it ought to say where it comes from.

Secretary LEAVITT. That seems like a logical statement to me. I don't know the nature of this dispute. I know that there has been discussion between GAO and differences of opinion about it. At this point, our role is to first of all do the best job we can in being able to educate people on the opportunity that's there and at the same time make certain we're within the rules. I can assure you we'll do our best to stay within them.

Senator HARKIN. I thank you. We will, as I said, when you send those anticipated figures up, any contracts you have with media firms and stuff like that, we would like to analyze that closely.

Secretary LEAVITT. Thank you.

Senator HARKIN. Thank you, Mr. Secretary. Thank you, Mr. Chairman.

Senator DEWINE. Senator Craig.

#### STATEMENT OF SENATOR LARRY CRAIG

##### PANDEMIC FLU VACCINE

Senator CRAIG. Thank you very much, Mr. Chairman. I would hope that any activity or publicity that has been garnered as a result of certain advertising and information flows does not put a chilling effect on what I believe is a fundamental responsibility of the agency to communicate with the public, and to do so in a forthright and direct way. Clearly as we struggled to bring folks on line with the prescription drug card and to get them into the system so that as we roll out the plan as you're talking about, there clearly needed to be an informational flow. There was a partnership at AARP at that time that was a cooperative effort, Mr. Secretary, that I think worked extremely well.

So while I do believe there ought to be full disclosure, I don't think you or I would dispute that, I would hope that anyone who might charge that you're doing something beyond without good grounds, this Senate spends a lot of time and money getting out our point of view, and more importantly, once a policy is developed and ready for the public, I think it's important that we communicate it effectively.

##### FLU VACCINE

One question of you: Last year I wore a different hat than I wear today, and that was chairman of the Select Committee on Aging—Special Committee on Aging. We spent a lot of time prior to and after the announcement by Chiron that they had been forced to close their Liverpool plant and could not supply to the marketplace and to Americans the necessary flu vaccine that we had antici-

pated. We worked very closely with your predecessor in making sure that somehow we made it through, and we are making it through this year it appears. At least thank goodness we have not had a major outbreak, but the flu is out there and it's taking lives as it does.

But I think you are right to be concerned of a pandemic, and therefore, clearly the need in this country to build a reliable supply of flu vaccine. We, by a—for a variety of reasons including liability, while our class action efforts of the past month may help some, we've run a lot of folks offshore or out of business. The business of making vaccines is not 100 percent perfect in all instances. There is liability without question.

Senator Bayh and I have introduced legislation, you're right. There are others who have looked at shaping the market or assisting the market. When we deal with the flu virus, and it is constantly in mutation, you cannot inventory this on the shelf and keep it there. It must be new with the season. You have to have the capability to produce it. I do believe there will come a day when you are right to be concerned about what's going on elsewhere in the world as it relates to flu vaccines. It is a killer of our elderly, there is no question about it.

Could you for a moment spend some time on that issue with us as to what you anticipate you'll be doing? I see the Liverpool plant is back up in operation. It looks like Chiron is back in the market. That's wonderful. But we're still—we still have a very fragile system. We're looking at new techniques beyond the egg to cell for production purposes. Enlighten us if you would as to where you see it at this moment, and what we might do to assist you in ensuring a constant and reliable supply.

Secretary LEAVITT. Judgements on how much and when and what to buy are complex and often times required to be made with incomplete information, or at least imperfect information.

Senator CRAIG. That's right.

Secretary LEAVITT. It's in some respects like many other commodity-type business or business decisions where there are peaks of use and the question as to whether you buy to the peak always or whether you buy what you think will be normal. The truth is they will not be manufactured unless there's a market, and often times government has to be that market. We've proposed in this budget for back-up guarantees some \$20 million in 2005 and \$30 million in 2006, and also \$120 million for pandemic work for alternative production.

I would like to just update you some, Senator, on efforts we are making to follow the avian flu in Asia. We have people on the ground who are now working with various governments in their clinics, in their—working with their governments, with their practitioners. We're trying to deploy more and more resources at the source. Pandemics have occurred on three different occasions during this century. There's no reason for us to believe they won't happen again. They strike quickly. We don't know when they will strike, we don't know where they will strike, and as you've suggested, we don't always know the strain of the flu, and we have to be in a position to respond quickly.

It is a matter of grave concern to me. I am following this literally on a daily basis. I receive a daily briefing now from CDC and others involved. Currently I believe that we are following the right path, but we'll keep you and other members of the committee informed as things develop.

Senator CRAIG. Well, I thank you very much. There are many of us following this. We're glad to see you fully engaged. You've made, in my opinion, the right statement. To ask companies to supply to an indeterminate market means that we have to stabilize the market, and the only way to do that is for government to be the stability. Therefore to, at the end of the cycle, to be able to buy out, if you will, excess, as long as the companies have met the level of projection, is something I think we ought to build a level of expectation for in the marketplace. It's in part why we don't have companies operating today. We bankrupt them by basically suggesting they supply to a market it didn't develop and then we weren't there to sustain them in the end.

So I thank you for that. I'm glad to see there's increased money in the budget for those purposes and that we're moving as well as we can in relation to pandemic knowledge. Thank you.

#### STATEMENT OF SENATOR MIKE DE WINE

Senator DEWINE. Mr. Secretary, welcome.

Secretary LEAVITT. Thank you, Senator.

#### COMMUNITY ALTERNATIVE FUNDING SYSTEMS

Senator DEWINE. Ohio's Community Alternative Funding Systems, the CAFS program, serves individuals with mental retardation and developmental disability. However, the CAFS program apparently does not comply with Federal mandates, and as a result, Ohio will not be providing Medicaid services to this fragile population. You and I have talked about this, our staffs have talked about this, and I just want to again mention it to you that as we, Ohio, works its way through this problem, I hope that you will continue to work with Ohio to try to work this out. We understand Ohio has to comply with Federal law, but we need to make this transition as smooth as we can as we find other ways to serve this population. These are kids, these are kids in school, these are kids who really are a most fragile population. So I just look forward to working with you on that.

Secretary LEAVITT. Thank you. May I say that there is no disagreement on the nobility of the purpose and a commitment to find a solution.

#### MEDICAID FUNDING

Senator DEWINE. Good. We appreciate it. We'll work with you. We appreciate you working with us. Thank you very much.

Last year, one of our Ohio children's hospitals in Cincinnati was pursuing a Federal grant trying to find money to continue a major project in improving the quality, the safety, and the efficiency of its care using technology, best practices, and sound management. But they looked around and they found that really there was no way to pursue Federal funding in regard to kids. It's rather ironic, I



think, that that is true, because if they had been doing it, if it was an adult hospital, they had been doing it, there's Medicare money available. There's not Medicaid money available.

So again we have a situation really where kids are discriminated against. I wonder what you can do to change that in your Department and what you see is the future to try to deal with this.

#### FLEXIBILITY IN MEDICAID

Secretary LEAVITT. I spoke briefly earlier about what I believe is a wide and broadly held view that Medicaid is rigidly inflexible and that it creates the kind of circumstances—we've talked a couple of times already today about where there are noble causes, noble pursuits that ought to be done, and there's no disagreement on the cause, but people are left without the capacity to respond to it.

That's one of the reasons that we hope very much that the Congress will act to provide more flexibility in Medicaid. I believe one of those areas would be the ability to construct benefit packages that would be tailored particularly in the instances of mothers and children. We believe more flexibility will not result in anything other than more people being covered as opposed to fewer.

Senator DEWINE. Well, this is the type of thing that, you know, our children's hospitals really need the ability to deal with, and I would hope you would take a look at that as we may possibly design something to deal with that.

#### TREATMENT OF CHILDREN WITH HIV/AIDS

Senator DEWINE. Let me move to another area. Currently few programs specifically target the treatment of children with HIV/AIDS in developing countries. A primary reason is the lack of appropriate pharmaceuticals for use in children. We all of course know that children are not small adults and treating them that way jeopardizes their lives. With 2.5 million children infected with HIV around the world, it's essential that we have appropriate medications to treat them.

How does your budget plan and your Department—how do you plan to ensure that HIV/AIDS drugs, both generic and brand name approved by the FDA expedited process, also include pediatric formulations as well as important dosing information needed for treating different age groups?

Secretary LEAVITT. Senator, NIH has provided \$25 million in 2004 and 2005, and they're proposing another \$25 million in the 2006 for pediatric drug research. I believe that information on the effects of those drugs in children is critically important as well, and I'm looking forward to working with you to ensure that we have success in this effort.

[The information follows:]

#### HIV/AIDS DRUGS

On May 17, 2004 FDA published guidance for the pharmaceutical industry encouraging manufacturers to submit marketing applications for fixed dose combination (FDC) and co-packaged versions of previously approved single entity antiretroviral therapies. The guidance encourages the development of pediatric formulations for these products. Also, subsequent to the publication of the draft guidance, FDA expanded the expedited review program to include single product generic applications. Most of the first line antiretroviral agents are currently available in pedi-

atric dosage forms, so these pediatric formulations can be made available through the generic drug approval process.

Regarding fixed dose and co-packaged combination products, only one company thus far has expressed interest to FDA in developing a pediatric combination product. This could be explained in part by the challenges associated with establishing appropriate doses for pediatric patients for a fixed dose combination product. Such combination products generally do not provide the dosing flexibility needed for pediatric HIV therapy. Also, many of the pediatric formulations are in the form of oral solutions that are not amenable to combination product development. Combination therapy in younger pediatric patients might best be accomplished through the use of individually formulated antiretroviral products that can be made available through the generic approval process. The adult combination products can be used in the older pediatric population.

Regarding the application of the Pediatric Research Equity Act (PREA) to PEPFAR (President's Emergency Plan for Aids Relief) applications, the Agency is enforcing PREA for these applications as it would with any other application. However, PREA does not apply to most generic products or co-packaged products. When PREA does apply to a drug (including HIV drugs) we do not hold up approval but grant deferrals as appropriate for these life-saving treatments.

In addition, the pediatric exclusivity provision of the 1997 FDA Modernization Act and the subsequent 2002 Best Pharmaceuticals for Children Act have generated many clinical studies and useful prescribing information for many products, including several for the treatment of HIV infection. FDA has an HIV Written Request Template to facilitate the development of products. Following are a few examples of products that have been approved for treatment of HIV infection in children. These approvals resulted from studies submitted in response to a Written Request from FDA.

Ziagen (abacavir), Zerit (stavidine), Videx (didanosine), and Viracept (nelfinavir mesylate), in combination with other antiretroviral agents, are indicated for the treatment of HIV-1 infection in children. Use of Ziagen in pediatric patients aged 3 months to 13 years is supported by pharmacokinetic studies and evidence from adequate and well-controlled studies of Ziagen in adults and pediatric patients. Use of Zerit in pediatric patients from birth through adolescence is supported by evidence from adequate and well-controlled studies of Zerit in adults with additional pharmacokinetic and safety data in pediatric patients. Use of Videx in pediatric patients two weeks of age through adolescence is supported by evidence from adequate and well-controlled studies of Videx in adults and pediatric patients. Use of Viracept in pediatric patients from age 2 to age 13 is supported by evidence from adequate and well-controlled studies of Viracept in adults with additional pharmacokinetic and safety data in pediatric patients.

In addition, in March 2003, the Pediatric Subcommittee of the AntiInfective Drugs Advisory Committee of the Food and Drug Administration, Center for Drug Evaluation and Research discussed the development of antiretroviral drugs in HIV-infected and HIV-exposed neonates younger than four weeks of age. The Advisory Committee supported the continued need for development of products for neonates.

These are just a few examples that demonstrate FDA's commitment to the principle that product development should include pediatric studies when pediatric use of the product is intended. In addition, through efforts to make safe and effective antiretrovirals available for treatment of HIV across much of the developing world, we expect to reduce the number of children born with HIV infection and thus significantly impact global health.

Senator DEWINE. Good. Well, my time is up, but we hope to continue to work with you on this. Thank you very much. Senator Kohl is gone. Senator Murray.

#### STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you very much, Mr. Chairman. Mr. Secretary, thank you for being here today. I can't think of an agency that doesn't have more direct impact on lives of every single one of the constituents we represent here, and it's a tremendous job and we appreciate you taking it on.

## HEAD START

I do want to make one comment on Head Start. We had a conversation about this before and in a written response you sent to me you said that you are committed to ensuring the implementation of the President's proposals on Head Start that provide an opportunity for more children to be served by local Head Start programs at the highest level of quality.

I liked the statement, but unfortunately the President's proposal does not provide for more kids to be in Head Start, and I just really urge you to go slow on this proposal. If we break the compact that these local communities have in providing Head Start, I think we're going to take away the basic tenet that Head Start was put together on. It's not just an education program. It's making sure that kids are ready to learn when they get to school.

So I just—I ask you again, I will tell you I'm going to be working hard to make sure that we do this right and you'll be hearing more from me on that, because I'm very concerned the President's proposal will eliminate an important compact and just essentially put in another bureaucratic layer of government that won't help any child get to school ready to learn.

## MIGRANT HEALTH CENTERS

What I did want to ask you about today, however, is the budget request which we are here to discuss today, and I am very concerned about the mixed messages that we're sending communities. I really appreciate the President's leadership on funding for the community in migrant health centers. I couldn't agree more with the administration's support for these centers, because they do provide prevention-based affordable health care. They're not just a safety net. They really do a good job in providing health care for low income, often uninsured patients that often fall through the cracks in our health care system. So I applaud the administration's request for another \$304 million. I think that's great.

But what I am concerned about is a number of the other budget policies that are coming at us will make it impossible for these community health centers to meet their mission and to provide the health care that we're asking them to. The other proposals on New Starts and Medicaid and the elimination of coordination services like the Healthy Community Access Program are going to have a huge impact.

We know that our community health centers are already seeing double digit increases in the number of patients that need care, and as the number of patients uninsured continue to increase, their load is going to continue to increase. We need to make sure that we're not just funding new health centers, but we're making sure that the existing ones get the support they need.

Medicaid on average accounts for more than 30 percent of the revenue for these community health centers, so any policy cuts in Medicaid is going to have a direct impact on that. I'm already hearing from all of my community health centers that they are deeply concerned about the proposed cuts in Medicaid. We're already dealing with a mental health crisis under Medicaid. I think you know CMS just notified Washington State that they can no longer de-

pend on the \$82 million annually to provide community-based mental health care for low income patients.

Another policy I'm very concerned about is you talked about providing flexibility, but you're taking away, but that's a point for another day. The community health centers are the ones who are going to absorb the impact of that on them.

Then the elimination of the Healthy Community Access Program that works out in our communities. I know the administration in the past has said it's not effective. I really invite you out to Washington State or to talk to some of our HCAP grantees, because they really are making a difference. Elimination of that is going to be very hard for our community health centers to be able to succeed.

So my question to you is, thank you for providing additional funds, but budget policies that impact these community health centers in very negative ways are going to make it impossible. How do you reconcile increasing the money but passing the policies that make it very difficult for them to be successful?

Secretary LEAVITT. Senator, let me respond on Head Start. I'll go through all of the three areas you talked about. The President's proposal would actually allow for 9,729 additional students to be served by Head Start. The President and the Secretary of HHS are enthusiastic about Head Start and want to make sure it continues not just to serve those, but to expand. I've had a number of meetings now with Secretary Spelling to talk about how we could coordinate activities between the Department of Education and HHS. We think that that will leverage those funds even further.

With respect to health center funds and the whole subject of community health centers, that's another area where we share enthusiasm. We think that the President's proposal puts us again on a path to complete his objective of 1,200 new and expanding centers. This one will add 40 in the areas with the lowest incomes.

We have made a policy decision to emphasize actual service delivery, and there are places in this budget, with health center funds being one of them, where the actual—where by statute only 15 percent of those funds could go for service delivery and went for other matters ancillary to it. So there was a priority put on our part for the actual delivery of funds.

With respect to Medicaid, clearly community health centers are dependent upon continued participation by Medicaid. I think, as you pointed out and others have, that it's nearly 35 percent of their overall budget. We want them to succeed. A cut in the number of dollars in Medicaid would in fact be alarming. However, this budget will reflect more than 7 percent more dollars going into Medicaid than did before. This is not a matter of cutting. We want Medicaid to increase. We want it to increase .2 of 1 percent than what had been proposed before, but there are very few large numbers in the President's budget that will reflect a 7 percent-plus increase, and Medicaid is one of them.

#### HEAD START

Senator MURRAY. Well, I appreciate your response. I know I'm out of time. I just would ask you again to go cautiously with Head Start, because it is more than just an education program, and it is a success story, and I want to make sure we don't undo that.

I just am concerned that if we just focus on new community health centers we are going to leave the ones that are out there not doing a good job and then we'll be back here saying, well, they don't do a good job, let's not fund any of them, and I don't want to go there. I think it's really important to understand the health care impact, the crisis, the budget numbers that are hitting these, the number of uninsured that are increasing, and we need to be able to do our part here. I will continue to work on that. I know you care as well, so thank you very much.

Secretary LEAVITT. Thank you.

Senator DEWINE. Senator Durbin.

#### STATEMENT OF SENATOR RICHARD J. DURBIN

Senator DURBIN. Thank you very much, Mr. Chairman. George Carlin is a great observer of life and has a routine relative to riding on airplanes, most of which cannot be repeated at this hearing.

But there is one thing he observes: When starting to land in an airplane, the flight attendant says, let me be the first to welcome you to Washington DC. Carlin asked, if you're on the same plane I'm on, how can you be welcoming me anywhere? I would like to welcome you to this committee, but since this is the first time I've ever been on this committee, I can't. I'm just happy to be here with you today.

Secretary LEAVITT. Thank you.

#### MEDICAID AND MEDICARE

Senator DURBIN. I can't officially welcome you, but I've wanted to be on this subcommittee for a long time and I'm glad that it finally happened. It's very critical and important.

#### SOCIAL SECURITY

The President is on a 60-day tour around America to cities to talk about the crisis or challenge or problem, or whatever is the word du jour of Social Security. There are many of us who believe that Social Security does present a challenge that we should address and address now with sensible, common sense approaches that over the long term will help us meet our needs.

I'd like to show you a chart though that compares the challenge of Social Security to other challenges. I'll make sure the Secretary can see it there. You'll note on this chart that over the period of time of our debate about the costs of Federal programs, we anticipate by 2075 a 48 percent increase in the cost of Social Security as a percentage of our gross domestic product. Look at the numbers for Medicare and Medicaid, dramatically larger, 318 percent for Medicare, 342 percent for Medicaid.

So if the President is looking down the track and seeing 40 or 50 years from now this light of a train coming toward us and warning us about this, certainly we should be sensitive to the fact that looming directly behind us is a locomotive that says health care in America that is about to run us over.

You are addressing through this budget some of the cost of programs like Medicaid and Medicare. Neither this administration nor this Congress apparently has the political will to address the much

larger issue we face in this country. If there were another line in this chart, the cost of health insurance by the year 2075, it might even be larger in terms of increase. So how can we address these things so tentatively in such a piecemeal fashion and expect to really resolve the difficulty?

#### AFFORDABLE HEALTH INSURANCE

I just left a meeting with the President of one of the largest unions in America. He says we're about to lose manufacturing through his union because of the cost of health care. I hear that from small and large businesses alike. Yet we're not talking about it. If the President were making a 60-day, 60-city tour about what to do to make sure that every American had affordable health insurance that provided basic protection for their family, he would have turnouts, unimaginable turnouts of people interested in this issue.

#### MEDICAID

So I ask you this. What is—what do you think we should do in this next year? Is the answer to cut coverage on Medicaid? Every time someone in Washington says flexibility, I grab my wallet, because flexibility means less money, I know that, I've been around here long enough. I understand we need to change some rules, but I'm afraid flexibility is just a cover for a reduction in cost.

Shouldn't we be asking for some advantage for consumers and taxpayers in this process? We're still in a position where Medicare cannot bargain under the new prescription drug plan to bring pharmaceutical costs down. Medicaid in most States is really limited as to how it can bargain with drug companies to bring the cost of drugs down for recipients in those States. Yet we know over the border in Canada drugs are a fraction of the cost.

How can we be honest and sincere about dealing with health care if all we're going to do is cut benefits for poor people and not address cost issues such as the ones that I just mentioned?

Secretary LEAVITT. Senator, I've become fond of observing that there is a point in the life of every problem when it's big enough you can see it but small enough you can still solve it. Your chart reflects three of them. The President has clearly taken two of them on this year. That's—two out of three is a very significant undertaking.

But the matter that you've reflected on, health care costs, clearly is one that we will all have to deal with. Now I, recognizing the limit of time, may I just say—point out four things that I believe can and should be done in this budget year to get us started?

#### MEDICAID REFORM

One is in fact Medicaid reform. These are reforms that will not result in anyone losing health insurance, but in fact will allow us to preserve health insurance for many who have it and who are at risk of losing it, and I believe would have the capacity of expanding health care to others for reasons that I've already enumerated and won't repeat.

## HEALTH IT

The second is health IT. I believe health IT is the new frontier in health care productivity. Many things in this budget would point us toward being able to harness the powers of technology.

But it leads us to, I think, a third, and that is we're measuring the wrong thing. We measure quantity of care, not the quality of care. We are not measuring outcomes. And I believe until we begin to measure performance outcomes and compensate providers and others on the basis of those outcomes, we will continue to see an unsatisfying result.

## ACCESS TO HEALTH INSURANCE

The fourth would be expanding health care to—or access to health insurance. The President's proposal would allocate \$125 billion over the next 10 years and would result in 12 to 14 million people who currently do not have coverage to receive it. So Medicaid reforms, IT, pay for performance, and expanding access to health insurance through health savings accounts and other mechanisms I believe would be at least steps in the direction that you've pointed.

Senator DURBIN. I think they are steps in that direction. There may be some different—I don't know if association health plans is part of what you're suggesting here. They raise a lot of questions about standards and actual coverage and the like and the financial stability of the company's offering.

## HEALTH SAVINGS ACCOUNTS

Health savings accounts again have been a wildly popular theory here since Golden Rule Insurance Company became the favorite of then-Speaker Gingrich. We keep hearing about it every year. I'd like to see some demonstrated proof that it really does offer the kind of health insurance coverage that we want to see in the long term.

I don't know, Mr. Chairman, if my time is expired here.

Senator DEWINE. Why don't you just continue.

Senator DURBIN. Thank you.

Senator DEWINE. Because I'm going to have some questions too, so why don't you just go ahead.

Senator DURBIN. Well, thank you very much.

Senator DEWINE. As long as the Secretary has a couple more minutes.

## TITLE X

Senator DURBIN. I will just try to make it as direct as I can and as brief as I can. Let me talk to you about Title X. Title X, of course, is the family planning program, particularly for low-income people. If there's one thing that divides this Congress and this Nation, it is the question of abortion, and we have spent more time and anguish over this issue, what is the right thing to do. Most people would conclude that the right thing to do is to give to that prospective mother and father the option of planning their family so that they don't find themselves in a position where there are un-

intended or unplanned pregnancies forcing decisions which may lead to abortion.

I take a look at where we are today. Your fiscal budget for 2006 flat funds Title X family planning programs at \$286 million. This level of funding does not keep up with inflation and meets the needs of fewer than half of the low-income women who qualify. If we are truly trying to reduce the number of unintended pregnancies and abortions, how can we do it with a budget that does not meet the obvious need for family planning information, counseling, medications for the lowest income people in America?

Secretary LEAVITT. Senator, you're correct in that the budget between 2005 and 2006 is the same. That follows, however, a year where we did increase our proposal by \$10 million. I'd also point out the fact that the Federal share of Medicaid during that period of time who served that same group went up \$65 million, and the Indian Health Service went up \$19 million.

So while that one category may have been level, the broader view was up \$84 million on—

Senator DURBIN. On Medicaid as opposed to Title X.

Secretary LEAVITT. On Medicaid and Indian Health Services, and they serve basically the same population.

Senator DURBIN. I would not disagree, but certainly that money is being spent on many, many other things, not focused as Title X is on family planning.

Let me ask you in the same vein, most parents that I know, certainly my family, raising children preached abstinence, saying to these children, my children and many other children, wait, don't make a mistake, make the right decision and have enough respect for yourself to make that right decision. That has become such a major part of our effort now in trying to reduce teen pregnancy and unintended pregnancy.

#### ABSTINENCE

The proposed budget includes a \$38 million increase for abstinence only until marriage programs. The groups that have taken a look at this, like the National Academy of Sciences' Institute of Medicine, have criticized this investment in these abstinence-only programs. Some investigations by the House Committee on Government Reform have found that the abstinence-only programs contain errors and distortions in the messages that they are giving to people and young people. One federally funded curriculum, for example, was found to be teaching students that sweat and tears are risk factors for HIV transmission, which I don't believe any reputable medical doctor would agree with.

So I ask you, when it comes to these abstinence-only programs and the amount of money that we're putting into them, do you believe that this is our best investment in terms of good public health policy to reach the goal of educating young people so that they make the right decisions about their own bodies?

Secretary LEAVITT. Senator, we serve many populations in many different ways. This is a commitment on the part of the administration to teach one principle that we know is true, and that is abstinence is 100 percent effective. I also recognize that there are times when one program or another will have the validity of one fact or



another or approach on all sides of the ideologic spectrum, and we ought not to be defending things that aren't true in any of those.

We need to have a commitment to the truth, and the President's commitment to include abstinence-only programs is real, because he believes, as do I, that it is in fact what we ought to be teaching our children.

Senator DURBIN. I don't quarrel with that premise, and as I said, most parents start there. Some parents and teachers and counselors and ministers come to the conclusion that more has to be said beyond "say no." So I won't go any further than to say I hope that we will test each of these programs to make sure that the information given is accurate and then be honest about the outcomes.

#### DIETARY SUPPLEMENTS

My last question if I might ask relates to dietary supplements. I've had a passion over this industry and the laws regulating it. I got up this morning and I took my vitamins, for the record, so I am not opposed to taking vitamins. I think it's good, it's healthy. I don't think it's going to hurt me. Maybe it'll help.

But some of these dietary supplement companies are selling products that have never been tested. They are making claims about their products' efficacy which they cannot substantiate. They are marketing their dietary supplements to children. The ephedra scandal of just a year or so ago is an indication of that element of the dietary supplement industry that was clearly doing all the things that I just mentioned to the detriment of the health of America.

Senator Hatch and I have debated this back and forth. We don't see it all the time eye to eye, but we have come to a conclusion, and I hope that you will consider supporting it, and that is that the dietary supplement industry should at a minimum make adverse event reports to the Food and Drug Administration. If some company is making a dietary supplement that results in a bad health outcome, a seriously bad health outcome or death, that should be reported to the Food and Drug Administration. That is not the law today.

What is your opinion? Do you believe that those who are marketing dietary supplements should be required to report adverse events to the Food and Drug Administration as those making over-the-counter drugs and pharmaceuticals are required?

[The information follows:]

#### DIETARY SUPPLEMENTS

With enactment of the DSHEA, Congress made the decision to create a new regulatory regime for dietary supplements modeled more on the Agency's regulation of food safety and less on the drug regulatory model. With the exception for new dietary ingredients, FDA's regulation of dietary supplements is essentially post-market program similar to food regulation.

Under the Dietary Supplement Health and Education Act (DSHEA), FDA relies on voluntary adverse event reports as a major component of our post-market regulatory surveillance efforts. Voluntary reporting systems are estimated to capture only a small percentage of adverse events, but they provide valuable signals of potential problems. When such a signal identifies a possible safety hazard, the burden is on FDA has the ability to gather and evaluate any scientific literature or information regarding whether the substance produces a safety hazard FDA has used this information to open investigations that led to removal of ephedra from the market and is currently investigating the marketing of steroids as dietary supplements.

FDA's enforcement actions are enhanced by a close working relationship with DEA, the FTC and other State and Federal agencies.

Another important aspect of FDA's regulatory and surveillance programs are current good manufacturing practice (cGMP) requirements for dietary supplements authorized in the Act. These regulations will establish industry-wide standards to ensure that dietary supplements are not adulterated. This final rule is in the last stage of review and is expected to be published in the near future.

In addition, FDA has a post-market surveillance program to support enforcement of labeling requirements for dietary supplements. This compliance program, Dietary Supplements—Import and Domestic, contains guidance to FDA field offices regarding field exams and sample collections to determine compliance with the labeling requirements for dietary supplements. Significant violations of the labeling requirements for dietary supplements may lead to an advisory action, such as a Warning Letter, or to a court action for seizure or injunction. Imported products that do not comply with FDA labeling requirements are subject to detention and refusal when offered for entry into the United States.

FDA will continue in its efforts to take action against dietary supplement products that threaten the public health and will continue to provide guidance to the industry and outreach to consumers in this regard. We further believe that the promulgation of the GMP rule will provide another measure of safety for dietary supplements, and we look forward to working with the Committee to further examine these issues and ensure that appropriate steps are being taken.

Secretary LEAVITT. Senator, I have not had the benefit of being able to hear you and Senator Hatch debate these issues. It sounds like a colorful and rather interesting thing to hear. I'll look forward to hearing more—to find that the two of you have agreed on this. Sounds like something I ought to learn about.

Senator DURBIN. Let me share it with you. I won't put you on the spot any more on this, but I hope you'll take a look at it. It could be a reasonable way to bring some regulation to an industry which by and large is doing a wonderful job, but there are some players in this industry who are not.

Mr. Chairman, thank you for your forbearance and patience, and Mr. Secretary, thank you for being here.

#### OLMSTEAD ACT

Senator DEWINE. Mr. Secretary, just a few more questions. President Bush signed an executive order in response to the 1999 Supreme Court decision in regard to the Olmstead Act. This Court said that the disabled have a right to live in a group home or other supportive system rather than being pushed into an institution, and the Court directed the government to develop opportunities for the disabled to better live in their communities. The Court also said forcing them into institutions is discriminatory.

The executive order told the agencies to put together plans to make this happen. How are you proceeding in reaching this goal?

Secretary LEAVITT. Senator, it would be better if I could provide you with specifics. The actual plan and the execution of that plan inside either our agencies our broader would be unknown to me. But I would like to point out that the President's money follows the person it is designed specifically to—

Senator DEWINE. That was my next question anyway.

Secretary LEAVITT. Good. Well—

Senator DEWINE. We can—you can proceed.

Secretary LEAVITT. One of the—

Senator DEWINE. But you will give us, Mr. Secretary, you can follow up then in regard to this question about—

Secretary LEAVITT. Yes.

Senator DEWINE [continuing]. What the plan is and what the timing would be on that.

Secretary LEAVITT. We will be responsive on that query, and I'll also point out as one of the specific Medicaid, for example, proposals that we would like to see adopted this year would be a capacity, a flexibility, again stepping away from the rigid inflexibility that is currently there to serve those who are disabled and particularly those who are elderly.

Medicaid is a good example of a policy that just needs to be changed, needs to be modernized. Medicaid was established in the 1960s. The state of practice at that point was to institutionalize basically those who were either disabled or elderly and disabled, and consequently Medicaid, without some waiver or without a change in the law, simply doesn't allow us to pay for any circumstances outside an institution, and that just needs to change. It's making the point that you have and we hope very much that Congress will act with some dispatch to give States that capacity.

#### DISABLED

Senator DEWINE. Your President's proposal and your budget, the money following the person, I wonder if you could elaborate on that in regard to how that will affect the disabled, and specifically how that will work in the 50 States. Are we talking about 50 State programs, or how will that blend with national uniformity and how these programs will be administered?

Secretary LEAVITT. Well, specifically it would create—

Senator DEWINE. This is—my understanding of this—excuse me—this is a—these are pile-up programs.

Secretary LEAVITT. That's right. It would create a 5-year demonstration that finances services for individuals who are in transition from institutions to the community. The Federal Government would fund 100 percent of the community-based services for the first year and then funding would revert back to the States at the current Federal match, which means the Federal Government on average would pay about 65 percent.

The demonstration would test whether the increased use of home and community-based services would reduce spending on institutional care as the advocates and as this Secretary believes that it will.

Senator DEWINE. How will that work in regard to the disabled community? I mean, this is designed in my understanding for the disabled community but also for older Americans. Is that correct?

Secretary LEAVITT. Well, the rationale of the program is that the proposal would encourage States to move from institutionalizing long-term care patients who are served by Medicaid into home and community services, which in turn may reduce the spending on institutional care. The proposal is an attempt to rebalance the system, as I've indicated, where long-term care has been essentially institutionalized under the Olmstead decision by increasing the care-setting choices and assisting individuals with disabilities. They will be able to live in the home and community-based settings.

This is where they want to be served. Frankly, it's where their families want to serve them. It leverages the great American asset

of people loving their families and choosing to care for them and it helps in the right spot. Disability groups have been very supportive of this and we'll continue to work closely with them and with you on various proposals as we learn more.

Senator DEWINE. Mr. Secretary, I'd like to commend FDA's actions in quickly enacting Best Pharmaceuticals for Children Act, as well as a pediatric rule. How those two programs interact can sometimes though be very tricky, but they interact nevertheless, and that's what they were designed to do.

[The information follows:]

#### BEST PHARMACEUTICALS FOR CHILDREN ACT

The BPCA is a critical tool in NIH's effort to ensure that adequate information is available concerning the effects and efficacy of pharmaceuticals in children. The NICHD is working with the FNIH and the Secretary to implement the provisions of the law, and to facilitate the testing of drugs.

#### BACKGROUND

The Best Pharmaceuticals for Children Act (BPCA) established procedures to identify health risks and effectiveness of drugs in children. The Secretary delegated the functions of developing the priority listing of drugs to be tested to NIH and FDA, and the program for testing those drugs to NIH. Dr. Zerhouni delegated the NIH duties to NICHD. Over the last few years we have had several communications with Sen. DeWine's staff about implementation issues. Most recently, they have raised questions about the testing of a particular on patent drug, Baclofen, which is proposed for treatment of spasticity in children with cerebral palsy.

#### BPCA

Under the BPCA program, different procedures are followed for testing on- and off-patent drugs for pediatric use and labeling. Following the BPCA's enumerated procedure for on patent drugs, NICHD tests a drug only after the manufacturer and current patent holder decline a request from the FDA to conduct the testing and after private donor decline to provide support through the Foundation for the National Institutes of Health (FNIH). (NICHD and FNIH have a Memorandum of Understanding in place to conduct the testing.) If the FNIH is unable to raise sufficient private funds to support the requested testing, and so-certifies to the Secretary, the Secretary refers the drug to NICHD for inclusion on the BPCA program priority list of drugs for testing in children.

#### ON-PATENT DRUGS

Senator DEWINE. I'd like to bring an issue to your attention. My staff has already raised this with NIH. And that is the on-patent drugs that are currently awaiting study in the NIH Foundation. The pediatric rule provides for the rule to be invoked when a Secretary makes a certification regarding insufficient funds. Preliminary discussions have suggested this would be an appropriate action for HHS, FDA, and NIH to take.

I'd ask that you have your staff take a look at this issue, you take a look at it, and get in touch with the appropriate staff at NIH and FDA and begin the process of invoking the pediatric rule so clinical trials can begin. I would ask you do this and get back in touch with me in regard to this so we can get some resolution and move forward.

Secretary LEAVITT. I will do so, Senator. Thank you.

#### GLOBAL AIDS FIGHT

Senator DEWINE. I appreciate it. Let me turn if I could to the CDC's work in the global AIDS fight, and you and I have talked

about this before. Specifically in the countries, the non-focus countries, countries such as India and China, let me ask you, does the CDC's global AIDS program do you believe have the infrastructure necessary to expand its programs in these non-focus countries? If not, what's needed to expand their response?

Second, let me ask you, will you support providing increased program support and resources to the global AIDS program and other HHS programs that are part of the emergency plan?

Secretary LEAVITT. The President has made a commitment to expand appropriations to \$15 billion to undertake that challenge. Obviously that will need to include the deployment of proper infrastructure in those countries as well as others. We're working hard now to target our efforts to provide for the greatest possible need. We've laid out a series of principles and we're working to follow those principles.

Senator DEWINE. I look forward to having further discussion with you in regard to this. It is a very difficult question, as I think your answer would indicate. Taking the finite resources that we have, even though this administration has made a major commitment, which I commend the administration for, and the Congress has done the same, when you look at the need, it's still finite resources, and trying to make a determination of how aggressively we move into countries like India and China is a very, very tough call.

But, you know, if we don't—if the world does not stem the emerging AIDS problem in India or China or Russia, the ramifications are going to be absolutely unbelievable. When it moves, AIDS moves in India, for example, into the general population, the results are going to be absolutely devastating, and it's getting very close to that.

So it's, you know, these are just tough questions, they're tough calls. I just look forward to working with you and sharing ideas.

Secretary LEAVITT. Thank you. I look forward to the same interaction.

Senator DEWINE. I appreciate it. Well, Mr. Secretary, we thank you very much for your time and attention and look forward to working with you on many issues.

Secretary LEAVITT. Thank you.

#### SUBCOMMITTEE RECESS

Senator DEWINE. Thank you very much Mr. Secretary.

The subcommittee will stand in recess to reconvene at 9:30 a.m., Wednesday, April 6, in room SD-124. At that time we will hear testimony from the Honorable Elias Zerhouni, Director, National Institutes of Health.

[Whereupon, at 11:45 a.m., Wednesday, March 16, the subcommittee was recessed, to reconvene at 9:30 a.m., Wednesday, April 6.]



**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION, AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

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**WEDNESDAY, APRIL 6, 2005**

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, Cochran, and Harkin.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

STATEMENT OF ELIAS ZERHOUNI, M.D., DIRECTOR

ACCOMPANIED BY:

DR. JAMES F. BATTEY, JR., M.D., Ph.D., DIRECTOR, NATIONAL IN-  
STITUTE ON DEAFNESS AND OTHER COMMUNICATION DIS-  
ORDERS

DR. ANTHONY S. FAUCI, M.D., DIRECTOR, NATIONAL INSTITUTE OF  
ALLERGY AND INFECTIOUS DISEASES

DR. ANDREW VON ESCHENBACH, M.D., DIRECTOR, NATIONAL CAN-  
CER INSTITUTE

OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Good morning, ladies and gentlemen. The hour of 9:30 has—having arrived, we will proceed with the hearing of the Appropriations Subcommittee on Labor, Health and Human Services, Education. Today our hearing will focus on the work of the National Institutes of Health, which I have characterized as the crown jewel of the Federal Government, and perhaps the only jewel of the Federal Government.

We have the distinguished director, Elias Zerhouni, Dr. Elias Zerhouni, with us today, and other members. We have in the past had all of the directors of the Institutes, and it is not realistic to hear from that number of witnesses, and knowing of the important work, we have decided this year to limit the witnesses to those who have presidential appointments. We have also included Dr. Battey because of some recent issues as to the new policy on ethics, which will be a subject of some of our discussion here today.

Before proceeding further, just a word or two about my health. I have a lot of questions about my health. I had my fourth treat-

ment last Friday and I am on the job. During the 2-week recess when I could not travel abroad, I was in Washington most of the time, and aside from an involuntary new hair style, I'm accommodating to all of the rigors of the situation. I find that among all of the alternatives, the best alternative is to come to work and fight tigers, and we've got a lot of tigers around here, and fighting tigers is a great distraction and a great cure. So just that little bit of recommendation to the foremost scientists in the world, just how to handle one person's temporary medical problem.

The work of the National Institutes of Health is a vital matter for America and for the world. Senator Harkin, who will be along in a few moments, and I, as is well known, have taken the lead on the increase in funding where we have moved from some \$12 billion to \$28 billion. This year the funding was almost flat, really not accommodating even inflation. Senator Harkin and I offered an amendment to add \$1.5 billion to the budget resolution, which passed.

It's been a long struggle. The first time we tried to add money to the budget resolution we lost 63 to 37, and we went back with a sharp pencil and established the priorities. That's become a virtual impossibility now with the very heavy demands on our subcommittee on education and health and community development block grants and many other items, and worker safety. It will be a battle to keep that extra \$1.5 billion in terms of real dollars that we will have.

We will want to discuss the issues of the new standards of ethics. When the issue came up before the House of Representatives, there was I think a, diplomatically stated, a pretty stern tone taken. When the matter came before this subcommittee, we reviewed the matter with Dr. Zerhouni and said we'd look forward to his response.

But we also gave the people who were being charged an opportunity to come in and speak for themselves and to defend themselves on an extemporaneous basis. They were in the audience. They were welcome to come up and to do—and to talk. We had that hearing back on January 22, 2004.

It's always a difficult matter to prescribe a cure, medically or politically or ethically. It may well be that there are some revisions which are necessary, and we're going to make some suggestions and engage in some dialogue. But the ultimate decisions have to rest with the professionals who are in the field.

One word about stem cells, which we will take up in the course of the hearing. There is great concern about the Federal policy on stem cells contrasted with what is happening in the States with the \$3 billion budget in California and the lure of top scientists to California. Now Massachusetts is coming in with a program. We have discussed in this subcommittee the concerns about a brain drain going to Europe. This is something that we have to deal with.

There was very strong sentiment in the Congress about broadening the use of stem cells, moving away not necessarily from nuclear transplantation. We're not talking about creating another Dolly or about those sort of tactics, but just to use the stem cells which otherwise will be thrown away. There are hundreds of thou-



sands which were created for in vitro fertilization and they're not being used, and they could be used to cure diseases.

We understand the situation with the administration, Dr. Zerhouni, and the White House point of view, and I have suggested to you before that you might look for some greater latitude for advocacy within the administration. You're very respectful and you're very diplomatic and your voice might be heard and be influential.

I've had an opportunity to talk to the President about the matter. He was in Pennsylvania 44 times during the campaign, and I was with him on most of the occasions. We had a lot of time to talk on the plane and in the car. His views are pretty firm, but so are mine, and so are, I think, a majority of the Congress, as you see with what's happening in the House. Senator Harkin, Senator Feinstein, Senator Hatch, Senator Kennedy, and I have re-introduced legislation. So that's a big matter for the research future of America and the world.

That's longer than I usually talk, but since there are no other members present, I felt a little more latitude. Dr. Zerhouni, we welcome you here. We thank you for taking on this tough job and we look forward to your testimony.

#### SUMMARY STATEMENT OF DR. ELIAS A. ZERHOUNI

Dr. ZERHOUNI. Thank you, Mr. Chairman, and first and foremost, let me tell you about our admiration for your continuing service while you're fighting cancer, and we're looking forward to seeing you support NIH, support medical research as you have in the past for many years to come.

I would like to also—

Senator SPECTER. Is there any shortcut to—Dr. Zerhouni—to returning Arlen Specter the kind of head of hair that Elias Zerhouni has?

Dr. ZERHOUNI. I would be very happy to share.

Senator SPECTER. I hope the camera will focus on Dr. Zerhouni's hair, so we don't just get this verbally.

Dr. ZERHOUNI. I will do everything to share that with you, sir.

Senator SPECTER. I don't want share, I want my own, Dr. Zerhouni.

Dr. ZERHOUNI. I have submitted for the record written testimony.

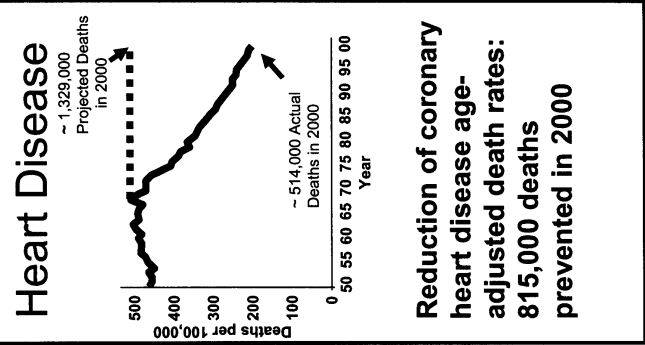
Senator SPECTER. Your full statement will be made a part of the record, Dr. Zerhouni, and in accordance with our standard practice, to the extent you can summarize, that would be helpful to leave the maximum amount of time for questions and answers. We have a vote scheduled at 10:00 and we have the new Prime Minister of the Ukraine speaking. But this is a very important hearing and I will return after the vote so we do full justice to the issues which we have here today.

#### THE PAST, THE PRESENT, AND THE FUTURE FOR NIH

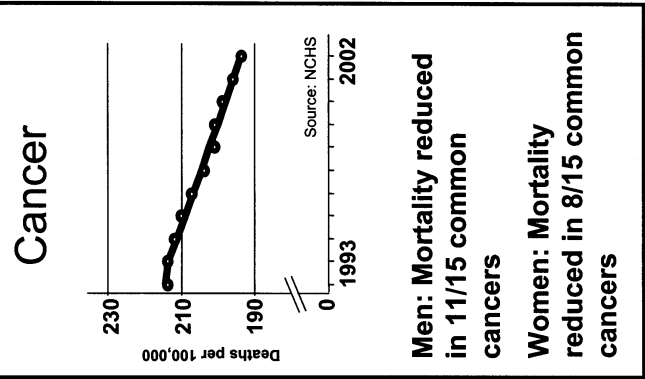
Dr. ZERHOUNI. Thank you. I will do so. First and foremost, let me summarize for us with a few slides where NIH is and where the budget is heading. Clearly, NIH has, as you said, been the crown jewel of medical research and of the Federal Government in promoting and advancing, through research, better health.



# Continuous Progress in Health Care



**Reduction of coronary heart disease age-adjusted death rates: 815,000 deaths prevented in 2000**

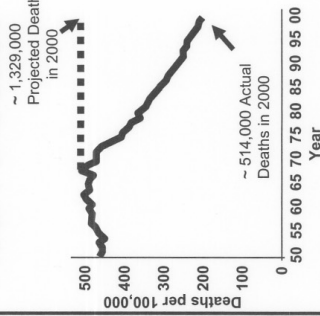


**Men: Mortality reduced in 11/15 common cancers**  
**Women: Mortality reduced in 8/15 common cancers**

# Continuous Progress in Health Care

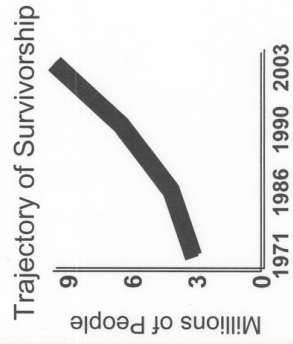


## Heart Disease



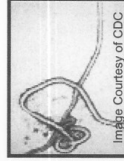
**Reduction of coronary heart disease age-adjusted death rates: 815,000 deaths prevented in 2000**

## Cancer



	Survival Rate (%) 1974-76	1992-99
All Cancers	50	63
Breast	75	87
Colon	50	62
Hodgkin's Disease	71	84
Prostate	67	98

## Infectious Agents



**Ebola:** First vaccine in trial in 2003

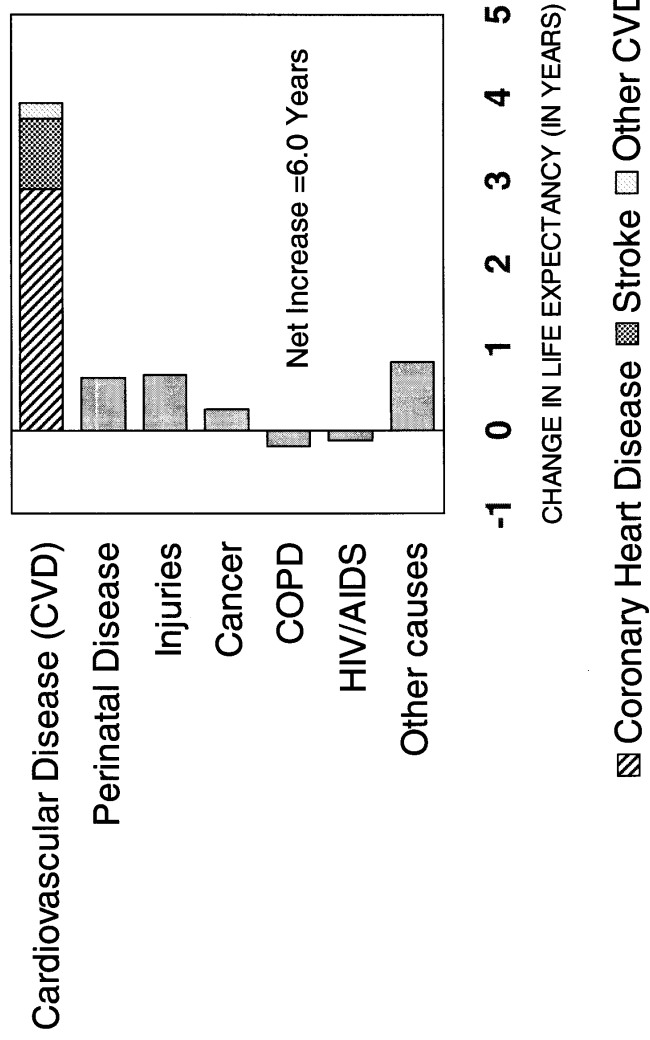


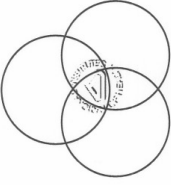

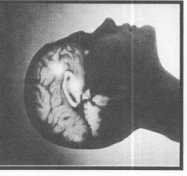
**Anthrax:** Crystallized Anthrax, new drug targets



**SARS:** Identified in < 1 month. First vaccine in trial in 2004

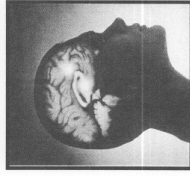
# Contributions to Change in Life Expectancy U.S., 1970 to 2000



Strengthening the NIH Vision		
<p><b>FY 2004</b></p>	 <p><b>NIH Roadmap for Medical Research</b></p> <ul style="list-style-type: none"> <li>▪ Involves entire NIH</li> <li>▪ Accelerates basic research discoveries</li> <li>▪ Speeds translation of those discoveries into clinical practice</li> <li>▪ Explicitly addresses roadblocks slowing pace of medical progress</li> </ul>	
<p><b>FY 2005</b></p>	 <p><b>NIH Strategic Plan for Obesity Research</b></p> <ul style="list-style-type: none"> <li>▪ Involves 19 Institutes and Centers</li> <li>▪ Research focuses on preventing and treating obesity:               <ul style="list-style-type: none"> <li>▪ lifestyle modification</li> <li>▪ pharmacologic</li> <li>▪ surgical</li> <li>▪ other medical approaches</li> </ul> </li> </ul> <p><small>Image © Time magazine, June 2004</small></p>	
<p><b>FY 2006</b></p>	 <p><b>NIH Neuroscience Blueprint</b></p> <ul style="list-style-type: none"> <li>▪ Involves 15 Institutes and Centers</li> <li>▪ Develops Tools</li> <li>▪ Creates resources</li> <li>▪ Public and private partnerships</li> <li>▪ Speeds treatment discovery</li> </ul>	



**FY 2006**



**NIH Neuroscience Blueprint**

- Involves 15 Institutes and Centers
- Develops Tools
- Creates resources
- Public and private partnerships
- Speeds treatment discovery

**FY 2005**

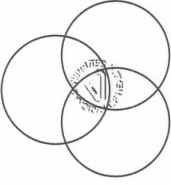


**NIH Strategic Plan for Obesity Research**

- Involves 19 Institutes and Centers
- Research focuses on preventing and treating obesity:
  - lifestyle modification
  - pharmacologic
  - surgical
  - other medical approaches

Image © Time magazine, June 2004

**FY 2004**



**NIH Roadmap for Medical Research**

- Involves entire NIH
- Accelerates basic research discoveries
- Speeds translation of those discoveries into clinical practice
- Explicitly addresses roadblocks slowing pace of medical progress

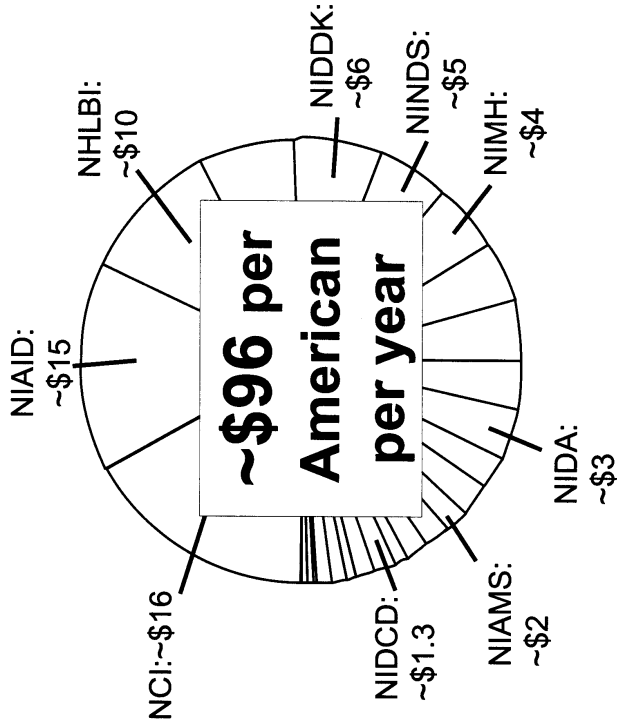
# The Scope of the Challenge



NIH invests  
~\$96/American/year  
into research to stem  
the rising burden of :

Hundreds of Common  
Diseases

>6000 Rare Diseases



## **NIH Budget: Five High Priorities**



### **Supporting Both New and Established Scientists**

- **New and Competing Research Project Grants + 247 Grants**

### **Accelerating Research for Treatments and Prevention Strategies**

- **NIH Roadmap for Medical Research + \$98 M**

### **Developing Countermeasures for Biological and Chemical Threats**

- **Biodefense Research + \$56 M**

### **Addressing Rising Burden of Nervous System Diseases**

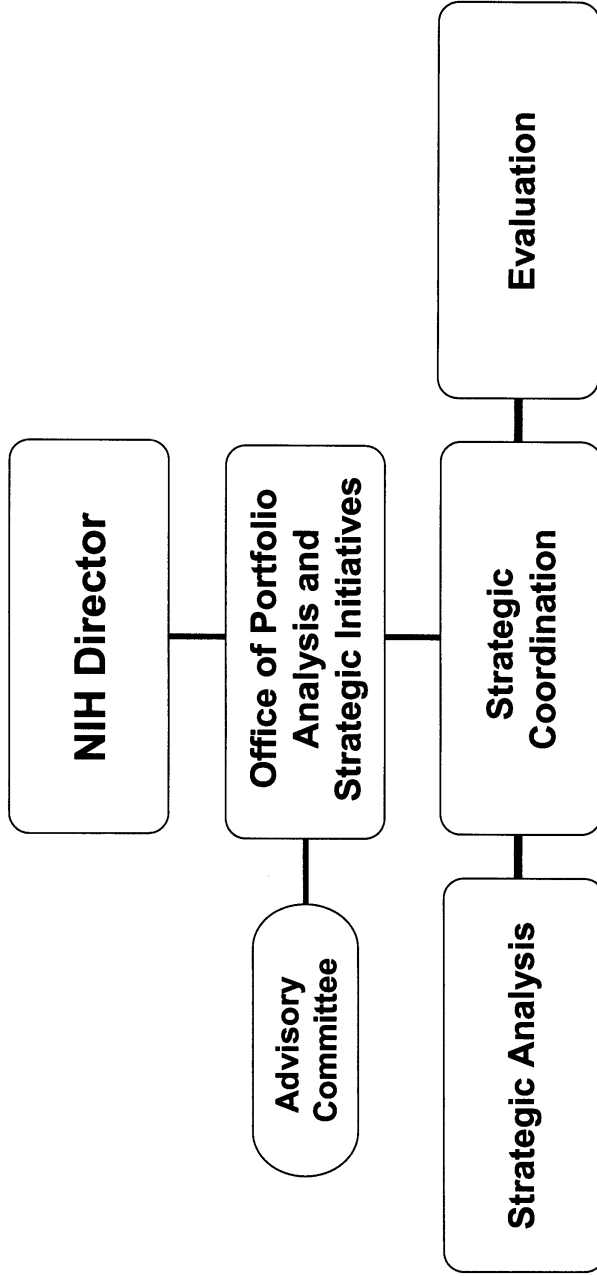
- **NIH Neuroscience Blueprint + \$26 M**

### **Seizing Scientific Opportunity**


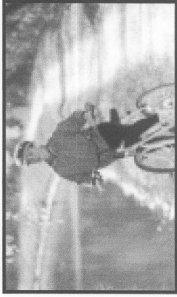

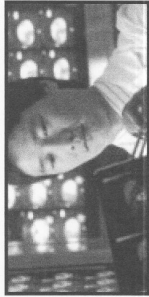

- **HIV-AIDS Vaccine Development + \$100 M**



# 21<sup>st</sup> Century Tools for Managing 21<sup>st</sup> Century Science


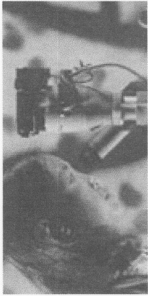








# NIH

Ideas  
People  
Resources  
Leadership



I'll show you some results that I think all of us know. In heart disease, we've had a 60 percent reduction in mortality over the past 30 years, primarily due to discoveries in terms of metabolism, of cholesterol, in terms of inflammation, in terms of the management of hypertension. You can see over the slides there that we've seen for the first time a marked decrease in both mortality and morbidity, with 815,000 lives saved this year—in 2000.

For the first time, over the past 10 years we're seeing a very real decrease in cancer mortality. The National Cancer Institute should really be commended for these results. We've seen, for example, mortality reduced in 11 of the 15 most common cancers in men and in 8 of the 15 most common cancers in women. We're continuing to see increased survivorship for cancer with a markedly increased number of Americans living with cancer today, from 3 to 9 million and rising.

I think you can see the survival rates between 1974, 1976, 1992, and 1999, and you can see improvements in all cancers. But you can see also in very specific cancers, survival rates right now in breast cancer are 87 percent, colon cancer 62 percent, Hodgkin's disease 84 percent, and prostate cancer 98 percent.

We're continuing to do research on infectious agents and the new threats of biodefense agents. And you can see that in 2003 for the first time we've developed an effective vaccine against ebola virus. Anthrax, we've crystallized the anthrax toxin and have identified new drug targets.

In SARS, I'd like to remind you that because of the doubling of the budget that you have spearheaded and the research and the new tools that were made available to human genome research, we were able to identify the SARS virus in less than a month. Today there is the first vaccine in trial already in the works, and two more have been developed as well.

So I think that the investment that you have really helped us with has paid off and is paying off. We're continuing to strengthen the NIH vision by doing systematic coordination across all the Institutes. In 2004 we presented the NIH Roadmap for Medical Research that involves all the Institutes and really engages in areas where no single Institute can do the job. In 2005, we announced the trans-NIH plan for obesity research, and in 2006, this year, the NIH neuroscience blueprint.

The scope of the challenge is enormous, as you well know. We have hundreds of common diseases and 6,000 rare diseases to take care of. Clearly, the budget that we have is large, \$28 billion. But from our standpoint of scientists and physicians, we look at it on a per-American basis. When you look at that, what you realize is that we have to manage \$96 per American per year. The NCI manages \$16 per American per year to combat all cancer, NIAID \$15, NHLBI \$10. It is in this context that we have to invest our dollars to make the most impact on our health care costs, which are fast rising and come to \$5,500 per American per year.

Clearly, the budget this year is going to have to lead to difficult choices, and we've established priorities, such as the support of new and established scientists with new grants. We've increased the number of grants available for competition, obviously at the expense of inflation factors and other choices we had to make. We are

accelerating research for treatments and prevention strategies through the NIH Roadmap for Medical Research. We're continuing to develop countermeasures for biological and chemical threats. This year we're announcing the neuroscience blueprint. We think that even though we have difficult budgets, it's important to do the right thing even if it's not the right budgetary time.

Again, this year we have many new candidate vaccines—

Senator SPECTER. What do you mean, Dr. Zerhouni, by doing the right thing even though if it's not the right budgetary time?

#### MAKING THE RIGHT CHOICES

Dr. ZERHOUNI. What I mean is despite the fact that there is a flat budget there are scientific opportunities in neurosciences, behavioral sciences. And we believe, with the 15 Institute directors that are primarily responsible for this area of science, that it was important to have a coordinated plan to advance our knowledge of the brain and the nervous system and the impact of behavioral—and behavioral factors on health.

This year we have several new vaccines available for HIV/AIDS that will need to be tested, and that is very costly. We have moved \$100 million within our tight budget to the priorities that we believe in 2006 will allow us to test for the first time very promising vaccines for HIV/AIDS.

Senator SPECTER. Where do you take that money from?

Dr. ZERHOUNI. Basically we've moved it from all categories of the total AIDS budget over the past 2 years, as we predicted with Dr. Fauci, that in 2006 we will need to engage in larger-scale clinical trials of HIV vaccines.

Last, I think that it is clear that as the organization known as NIH has grown more complex, it is also important to coordinate and understand better the portfolio of investments we're making, especially when you consider that we are managing \$96 per American per year. You want to make sure that all of that investment is maximally utilized. We are announcing the creation of a new Office of Portfolio Analysis and Strategic Initiatives in 2006 and requesting budgetary support for that office to do both strategic analysis of what is it we've done—

#### PROPOSAL TO CREATE THE OFFICE OF PORTFOLIO ANALYSIS AND STRATEGIC INITIATIVES

Senator SPECTER. What do you mean or need by budgetary support?

Dr. ZERHOUNI. We've requested a budget line for the Office of the Director to create this office and support it.

Senator SPECTER. How much is that line?

Dr. ZERHOUNI. We've started with a \$2 million request.

Senator SPECTER. \$2 million?

#### PREPARED STATEMENTS

Dr. ZERHOUNI. Yes. This office is going to allow us to develop better coding, better understanding of our databases, and coordinate them across Institutes so that we can have a standard way of looking at the entire activities of the Agency. We will work through the

Institutes and centers to coordinate, as we've shown in the past with the trans-NIH obesity plan, that we could in fact find areas of synergy and improve on them, and obviously evaluate whether or not we are. As you often ask us: "What have we accomplished?" I think we need to evaluate it systematically to show you and the American people supporting us the results of this research.

[The statements follows:]

#### PREPARED STATEMENT OF DR. ELIAS ZERHOUNI

Mr. Chairman, Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the Office of the Director (OD). The fiscal year 2006 budget includes, \$385,195,000, an increase of \$27,149,000 over the fiscal year 2005 enacted level of \$358,046,000 comparable for transfers proposed in the President's request. The OD provides leadership, coordination, and guidance in the formulation of policy and procedures related to biomedical research and research training programs. The OD also is responsible for a number of special programs and for management of centralized support services to the operations of the entire NIH.

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 budget and 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 and Public Liaison; Legislative Policy and Analysis; Equal Opportunity; Budget; and Management. This request contains funds to support the functions of these offices.

In addition, the OD also maintains several trans-NIH offices and programs to foster and encourage research on specific, important health needs. I will now discuss the budget request for the OD in greater detail.

#### NIH ROADMAP FOR MEDICAL RESEARCH

The NIH Roadmap for Medical Research supports trans-agency research and training programs aimed at accelerating the pace of discovery and improving the translation of research findings into health interventions. The development of new tools and technologies will help scientists understand intricate cellular processes and will make large volumes of biologic data publicly available for analysis and use in other model systems. Nanomedicine concept development awards are defining the scope of future centers to explore molecular inventions and interventions for curing disease or repairing tissues. Innovative team approaches will facilitate the creation of new biomedical and behavioral interdisciplinary fields and contribute to our understanding of complex diseases and conditions. Studies examining outcomes such as pain, fatigue and obesity will be enhanced by NIH Roadmap projects supporting the integration of behavioral and social sciences with biomedical and physical sciences. The clinical research initiatives are exploring ways to promote the integration and extension of clinical research networks, support translational research, and facilitate the coordination and harmonization of clinical research policies across federal agencies. Critical to these new efforts will be an infusion of trained scientists and clinical researchers at all stages of their careers, able to apply interdisciplinary and multidisciplinary approaches to complex biomedical problems. And for the first time, physicians, nurses and dentists are being trained together to become leaders in this clinical research community. These and other projects will enhance the capacity of scientists to harness the knowledge base for specific applications in all areas of investigation. The fiscal year 2006 budget request for NIH Roadmap for Medical Research is \$83,000,000, an increase of \$23,280,000 over the fiscal year 2005 level.

#### THE OFFICE OF AIDS RESEARCH

The Office of AIDS Research (OAR) plays a unique role at NIH, establishing a roadmap for the AIDS research program. OAR coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program. Our response

to the AIDS epidemic requires a unique and complex multi-institute, multi-disciplinary, global research program. Perhaps no other disease so thoroughly transcends every area of clinical medicine and basic scientific investigation, crossing the boundaries of the NIH Institutes and Centers. This diverse research portfolio demands an unprecedented level of scientific coordination and management of research funds to identify the highest priority areas of scientific opportunity, enhance collaboration, minimize duplication, and ensure that precious research dollars are invested effectively and efficiently, allowing NIH to pursue a united research front against the global AIDS epidemic. OAR oversees the development of the annual comprehensive NIH AIDS-related research plan and budget, based on scientific consensus about the most compelling scientific priorities and opportunities that will lead to better therapies and prevention strategies for HIV disease. The Plan serves as the framework for developing the annual AIDS research budget for each Institute and Center; for determining the use of AIDS-designated dollars; and for tracking and monitoring those expenditures. OAR also identifies and facilitates multi-institute participation in priority areas of research and facilitates NIH involvement in international AIDS research activities. The fiscal year 2006 budget request for OAR is \$60,899,000, which is the same as the fiscal year 2005 level.

#### THE OFFICE OF RESEARCH ON WOMEN'S HEALTH

The Office of Research on Women's Health (ORWH), the focal point for women's health research for the Office of the Director, strengthens, enhances and supports research related to diseases, disorders, and conditions that affect women, and sex/gender studies on differences/similarities between men and women; ensures that women are appropriately represented in biomedical and biobehavioral research studies supported by the NIH to facilitate analyses by sex/gender; and develops opportunities for the advancement of women in biomedical careers and investigators in women's health research. These ORWH efforts are in full partnership with the NIH Institutes and Centers. New research has been expanded in the ORWH-funded Specialized Centers of Research through interdisciplinary research in women's health and sex and gender factors and through the unique ORWH interdisciplinary career development program that fosters the mentored development of junior faculty and assists them in bridging advanced training towards a goal of research independence. The fiscal year 2006 budget request is \$41,363,000, an increase of \$148,000 over the fiscal year 2005 level.

#### THE OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

The NIH has a long history of funding health-related behavioral and social sciences research, and the results of this work have contributed significantly to our understanding, treatment, and prevention of disease. The Office of Behavioral and Social Sciences Research (OBSSR) furthers NIH's ability to capitalize on the scientific opportunities that exist in behavioral and social sciences research by providing leadership in identifying and implementing research programs that are likely to improve our understanding of the processes underlying health and disease and provide directions for intervention. OBSSR works to integrate a behavioral and social science approach across the programs of the NIH.

In response to a 2004 Institute of Medicine study entitled, "Improving Medical Education: Enhancing the Behavioral and Social Science Content of Medical School Curricula", OBSSR developed a program to promote the design and implementation of medical school curricula with coverage of behavioral and social sciences. This program will provide a mechanism whereby medical school students will receive training about issues such as the influence of psychological, biological, and social factors on health and disease; the role of physicians' beliefs, behaviors, and values in patient care; managing difficult physician-patient interactions; and the impact of policy on health behaviors and patient care. In addition to the benefits realized by individual physicians in training, funded medical schools may develop the infrastructures to permanently integrate behavioral and social sciences into their curricula. To continue such groundbreaking work in the behavioral and social sciences, the fiscal year 2006 budget request for OBSSR is \$26,185,000, an increase of \$94,000 over the fiscal year 2005 level.

#### THE OFFICE OF DISEASE PREVENTION

The primary mission of the Office of Disease Prevention (ODP) is to stimulate disease prevention research across the NIH and to coordinate and collaborate on related activities with other federal agencies as well as the private sector. There are several other offices within the ODP organizational structure.

The Office of Medical Applications of Research (OMAR) has as its mission to work with NIH Institutes, Centers, and Offices to assess, translate and disseminate the results of biomedical research that can be used in the delivery of important health interventions to the public. The ODP has two additional specific programs/offices that place emphasis on particular aspects of the prevention and treatment of disease the Office of Dietary Supplements (ODS) and the Office of Rare Diseases (ORD).

In fiscal year 2006, the ODS within ODP requests a budget of \$27,078,000, an increase of \$97,000 over the fiscal year 2005 level. ODS promotes the scientific study of the use of dietary supplements by supporting investigator-initiated research, and stimulating research through the conduct of conferences and presentations at national and international meetings. Other current ODS efforts include:

- Sponsorship of systematic review of the relationship between omega-3 fatty acids and a number of clinical indications, particularly coronary heart disease.
- Collaborations for the development, validation, and dissemination of analytical methods and reference materials for dietary supplements.
- Support and development of databases of dietary supplement information including:
  - National Health and Nutrition Examination Survey (NHANES);
  - Collaboration with USDA to develop an analytically-based database of dietary supplement ingredients;
  - Plan to contract for development of a dietary supplement label database;
  - International Bibliographic Information on Dietary Supplements (IBIDS);
  - CARDS, a database of federally funded research on dietary supplements.
- Collaboration with other federal agencies to develop a coordinated approach to assessment of the health effects of bioactive factors in food and dietary supplements. Publishes Fact Sheets on dietary supplements for consumers.

Another component of ODP, the ORD, was formally established through the Rare Diseases Act of 2002, Public Law 107–280. The budget request for fiscal year 2006 for ORD is \$15,649,000, an increase of \$56,000 over the fiscal year 2005 level. The following are four highlights of ORD activities: (1) An Extramural Rare Diseases Clinical Research Network that involves 10 consortia, more than 70 sites, and 30 patient support organizations for almost 50 rare diseases. Thirty-three clinical protocols are under development. (2) The Rare Diseases Intramural Research Program is a collaborative effort between the ORD and the National Human Genome Research Institute at the NIH Clinical Center. Recently, the program initiated annual contracts for 25 molecular diagnostic tests for specific rare diseases that will be made available by the contractor to the public at reasonable cost. (3) ORD also co-funds annually approximately 100 scientific conferences for scientific opportunities or where research is lagging or lacking. (4) The newly established Trans-NIH Rare Diseases Research Working Group is developing an assessment of rare diseases bi-specimen collection, storage, and delivery issues, of genetic tests in extramural research programs, and plans for a conference on amyloidosis.

#### THE OFFICE OF SCIENCE EDUCATION

The Office of Science Education (OSE) develops science education programs to enhance efforts to attract young people to biomedical and behavioral science careers and to improve science literacy in both adults and children. The OSE creates programs to improve science education in schools (the *NIH Curriculum Supplement Series*); creates programs that stimulate interest in health and medical science careers (*LifeWorks Web site*); creates programs to advance public understanding of medical science, research, and careers; and advises NIH leadership about science education issues. Programs target diverse populations including under-served communities, women, and minorities, with a special emphasis on the teachers of students from Kindergarten through grade 12. The OSE Web site is a central source of information about available education resources and programs. <http://science.education.nih.gov>. The fiscal year 2006 budget request for OSE is \$3,878,000, the same as the fiscal year 2005 level.

#### LOAN REPAYMENT AND SCHOLARSHIP PROGRAM

The NIH, through the Office of Loan Repayment and Scholarship (OLRS), administers the Loan Repayment and Undergraduate Scholarship Programs. The NIH Loan Repayment Programs (LRPs) seek to recruit and retain highly qualified physicians, dentists, and other health professionals with doctoral-level degrees to biomedical and behavioral research careers by countering the growing economic disincentives to embark on such careers, using as an incentive the repayment of educational loans. There are loan repayment programs designed to attract individuals to clinical research, pediatric research, health disparities research, and contracep-

tion and infertility research, and to attract individuals from disadvantaged backgrounds into clinical research. The AIDS, intramural Clinical, and General Research Loan Repayment Programs are designed to attract investigators and physicians to the NIH's intramural research and research training programs. The NIH Undergraduate Scholarship Program (UGSP) is a scholarship program designed to support and enhance the training of undergraduate students from disadvantaged backgrounds in biomedical research careers and employment at the NIH.

The fiscal year 2006 budget request for OLRs is \$7,213,000, the same as the fiscal year 2005 level.

#### OFFICE OF PORTFOLIO ANALYSIS AND STRATEGIC INITIATIVES

In fiscal year 2006, the NIH plans to create a new office within the Office of the Director—the Office of Portfolio Analysis and Strategic Initiatives (OPASI)—which will provide tools to facilitate planning for trans-NIH initiatives, including an improved process for collecting IC data on expenditures on various diseases, conditions, and research fields, and improvements in data about burden of disease. The office will also develop, with input from the ICs, common processes and formats, where necessary, for the conduct of NIH-wide planning and evaluation. For trans-NIH planning efforts, the office will seek broad public input—from the public, health care providers, policymakers, and scientists—in addition to soliciting advice from within NIH. The office will also coordinate and make more effective use of the NIH-wide evaluation process. The budget request for OPASI is \$2,000,000.

Thank you, Mr. Chairman for giving me the opportunity to present this statement; I will be pleased to answer questions that the Committee may have.

#### NATIONAL INSTITUTES OF HEALTH BUILDINGS AND FACILITIES PROGRAM

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 for fiscal year 2006, a sum of \$81,900,000.

#### ROLE IN THE RESEARCH MISSION

State-of-the-science research and support facilities are a vital part of the research enterprise. The National Institutes of Health's (NIH) Buildings and Facilities (B&F) program designs, constructs, repairs and improves the agency's portfolio of laboratory, clinical, animal, administrative and support facilities at its six installations in four states. These facilities house researchers from the NIH Institutes' and Centers (ICs) intramural basic, translational, and clinical research programs; science administrators who oversee NIH's grants; the NIH leadership, and various programs that support agency operations. The fiscal year 2006 B&F budget request focuses on the need for responsible utilization and stewardship of NIH's past and recent investments in the "bricks and mortar" of the research enterprise. In order to stay abreast of the changing needs of the NIH programs, it is imperative that we provide reliable, safe and secure research support facilities that are appropriately equipped, operated and maintained.

The B&F budget request is the product of a comprehensive, corporate capital facilities planning process. This process begins with extensive consultation across the research community and the NIH's professional facilities staff. It works through the Facilities Working Group, an advisory committee to the NIH Steering Committee, and the HHS Capital Investment Review Board. Through this process, the program demand for more effective and efficient facilities designed to support current and emerging investigative techniques, technologies, and tools is integrated with, and balanced against, the need to repair, renovate, and improve the existing building stock to keep it in service and to optimize its utility.

The fiscal year 2006 request provides the necessary funding support for the ongoing safety, renovation and repair, and related projects that are vital to proper stewardship of the entire portfolio.

The fiscal year 2006 B&F budget request is organized among three broad Program Activities: Essential Safety and Regulatory Compliance, Repairs and Improvements and Construction. The fiscal year 2006 request provides funds for specific projects in each of the program areas. The projects and programs enumerated are the end result of the aforementioned NIH facilities planning process and are the NIH's capital facility priorities for fiscal year 2006.

#### FISCAL YEAR 2006 BUDGET SUMMARY

The fiscal year 2006 budget request for Buildings and Facilities is \$81.9 million. The B&F request contains a total of \$14 million for Essential Safety and Regulatory

Compliance programs composed of \$2 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; \$1.5 million to systematically remove existing barriers to persons with disabilities from the interior of NIH buildings; \$0.5 million to address indoor air quality concerns and requirements at NIH facilities; and \$5 million for the continued support of the rehabilitation of animal research facilities. In addition, the fiscal year 2006 request includes \$66.9 million in Repairs and Improvements for the continuing program of repairs, improvements, and maintenance that is the vital means of maintaining the complex research facilities infrastructure of the NIH; and \$1 million in Construction for pre-project planning including concept development studies and analyses of NIH-wide facility projects proposed in the facilities plan.

My colleagues and I will be happy to respond to any questions you may have.

#### OFFICE OF AIDS RESEARCH

#### FISCAL YEAR 2006 NIH AIDS RESEARCH BY-PASS BUDGET ESTIMATE

#### INTRODUCTION

In its report on the fiscal year 2005 budget for the Department of Health and Human Services, the Senate Committee on Appropriations stated:

“The NIH Office of AIDS Research [OAR] coordinates the scientific, budgetary, legislative, and policy elements of the NIH AIDS research program. Congress provided new authorities to the OAR to fulfill these responsibilities in the NIH Revitalization Action Amendments of 1993. The law mandates the OAR to develop an annual comprehensive plan and budget for all NIH AIDS research and to prepare a Presidential bypass budget.” (Senate Report 108–345, page 175)

Public Law 103–43, the National Institutes of Health Revitalization Act of 1993, requires that “the Director of the Office of AIDS Research establish a comprehensive plan for the conduct and support of all AIDS activities of the agencies of the National Institutes of Health.” It also requires that the Director “shall prepare and submit directly to the President, for review and transmittal to the Congress, a budget estimate for carrying out the Plan for the fiscal year . . .” That budget “shall estimate the amounts necessary for the agencies of the National Institutes of Health to carry out all AIDS activities determined by the Director of the Office to be appropriate, without regard to the probability that such amounts will be appropriated.”

In accordance with the law, the Office of AIDS Research (OAR) has developed the fiscal year 2006 Professional Judgment (By-Pass) Budget Estimate for NIH AIDS Research to carry out the scientific priorities of the fiscal year 2006 NIH Plan for HIV-Related Research. This By-Pass budget estimate is based on the following criteria: the commitment to support only the highest quality research; and the urgent need to pursue priority scientific opportunities.

#### OMB PART

The NIH AIDS program received an overall score of 83 in the 2005 PART. This score included a 100 percent in the Program Purpose and Design section. The human and economic toll of the AIDS pandemic requires a unique response that is complex, comprehensive, multi-disciplinary, and global. The NIH role in this response is unprecedented, comprising a comprehensive program of basic, clinical, and behavioral research on HIV disease to better understand the basic biology of HIV and develop effective therapies and prevention strategies. PART demonstrated that NIH provides effective scientific coordination and management of this diverse AIDS research portfolio through a comprehensive planning and budget development process, which was utilized to develop the fiscal year 2006 By-Pass Budget Request.

#### OAR COMPREHENSIVE PLAN

The OAR has established a unique and effective model to develop a consensus on the scientific priorities of the annual comprehensive AIDS research plan, called the NIH Plan for HIV-Related Research, that is based on the most compelling scientific priorities that will lead to better therapies and prevention strategies for HIV infection and AIDS. The planning process involves the NIH Institute and Center Directors; NIH intramural and extramural scientists and program managers; scientists and researchers from other government agencies, academia, foundations, and industry; HIV-infected individuals; and other community representatives. The plan also is reviewed by the OAR Advisory Council.



The NIH fiscal year 2006 Plan for HIV-Related Research is divided into five Scientific Areas including: Natural History and Epidemiology; Etiology and Pathogenesis; Therapeutics; Vaccines; and Behavioral and Social Science. The plan further addresses critical issues that cut across all of the scientific areas: Microbicides; HIV Prevention Research; Racial and Ethnic Minorities; Women and Girls; International Research; Training, Infrastructure, and Capacity Building; and Information Dissemination.

The fiscal year 2006 NIH AIDS research agenda continues the following overarching themes: a strong foundation of basic science; HIV prevention research, including development of vaccines, microbicides, behavioral interventions, and strategies to prevent perinatal transmissions; therapeutics research to develop simpler, less toxic, and cheaper drugs and drug regimens to treat HIV infection and its associated illnesses, malignancies, and other complications; international research, particularly to address the crucial research and training needs in developing countries; and research targeting the disproportionate impact of the AIDS epidemic on racial and ethnic minority populations in the United States.

The Plan shapes NIH investments in biomedical and behavioral AIDS research and provides the framework to translate critical research findings to benefit populations desperately in need both in our country and abroad. The Plan serves as the framework for developing the annual NIH AIDS research budget; for determining the use of NIH AIDS-designated funds; for tracking and monitoring AIDS-related expenditures; and for informing the scientific community, the public, and the AIDS-affected community about NIH AIDS research priorities. The entire plan can be found on the OAR web site: [http://www.nih.gov/od/oar/public/pubs/fy2006/00\\_Overview\\_fiscal\\_year\\_2006.pdf](http://www.nih.gov/od/oar/public/pubs/fy2006/00_Overview_fiscal_year_2006.pdf)

#### OAR BUDGET DEVELOPMENT PROCESS

The Plan initiates the budget development process. Based on the objectives and priorities established in the Plan, the NIH Institutes and Centers (ICs) prepare their AIDS research budget requests, detailing new or expanded program initiatives for each scientific area. The OAR reviews the IC initiatives in relation to the Plan, to OAR priorities, and to other IC submissions to eliminate redundancy and/or to assure cross-institute collaboration. The OAR allocates the AIDS research budget levels to each IC based on the scientific priority of the proposed initiatives.

This process allows the OAR to ensure that AIDS research funds will be provided to the most compelling scientific opportunities, rather than distribution based solely on a formula.

#### OAR BY-PASS BUDGET PRIORITIES

The fiscal year 2006 NIH By-Pass Budget for HIV/AIDS Research responds to several crucial scientific opportunities and needs. In fiscal year 2005, OAR initiated a comprehensive trans-NIH review of all grants and contracts supported with AIDS-designated funds to ensure that these projects represent the highest scientific priorities and opportunities. This process also included: (1) a review of the appropriateness of definitions of HIV/AIDS research in the institutes (i.e., coding of research as AIDS or AIDS-related) and the mix of investments in key priority areas in view of the current epidemic; and (2) a series of meetings with IC representatives to assess their AIDS portfolios relative to AIDS and AIDS-related priorities. This process will result in the redirecting of AIDS funds to higher priority projects and new scientific opportunities in fiscal year 2006.

NIH-sponsored HIV/AIDS research continues to provide the important scientific foundation necessary to design, develop, and evaluate new and better vaccine candidates, therapeutic agents and regimens, and prevention interventions. In particular, this By-Pass budget places a renewed priority on the discovery, development, and pre-clinical testing of additional HIV vaccine candidates. The NIH priority in AIDS vaccine research to date has resulted in approximately 70 clinical trials of nearly 40 vaccine candidates. The evaluation of an AIDS vaccine will require extensive testing in the United States and in international settings where there is a high incidence of HIV. High priority is placed in this budget on funding to move promising vaccine candidates into large-scale clinical trials to evaluate the potential for efficacy.

In the area of AIDS therapeutics research, current therapeutic regimens have resulted in extended survival and improved quality of life for many HIV-infected individuals in the United States and Western Europe. However, a growing proportion of patients receiving therapy are demonstrating treatment failure, experiencing serious drug toxicities and side effects, and developing drug resistance. This By-Pass budget provides critical support for the development of new and better drugs using

sophisticated structural biology, combinatorial chemistry, and macromolecular techniques. The goal of this research is to develop new, safe, less toxic, less expensive, and more effective therapeutic agents and regimens.

The increasing incidence of metabolic disorders, cardiovascular complications, major organ dysfunction, and physical changes associated with current antiretroviral drugs underscores the critical need for new and better treatment regimens. Improved regimens also are needed to treat HIV co-infections such as hepatitis B and C, as well as other opportunistic infections to reduce drug interactions and problems with adherence to complicated treatment regimens.

In fiscal year 2005, the Office of AIDS Research spearheaded a critical and unique multi-IC inter-disciplinary collaboration to formalize plans for the innovative restructuring of the NIH clinical trials networks for HIV therapeutics, vaccines and prevention interventions in fiscal year 2006. OAR convened meetings of relevant IC high-level staff, established an OAR Working Group of United States and international clinical trialists, and convened a public meeting of over 145 participants from universities, medical schools, the pharmaceutical and biotechnology industries, professional scientific societies, community advisory boards, constituency groups, and NIH IC program staff to develop a set of principles to guide the development of Request For Application (RFAs) for these multi-IC supported clinical programs. This effort made a significant contribution to the process of the recompetition of these networks in fiscal year 2006 and to ensuring that they will operate effectively and cooperatively, making the best use of research funds.

The alarming continued spread of the pandemic in Southeast and Central Asia, Eastern Europe, Latin America, and the Caribbean underscores the urgent need for more affordable and sustainable prevention and treatment approaches that can be implemented in resource-limited nations. The high incidence of Hepatitis B and Hepatitis C, malaria, and TB in many of these nations further complicates the treatment and clinical management of HIV-infected individuals. This budget provides increased funds for the development and evaluation of new regimens for these HIV co-infections that will allow the treatment of these diseases without serious drug interactions and toxicities.

The By-Pass budget provides funds for NIH international AIDS research including: HIV vaccine candidates and chemical and physical barrier methods, such as microbicides, to prevent sexual transmission; behavioral strategies targeted to the individual, family, and community to alter risk behaviors associated with sexual activity and drug and alcohol use; drug and non-drug strategies to prevent mother-to-child transmission (MTCT); therapeutics for HIV-related co-infections and other conditions; and approaches to using Antiretroviral Therapy (ART) in resource-poor settings. Specific international infrastructure needs include: (1) developing research sites through establishment of stable, targeted cohorts, development of recruitment strategies, and enhancement of laboratory, clinical, and data management capabilities; (2) increasing the number of scientists, clinicians, and health care workers trained in basic, clinical, and behavioral research, data management, and ethical considerations; (3) developing research collaborations; and (4) transferring appropriate clinical and laboratory technologies.

#### OAR BY-PASS BUDGET ESTIMATE

NIH is enhancing collaboration, minimizing duplication, and ensuring that research dollars are invested in the highest priority areas of scientific opportunity that will allow NIH to meet its scientific goals.

The total fiscal year 2006 By-Pass budget estimate for all NIH AIDS research is \$3.387 billion. This represents an increase of \$442 million or 15 percent over the fiscal year 2005 current estimate of \$2.945 billion.

The NIH Office of AIDS Research is providing the following materials: NIH fiscal year 2006 Plan for HIV-Related Research; NIH Research Mechanism Table; and Table of Funding by the NIH fiscal year 2006 Plan for HIV-Related Research.

## ATTACHMENT 1.—OFFICE OF AIDS RESEARCH FISCAL YEAR 2006 BY-PASS SUMMARY MECHANISM

[Dollars in millions]

	Fiscal years							
	2004 estimate		2005 estimate		2006 by-pass		2006 over 2005 dollar change	
	No.	Amount	No.	Amount	No.	Amount	Percent	Amount
Research Projects:								
Noncompeting .....	2,245	\$1,173	2,407	\$1,268	2,370	\$1,087	- 14.3	-\$181
Administrative supplements .....	(14)	18	(16)	19	(20)	17	- 10.5	- 2
Competing .....	1,035	376	804	307	1,178	712	131.9	405
Subtotal, RPGs .....	3,266	1,567	3,195	1,594	3,528	1,816	13.9	222
SBIR/STTR .....	91	31	103	35	105	41	17.1	6
Total, RPGs .....	3,357	1,598	3,298	1,629	3,633	1,857	14.0	228
Research Centers:								
Specialized/comprehensive .....	61	104	61	111	63	120	8.1	9
Clinical research .....	43	43	45	45	49	49	8.9	4
Biotechnology .....	6	6	1	7	7	7		
Comparative medicine .....	17	48	17	52	17	65	25.0	13
Research centers in minority institutions .....	10	10	10	10	11	11	10.0	1
Subtotal, Centers .....	78	211	79	225	80	252		27
Other Research:								
Research careers .....	235	30	240	31	235	34	9.7	3
Cancer education .....								
Cooperative clinical research .....	25	44	25	44	25	44		
Biomedical research support .....	1	2	1	2	1	3	50.0	1
Minority biomedical research support .....	2	1	2	1	3	1		
Other .....	115	62	114	64	115	72	12.5	8
Subtotal, Other Research .....	378	139	382	142	379	154		12
Total, Research Grants .....	3,813	1,948	3,759	1,996	4,092	2,263		
FTTPs								
Training:								
Individual .....	62	3	62	3	62	3		
Institutional .....	703	31	723	32	737	33	3.1	1
Total, Training .....	765	34	785	35	799	36	2.9	1
Research & development contracts .....	181	364	190	415	225	553	33.3	138
(SBIR/STTR) .....	(10)	(2)	(10)	(2)	(10)	(1)	- 50.0	(1)
Intramural research .....		325		331		356	7.6	25
Research management and support .....		96		99		106	7.1	7
Construction .....		5						
Library of Medicine .....		7		8		10	25.0	2
Office of the Director .....		61		61		63	3.3	2
Buildings and Facilities .....								
Total, Budget Authority .....		2,840		2,945		3,387	15.0	442

ATTACHMENT 2.—OFFICE OF AIDS RESEARCH, FISCAL YEAR 2006 BY-PASS, FUNDING BY THE NIH  
PLAN FOR HIV-RELATED RESEARCH

(Dollars in millions)

	Fiscal year							
	2002 actual	2003 actual	2004 esti- mate	2005 esti- mate	2006 by- pass	2006 over 2005		
						Dollar change	Percent of incre- ment	Percent change
Natural History and Epidemiology .....	\$276	\$295	\$293	\$296	\$315	\$19	4.3	6.4
Etiology and Pathogenesis .....	685	727	716	728	812	84	19.0	11.5
Therapeutics .....	689	726	754	771	848	77	17.4	10.0
Vaccines .....	329	407	467	529	714	185	41.9	35.0
Behavioral and Social Science .....	346	370	402	408	457	49	11.1	12.0
Training and Infrastructure .....	121	137	165	169	191	22	5.0	13.0
Information Dissemination .....	53	55	43	44	50	6	1.4	13.6
<b>Total .....</b>	<b>2,499</b>	<b>2,717</b>	<b>2,840</b>	<b>2,945</b>	<b>3,387</b>	<b>442</b>	<b>100</b>	<b>15.0</b>

PREPARED STATEMENT OF DR. ANTHONY S. FAUCI

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health (NIH). The fiscal year 2006 budget of \$4,459,395,000 includes an increase of \$56,554,000 over the fiscal year 2005 enacted level of \$4,402,841,000, comparable for transfers proposed in the President's request.

NIAID conducts research to understand, treat, and prevent infectious and immune-related diseases. Infectious diseases include well-known killers such as tuberculosis and malaria, emerging or re-emerging threats such as HIV/AIDS, SARS, West Nile Virus and influenza, and "deliberately emerging" threats from potential agents of bioterrorism such as those that cause anthrax and smallpox. Examples of immune-related diseases include autoimmune disorders such as type 1 diabetes, systemic lupus erythematosus, rheumatoid arthritis, transplantation-related illnesses, asthma, and allergies.

Historically, NIAID has accomplished its mission with a strong commitment to basic and targeted research in immunology, microbiology, and infectious disease. In the 57 years since NIAID was founded, this approach has led directly to new therapies, vaccines, diagnostic tests, and other technologies that have improved the health of millions of people worldwide. In recent years, however, the growing realization that the nation needs a stronger defense against both naturally and deliberately emerging infectious diseases has led NIAID to adopt a new research paradigm that accelerates the development of safe and effective medical countermeasures. To accomplish this, we have sought creative ways to modify our traditional process of research and development to move potential products ahead more rapidly while continuing to preserve the excellence in basic research that is a hallmark of NIAID, and all of NIH. The result is that we now take a much more proactive role in collaborating with academia, industry and other partners to move promising concepts into advanced product development and clinical testing.

BIODEFENSE RESEARCH

In the wake of the 2001 terrorist attacks, NIAID substantially expanded and accelerated its biodefense research program. The fiscal year 2006 President's budget request for NIAID includes \$1,664,505,000 for these biodefense research and development activities. The NIAID Strategic Plan for Biodefense Research provides a blueprint for the construction of three essential pillars of the NIAID biodefense research program: infrastructure needed to safely conduct research on dangerous pathogens (\$30,000,000 in fiscal year 2006); basic research on microbes and host immune defenses that serves as the foundation for applied research (\$612,190,000 in fiscal year 2006); and targeted, milestone-driven research and development of medical countermeasures to create the vaccines, therapeutics and diagnostics that we would need in the event of a bioterror attack (\$1,022,315,000 in fiscal year 2006).

The investment Congress has made in the NIAID biodefense research program has already begun to return substantial dividends in all three of these aspects of

biodefense research. Dramatic advances have been achieved in the development of medical countermeasures against an attack with biological agents, and, although there is much more to be accomplished, we are in a far stronger position today than we were only a few years ago. In September 2001, we had 15.4 million doses of smallpox vaccine available; today, we have more than 300 million doses. A next-generation smallpox vaccine called modified vaccinia Ankara (MVA) is in clinical testing and other vaccine candidates are in pre-clinical development stages. A new oral form of the antiviral drug cidofovir is in advanced product development for use in the event of a smallpox attack, as well as to treat the rare but serious complications of the classic smallpox vaccine. For anthrax, NIAID has aggressively pursued development of a new vaccine called rPA; the Department of Health and Human Services (DHHS) has contracted with VaxGen, Inc. to purchase 75 million doses of rPA under the BioShield legislation passed last year. This vaccine is derived using molecular biological methodologies and is produced using modern vaccine manufacturing techniques and may require fewer doses than the currently licensed vaccine. New anthrax therapies that can neutralize the anthrax toxin, such as monoclonal and polyclonal antibodies, are being developed. Candidate antibody treatments for the toxin that causes botulism are in development, as is a new vaccine to prevent the disease. Finally, an Ebola recombinant DNA vaccine is in initial human clinical trials at the NIAID Vaccine Research Center.

With regard to research infrastructure, many integrated research facilities are under construction to safely contain and study pathogens, including several new bio-defense laboratories that will be owned and operated by NIAID. In addition, sites have been selected for the construction of two National Biocontainment Laboratories (NBLs) and nine Regional Biocontainment Laboratories (RBLs) at major universities around the United States. All of these research laboratories will provide the secure facilities needed to carry out the nation's expanded biodefense research program in settings that protect workers and the surrounding communities. NIAID also has funded eight Regional Centers of Excellence for Biodefense and Emerging Infectious Diseases Research (RCEs). This nationwide network of multidisciplinary academic centers will conduct wide-ranging research to better understand infectious agents that could be used in bioterrorism, and will develop diagnostics, therapeutics and vaccines needed for biodefense against these agents. In 2005, NIAID will fund two additional RCEs and three to four additional RBLs. NIAID also has developed and expanded contracts to screen new drugs against bioterrorism threat agents, developed new animal models for bioterrorism threat agents, and established a bio-defense reagent and specimen repository.

Advances in Medicine rest on a foundation of basic research into the fundamental properties and mechanisms of life. In biodefense, these basic studies include sequencing and understanding of microbial genomes (genomics) and their products (proteomics), deciphering how microbes cause disease (pathogenesis), and examining how the human immune system and pathogens interact (immunology). NIAID-funded basic researchers have made significant progress since 2001 in each of these areas. For example, researchers have now determined the genetic sequence of at least one strain of every pathogen identified as a potential bioterror threat, and NIAID has established the Pathogen Functional Genomics Resource Center to help researchers apply and analyze these new genome sequence data. In pathogenesis, NIH researchers recently determined the three-dimensional structure of the anthrax toxin bound tightly to a target cell surface receptor. This finding has provided new leads for the development of novel antitoxins that could save lives late in the course of anthrax disease when large amounts of toxin are present and antibiotics alone are no longer sufficient to save the patient. Finally, basic molecular and cellular studies of the human innate immune system, which is comprised of broadly active "first responder" cells and other mechanisms that are the first line of defense against infection, have been moving forward rapidly. These advances suggest it may be possible to develop fast-acting countermeasures that boost innate immune responses to mitigate the effects of a broad spectrum of bioterror pathogens or toxins. Manipulation of the innate immune system also could lead to the development of powerful adjuvants that can be used to increase the effectiveness of vaccines.

The knowledge and products that will flow from the NIAID biodefense research program, including research results, intellectual capital, laboratory resources, and countermeasures in the form of diagnostics, therapeutics, and vaccines, will help us cope with naturally emerging, re-emerging, and deliberately released microbes alike. Recent experience tells us that knowledge developed to understand one pathogen invariably applies to others. For example, when HIV first emerged, antiviral drug development was in its infancy. Now, new technologies have led to the development of more than 20 antiretroviral drugs that can effectively suppress HIV replication and dramatically reduce AIDS morbidity and mortality. These same technologies,

and the lessons learned about antiviral drug development, are being applied to the development of new generations of drugs against many viruses, including influenza, SARS, smallpox, and Ebola. Even if we are never confronted with another bioterror attack, the biodefense research and preparations being carried out now will without question prove to be very valuable.

#### HIV/AIDS RESEARCH

Only a few statistics are needed to present a profoundly disturbing picture of the still-emerging HIV/AIDS pandemic. Approximately 40 million people worldwide are living with HIV/AIDS, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS). Every year, more than 5 million people worldwide are newly infected with the virus—about 14,000 each day; more than 95 percent of these people live in low and middle income countries. In the United States, nearly one million people are living with HIV/AIDS, and approximately 40,000 new infections occur annually, according to the Centers for Disease Control and Prevention. The death toll continues to climb steadily; worldwide, more than 20 million people with HIV have died since the pandemic began, including more than 520,000 in the United States. In 2004, there were 3 million deaths due to HIV/AIDS. As shocking as these numbers are, they do not adequately communicate the physical and emotional devastation to individuals, families, and communities coping with HIV/AIDS, nor do they capture the terrible impact of HIV/AIDS on the economies and security of nations, and indeed on entire regions.

Even as the burden of HIV/AIDS continues to grow, recent progress in research is providing reasons for optimism. For example, several new antiretroviral drugs recently have entered the market, all of which were built on NIAID-sponsored research and/or were tested in NIAID clinical trials networks; many other new anti-HIV drugs are in clinical trials. Other novel approaches to anti-HIV drugs are in the research “pipeline.” For example, NIAID scientists, in collaboration with extramural colleagues and with industry, recently conducted a clinical trial to test a product, anti-CCR5, that binds to a new therapeutic target, the HIV co-receptor, thus preventing HIV infection of host cells.

The development of a safe and effective HIV vaccine is one of NIAID’s highest priorities. The scientific barriers to the creation of such a vaccine are extraordinarily high, and better coordination, collaboration and transparency of research worldwide would help to overcome them. To facilitate such an approach, NIAID participated heavily in the creation of a new initiative called the Global HIV/AIDS Vaccine Enterprise, which was endorsed by President Bush and the other G8 countries at their June, 2004 Summit meeting in Sea Island, GA. The project creates a worldwide consortium of people and organizations with a stake in HIV vaccine research who agree to harmonize their individual HIV vaccine efforts by following a unified Strategic Plan for HIV vaccine development. This plan was published on a publicly-accessible website in February 2005.

Other measures to prevent HIV transmission also are being vigorously pursued. For example, when I testified here last year I discussed our efforts to develop topically applied microbicides that women could use to protect themselves from HIV and other sexually transmitted pathogens. More than 50 candidate agents have shown activity against HIV and other sexually transmitted diseases in the laboratory, and several of these have been shown to be safe and effective in animal models. In February 2005, a large international study, sponsored by NIAID and involving more than 3,000 women at high risk of acquiring HIV in the United States and five African countries, opened for enrollment. If these microbicides are proven to be safe and effective, they likely will become a very important means of slowing the pace of the HIV/AIDS epidemic.

#### RESEARCH ON OTHER EMERGING AND RE-EMERGING INFECTIOUS DISEASES

Infectious diseases do not remain static, but continually and dramatically change over time. New pathogens, such as the Severe Acute Respiratory Syndrome (SARS) coronavirus, can emerge suddenly and familiar ones, such as influenza virus and West Nile virus, can re-emerge with new properties or in unfamiliar settings. We must always be on guard for such changes and be prepared to react to them as quickly as possible. SARS is a prototypical example of a newly-emerging infectious disease. When SARS first came to the world’s attention in early 2003 as an unknown, highly lethal and transmissible disease, researchers and public health authorities the world over immediately began to collaborate to understand it. In short order, NIAID-supported researchers and others in Hong Kong showed that SARS was caused by a previously unrecognized coronavirus, epidemiologists unraveled its

modes of transmission, and public health authorities were able to contain the initial outbreak.

Since then, NIAID has continued to pursue several approaches to the development of SARS antiviral therapies. For example, NIAID screening contracts have supported the evaluation of more than 20,000 chemicals for anti-SARS coronavirus activity. More than 1,400 compounds with activity against SARS coronavirus have been identified, including alpha interferon, a drug already approved by the FDA for the treatment of hepatitis B and C infections.

NIAID scientists and grantees also are working on several approaches to a SARS vaccine, including one that entered human clinical testing in December 2004. It is truly remarkable that two years ago we were facing an unknown global health threat, and now we are already testing a promising vaccine that may help us to counter that threat should it re-emerge.

When West Nile virus (WNV) first appeared in the Western hemisphere in 1999, NIAID immediately increased its basic research on the virus and undertook the development of new vaccines and treatments for the disease. NIAID currently supports the development of three types of WNV vaccine—one of which has entered initial clinical testing—and is developing candidate WNV therapies. For example, in 2004, NIAID expanded an ongoing clinical study in human volunteers that is evaluating the safety and efficacy of the administration of antibodies against the virus as a means of treating or preventing West Nile virus encephalitis.

Influenza is a classic example of a re-emerging disease. Because the influenza virus continually changes, the U.S. influenza vaccine supply must be renewed each year. Although the egg-based technology currently in use has served us reasonably well for more than 40 years, it has limitations in flexibility in that surges in the need for additional or new vaccines cannot be readily accommodated due to the advance time that is required to provide for the annual requirement for hundreds of millions of fertilized chicken eggs to manufacture the vaccine. In addition, there is the ever present risk of contamination and the vicissitudes of yield of virus from this technique. The serious vaccine shortage that occurred this flu season underscores the difficulties we face in annually renewing the influenza vaccine supply, and highlights the pressing need to move toward adoption of newer vaccine manufacturing techniques to improve the flexibility and speed with which vaccines can be made.

NIAID supports several research projects and other initiatives intended to foster the development of new influenza vaccines and manufacturing methods that are simpler and more reliable, yield products that work against multiple influenza strains, and provide greater protection. DHHS has requested \$120 million in fiscal year 2006 to help shift vaccine manufacture toward new cell-culture technologies, new production technologies, as well as to provide for year-round availability of eggs to provide for a secure supply and surge capacity. In addition, a technique developed by NIAID-supported scientists called reverse genetics allows scientists to manipulate the genomes of influenza viruses to make the process of development of seed viruses for vaccines faster and more predictable.

Although the impact of influenza in a normal epidemic year is substantial, influenza viruses from animals occasionally cross into humans and, if the virus then acquires the ability to be easily transmitted between people, can cause a much more serious influenza pandemic. NIAID conducts a great deal of research to understand the viral biology and epidemiology that underpinned past pandemics and funds surveillance activities in Asia to detect the emergence of influenza viruses with pandemic potential. In addition, the DHHS draft Pandemic Influenza Response and Preparedness Plan directs NIAID to help develop and produce an effective vaccine as rapidly as possible that could be used should a pandemic alert be declared.

In recent years, avian influenza virus strains that can infect humans have emerged; the most worrisome are known as H9N2 and H5N1. In 1999 and 2003, an H9N2 influenza strain caused illness in people in Hong Kong. The H5N1 "bird flu" influenza strain was first detected in 1997 and has spread widely among wild and domestic birds. This latter virus has infected at least 55 people and killed 42 since January 2004, and there has been at least one documented case of human-to-human transmission.

NIAID has taken several steps to develop vaccines against both of these potential pandemic strains. NIAID contracted with Chiron Corporation to produce investigational batches of an inactivated H9N2 vaccine, which will be evaluated clinically by NIAID this year. For H5N1, Aventis-Pasteur, Inc. and Chiron are both producing investigational lots of inactivated H5N1 vaccine preparations; additionally, DHHS has contracted with Aventis to produce up to 2 million doses to be stockpiled for emergency use, if needed, to vaccinate health workers, researchers, and, if indicated,

the public in affected areas. Development and evaluation of a combination antiviral regimen against these potential pandemic influenza strains are also now under way.

#### RESEARCH ON IMMUNE-MEDIATED DISEASES

Immune-mediated diseases, including autoimmune diseases, allergic diseases, and asthma are important health challenges in the United States and abroad. One of the most promising strategies for developing treatments for a wide variety of these disorders is known as immune tolerance, in which researchers hope to selectively turn off injurious immune responses while leaving intact the protective responses needed to fight infection. To foster this research, NIAID sponsors the Immune Tolerance Network (ITN), a consortium of more than 80 investigators in the United States, Canada, Western Europe, and Australia dedicated to the clinical evaluation of promising therapies that can induce immune tolerance. The ITN will be re-competed in fiscal year 2006.

Reducing the growing burden of asthma among inner-city minority children is another NIAID priority. NIAID-supported investigators recently reported the largest study of its kind, showing that an intervention to reduce exposure to indoor allergens and tobacco smoke substantially reduced asthma severity and healthcare utilization among inner-city children. In 2004, NIAID's Inner-City Asthma Consortium launched a large study to define and analyze immunological and environmental influences upon the development of childhood asthma in a cohort of urban children followed from birth.

In closing, Mr. Chairman, I would like to take a moment to remember John R. La Montagne, Ph.D., the former deputy director of NIAID, who died suddenly on November 2 while traveling to a meeting of the Pan American Health Organization in Mexico City. Human infrastructure, in the form of a highly trained and deeply committed work force, is a critical component of any kind of medical research. Throughout John's almost 30 years at NIAID, his leadership and dedication to improving global health, as well as his generosity, wit, even-handedness and kindness, made him a cornerstone of the human infrastructure at NIAID. Personally, he was a dear friend and one of the finest people I have ever known. He is sorely missed.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee might have.

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#### PREPARED STATEMENT OF DR. ANDREW C. VON ESCHENBACH

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Cancer Institute (NCI) for fiscal year 2006. The fiscal year 2006 budget includes \$4,841,774,000, an increase of \$16,516,000 over the fiscal year 2005 enacted level of \$4,825,258,000 comparable for transfers proposed in the President's request.

#### LONG-TERM GOAL

The accelerating progress that the National Cancer Institute (NCI) and its partners in the cancer community have made over the past three decades in understanding the molecular mysteries of cancer is now extending the years and enhancing the quality of patients' lives. Now we are closer to the reality of eliminating the suffering and death due to cancer—the goal that NCI set to be achieved by 2015. The fiscal year 2006 budget continues to accelerate the discovery, development, and delivery of the interventions that will transform our traditional view of cancer as a death sentence into a disease that we can prevent, eliminate, or control. Accomplishing this goal is the legacy we strive to leave our children.

Our increased knowledge in several clinical approaches has led to new treatments approved for use. For example, our understanding of the molecular mechanisms required for tumors to develop the blood supply necessary for their growth led to the Food and Drug Administration's (FDA) approval of the monoclonal antibody Avastin® as a first-line treatment for patients with metastatic colorectal cancer. Similarly, knowledge of the growth factors necessary to stimulate cancer cell proliferation led to development and approval of another targeted monoclonal antibody Erbitux® for the treatment of metastatic colorectal carcinoma and to the accelerated approval of Alimta® for locally advanced or metastatic non-small cell lung cancer. These are just a few of the new drugs offering fresh hope for patients with advanced cancer.

We have made progress in preventing cancer from ever developing in the first place, especially in people at high risk. An example is the creation of a vaccine that



has prevented women from becoming persistently infected with human papilloma viruses (HPV), an infection that is responsible for half of all cervical cancers.

Now we must quicken the pace of progress because the trajectory is clear: discovery of cancer's genetic and molecular mechanisms leads to development of innovative interventions that—when delivered to patients—save lives. Building on this knowledge, the promise of tomorrow's advances is just over the horizon. This hopeful prospect will be realized by investing in strategic research areas, including: cancer genomics, biomarkers, molecular imaging, nanotechnology, and bioinformatics.

#### ADVANCED TECHNOLOGY INITIATIVES

The technology revolution is speeding up and enabling the discovery process. Recent advances in molecularly-targeted imaging will allow us to locate very small tumors and interrogate their features. Nanotechnology has emerged as a key strategy for imaging molecular features of cancer that are notoriously difficult to detect. In one case, a team of NCI-supported scientists has crafted a nano-sized device—less than 1/80,000 the width of a human hair—to identify areas of new blood vessel growth, which is characteristic of growing tumors. Further, drugs attached to agents that seek out the proteins on cancer cells will target therapy to exactly where it is needed without damage to healthy cells.

The development, integration, and coordination of advanced technologies are pivotal to enabling the biomedical and cancer research advances that are necessary to achieve NCI's 2015 goal. The Institute has played a crucial role in charting the path and collaborating in efforts to support bold new programs in this crucial arena.

For instance, the National Advanced Technologies Initiative for cancer (NATIC) is a plan to create a nationwide “virtual” laboratory for cancer. The NATIC plan envisions a network of state and regional technology “hubs” focused on several strategic areas, including advanced computing, nanotechnology, and biorepositories.

NCI has already begun development of the cancer Biomedical Informatics Grid (caBIG) to create a “world-wide web” for cancer research. The goal is to create a network of interconnected data, applications, individuals, and institutions that will redefine how cancer research is conducted and care is provided. During its initial year, the caBIG enterprise began bearing its first fruits with the release of NCI's caArray, a prototype software application that is made freely available to facilitate the sharing and analysis of microarray data by the medical research community. NCI and its partners in academia and industry are also developing an online information infrastructure to support clinical trials management and electronic drug approval submissions to the FDA. The first system module—the Federal Investigator Registry (Firebird)—starts pilot testing this spring.

In addition, NCI has for the first time adopted a modern business model approach to our research and development program for cancer-imaging technologies. This entailed creation of an Imaging Integration/Implementation (I<sup>2</sup>) Team that recently submitted a proposed business plan for a new entity to be called I<sup>2</sup> Imaging, Inc. The goal is to create distinct product lines to organize NCI's imaging program and clearly define measurable goals for each of the product lines. The plan includes four R&D programs encompassing imaging technologies for: (a) understanding of cancer biology and microenvironments; (b) cancer prevention and preemption; (c) development and preclinical validation of therapies; and (d) tools for clinical trial support.

#### STRATEGIC RESEARCH INITIATIVES

Exponential advances in cancer research are defining, with ever increasing specificity, the many genetic, molecular, and cellular events that influence the cancer process. We now understand cancer as an ongoing process that can be interrupted at many stages—from susceptibility to initiation to disease progression. We are translating this new knowledge into innovative strategies to prevent cancer from developing, eliminate it early when it does occur, and modulate its devastating effects. This involves NCI making strategic investments in several research areas.

*Cancer prevention, early detection, and prediction.*—New evidence-based interventions encourage lifestyle improvements in diet and physical activity, discourage tobacco use, and promote safe and fully-tested chemoprevention approaches for people at risk. Pioneering proteomic and biomarker advances, and the promise of nanotechnology, give us new hope for the early detection of cancer and prediction of patient responses to treatment.

*Development of strategic cancer interventions.*—One of NCI's key strategies is to optimize the development and speed delivery of targeted cancer diagnostics, therapies, and preventives to patients. This is evidenced by NCI's investments into the Cancer Genome Anatomy Project, Academic Public-Private Partnership programs, and Rapid Access to Intervention Development (RAID).

*An integrated clinical trials system.*—NCI provides leadership, resources, and expertise for clinical trials programs that span the discovery of novel molecules to the evaluation of new agents and interventions. To make clinical trials more efficient and to accelerate and improve the regulatory approval process, NCI is enhancing its working relationship with the FDA and the Department of Health and Human Services' (DHHS) Office of Human Research Protections to develop more streamlined policies and procedures for the conduct of clinical trials.

*Integrative cancer biology.*—Integrative cancer biology is the study of cancer as a complex biological system. NCI's initiatives in this cutting-edge area include creating computational models of the complex networks within and among cancer cells, building our understanding of the tumor microenvironment, and studying the role of the tumor macroenvironment in cancer development.

*Molecular epidemiology.*—NCI is developing novel ways to unravel the complexities of inherited and environmental contributions to cancer causation. Future investments will help scientists uncover risk factors, identify genetically susceptible individuals, and generate individual and public health strategies to avoid or mitigate adverse genetic exposures.

#### INTERAGENCY COLLABORATIONS

Cancer is a large and complex problem with scientific, medical, social, cultural, and economic dimensions. Addressing this problem requires that NCI work across institutional and sector boundaries, share knowledge, and bring together the diverse members of the DHHS family of agencies, as well as other Federal offices, that can help develop systems-based solutions to the cancer problem. Just within the National Institutes of Health (NIH), NCI collaborates with virtually all of the 27 Institutes and Centers. Likewise, NCI also has many ongoing collaborations with several DHHS agencies. The ultimate beneficiaries of this continued cooperative effort will be cancer patients and their families.

NCI and FDA created an Interagency Oncology Task Force (IOTF) to remove bottlenecks in the process of developing and approving safe, more effective cancer interventions. IOTF, which is comprised of senior representatives from both agencies, has been meeting regularly to define key areas of mutual interest and concern. As a result, the NCI-FDA Cancer Training Fellowship Program was launched in 2005. The program will train a cadre of scientists in research and research-related regulatory review so that they can develop skill sets that bridge the two distinct processes.

NCI is also an active participant in the Medical Innovation Task Force established last year by DHHS. The group—which also includes the FDA, the Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, and the NIH—is weighing new ideas and solutions to encourage innovation in health care. The interagency panel seeks to speed the delivery to market of effective new medical technologies, such as drugs, biological products, and medical devices.

#### NIH ROADMAP

NCI's contributions to NIH Roadmap initiatives will increase NCI's ability to support the collaborative research critical to cancer studies. Cooperation across the cancer continuum is vital for continued progress. The NIH Roadmap mechanisms support research in cancer biology that will also enhance continued interdisciplinary research to address vital questions related to cancer and the immune system, the interface of aging and cancer, and the role of microbial agents in the etiology of human cancers. By encouraging interdisciplinary teams to evolve in both directed and serendipitous ways, these new funding mechanisms complement and enlarge NCI's efforts toward the integration and cross-fertilization of research efforts that span the cancer spectrum.

#### CHALLENGES AND OPPORTUNITIES

In the coming years, we will face a number of critical challenges and opportunities. We stand on the brink of a new age of "personalized oncology"—delivering the right treatment to the right patient at the right time to halt cancer-causing processes in the body before they cascade into advanced disease states. NCI is driven to meet the 2015 challenge goal. Cancer is a public health and financial challenge for the United States. NIH estimates that in 2003, the total cost of cancer was over \$189 billion: \$64 billion in direct medical costs (much of it paid by Medicare) and \$125 billion from lost productivity due to illness and premature death. More telling, 570,000 Americans lost their lives to the disease last year, according to the American Cancer Society. Furthermore, the fact that cancer occurs primarily in individuals over the age of 50 means that more of our citizens will suffer the terrible bur-

den of this disease in the future due to the aging and changing demographics of our population. NCI and its partners are committed to making progress toward the goal of eliminating suffering and death due to cancer in the next 10 years.

Thank you, Mr. Chairman. I would be pleased to answer any question that the Committee may have.

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PREPARED STATEMENT OF DR. BARBARA ALVING, ACTING DIRECTOR, NATIONAL  
CENTER FOR RESEARCH RESOURCES

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Center for Research Resources (NCRR) for fiscal year 2006, a sum of \$1,100,203,000, which reflects a net decrease of \$14,887,000 over the comparable fiscal year 2005 appropriation. Within the total is \$162,618,000 for AIDS research.

I am delighted to have this opportunity to share with you the scientific advances achieved by NCRR-supported investigators and the future directions for NCRR programs. As the "research resources" component of the National Institutes of Health, NCRR's mission is to ensure that scientists have the necessary tools and access to research environments to conduct their progressively more complex research on human disease. With ready access to essential tools, our nation's top scientists may creatively explore promising new research avenues that will ultimately enhance human health.

Because of its cross-disciplinary programs, NCRR supports research tools and infrastructure that enable all lines of biomedical inquiry, from studies of molecular structures to clinical trials that evaluate potential therapies. Most NCRR-supported research resources are shared and accessible to scientists nationwide. These shared resources include advanced instrumentation and novel technologies, animal models of human disease, and electronic networks for collaborations among investigators in less populated areas. In addition, through the Institutional Development Award program, NCRR provides support to institutions in 23 states and Puerto Rico to develop new research facilities, equipped with state-of-the-art research tools.

NCRR encourages resource sharing because it broadens access to essential tools, is cost effective, and leverages precious federal research support. Each year, NCRR-funded research resources are used by more than 35,000 investigators who receive their primary research support from other NIH components, other federal agencies, and the private sector. Let me briefly describe just a few of the science advances that these researchers achieved over the past year.

OBESEITY STUDIES AIDED BY ANIMAL AND CLINICAL RESOURCES

Scientists who seek to determine the genetic defects of many human diseases are often stymied by the fact that common conditions—from obesity to psychiatric disorders—are influenced by multiple genes. Therefore, researchers have turned to inbred mice as a model system for detecting genetic regions that contribute to complex disease. Using unique mouse strains available through an NCRR resource, scientists examined genetic factors that affect many complex traits, including obesity and anxiety. With this approach about 150 previously undiscovered genetic regions were discovered. This effort may narrow the search for specific genes that contribute to obesity and also pave the way for finding similar genes in humans.

NCRR's General Clinical Research Centers (GCRCs) provide an ideal research environment for studies of obesity, an increasing public health concern. Particularly valuable are the GCRCs' highly trained staff and state-of-the-art equipment that can analyze a patient's metabolism and track consumption of all foods, down to the level of micronutrients. At the University of California, Los Angeles, researchers depend on the GCRC for their carefully controlled studies of the hormones that affect appetite and metabolism. One study found that injections of the hormone leptin can reduce body weight by more than 50 percent in obese individuals born with leptin deficiency. At Yale University's GCRC, scientists evaluated hundreds of overweight children and adolescents and found that about half of the severely obese have a condition that raises their risk of heart disease and type 2 diabetes. Ultimately, better understanding of the risk factors and potential therapies for obesity could lead to a leaner, healthier population.

ADVANCES IN TRANSPLANTATION RESEARCH

As mentioned earlier, the GCRCs continue to have a significant role for advancing human health. For instance, the GCRCs enabled pioneering clinical studies related to transplantation, from the earliest successes with organ transplants in the 1960s

to the current microtransplants of genes into cells. One recent success, reported in the *Journal of the American Medical Association* this past February, showed that islet cells from a single human pancreas can be transplanted into up to eight patients with type 1 diabetes, a condition in which the pancreatic islet cells do not make insulin. All eight transplant recipients achieved normal glucose levels without the need for insulin injections. Ongoing advances in transplantation illustrate how federally funded efforts—among molecular biologists, geneticists, animal researchers, and clinical investigators—lay a solid foundation for improving human health through the effort of a team of investigators.

#### BIODEFENSE AND TECHNOLOGY RESOURCES

Besides clinical and comparative medicine resources, NCRR also supports biomedical technology centers that develop and provide scientists with access to innovative instruments, technologies, and computational tools. These technology centers have enabled recent advances to help scientists determine how infectious agents, like anthrax, induce their deleterious clinical effects. The anthrax bacterium is unusual because it produces large amounts of a toxin that can kill a patient even after the bacterium itself has been destroyed by antibiotics. A research team used x-ray data collected at an NCRR-supported synchrotron resource to examine the structures of molecules that might disarm the deadly toxin. Synchrotrons are large machines (about the size of a football field) that accelerate electrons to almost the speed of light to produce intense x-rays with adjustable wavelengths that can be exploited to reveal the 3 dimensional structures of molecules. Further structural studies may lead to the development of effective toxin-blocking therapies for inhalational anthrax infections.

In another study, scientists developed improved techniques for identifying microbes by their DNA “fingerprints”—a critical advance in this age of bioterrorism and emerging diseases—and shorten the timeframe needed to identify the toxic agent. Using laser technology at an NCRR-supported flow cytometry resource, scientists analyzed and measured tiny samples of DNA from a *Staphylococcus aureus* bacterium. The analysis can be completed in just 30 minutes, compared to the 24 hours normally required to analyze DNA. Advanced computational methods linked to the new technology may boost efforts to detect and track microbial threats and provide sufficient time to alert individuals at risk.

#### INFORMATICS AND INTERDISCIPLINARY SCIENCE

NCRR's shared resources provide a fertile environment for interdisciplinary collaboration. Such studies are essential for addressing important but complex research problems that scientists grapple with today. For instance, NCRR supports a large-scale interdisciplinary effort known as the Biomedical Informatics Research Network (BIRN). That effort draws on multiple resources to examine increasingly complex problems in neuroscience. BIRN is the nation's first test bed for online sharing of research resources and expertise, and for effective data mining for both basic and clinical research. The initial effort focuses on neuroscience, since that discipline holds the largest data sets and requires the capacity to transmit large, information-rich images of the brain. BIRN will be extended to other research areas. Ultimately, the network will enhance the translation of basic research to the patient.

#### NIH ROADMAP

The NIH Roadmap complements many NCRR programs, and as a result NCRR staff members are involved in virtually every Roadmap Working Group. NCRR is leading the Exploratory Centers for Interdisciplinary Research program. These Centers are developing approaches that will allow researchers from very different scientific disciplines to work together to solve difficult biomedical or behavioral problems. NCRR is also leading the National Technology Centers for Networks and Pathways program that aims to develop new technologies to study molecular interactions within intact cells. NCRR has a significant role in another Roadmap initiative, the National Centers for Biomedical Computing, that will provide the infrastructure needed to promote productive interactions between computational scientists and biomedical researchers.

#### STRATEGIC PLANNING AND FUTURE INITIATIVES

This past year, NCRR published a new strategic plan for 2004–2008. Titled *Challenges and Critical Choices*, the plan was developed based on input from thousands of researchers and administrators for research-intensive organizations nationwide. This strategic plan now guides NCRR's priorities for programmatic investments. I

would like to briefly describe just a few of the initiatives that NCRP has launched, or plans to launch, to address the plan's recommendations.

*Informatics for Clinical Research*

The scientists who participated in NCRP's strategic planning process highlighted cyberspace infrastructure that would significantly enhance information sharing, access to and management of vast datasets, and transmission of large data objects like brain images as a priority. NCRP has initiated an assessment to determine current capabilities and future requirements for electronic communication and information management across research centers, including the GCRCs, Research Centers in Minority Institutions, and biomedical technology research centers. One long-term goal is to support collaborations among investigators located in less densely populated states.

*Enhance Protection of Clinical Research Subjects*

Another important trend identified during NCRP's strategic planning process involves the public's growing concern for the safety of participants in clinical research studies. NCRP created a Research Subject Advocate (RSA) program to assure appropriate safety monitoring of research subjects for GCRC-based studies and to ensure that investigators are aware of their responsibilities under State and Federal law. Because the RSA program has had such a positive impact, NCRP remains committed to strengthening the program.

*Expand Availability of Nonhuman Primate Stem Cells*

Another NCRP initiative will focus on stem cells, which hold the potential for treating a variety of disorders. But extensive animal studies are needed to identify the molecules, cytokines or other agents that modulate stem cell differentiation. NCRP proposes to support research to identify these factors and to isolate several different embryonic stem cell lines from the rhesus macaque, baboon, and a few other nonhuman primate species. Isolated cell lines will be distributed to qualified scientists via a national resource, and a companion database will track relevant data for each cell line. Information gleaned from these studies may be applicable to the study of human stem cells.

CONCLUSION

In closing, as biomedical research becomes more complex, specialized research resources are required to address emerging trends and build bridges across disciplines. NCRP plays a cross-cutting, trans-NIH role in biomedical research, supporting state-of-the-art resources that enable collaboration and stimulate scientific discovery. These research resources play an essential role in advancing human health.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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PREPARED STATEMENT OF DR. DUANE ALEXANDER, DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Child Health and Human Development (NICHD). The fiscal year 2006 budget includes \$1,277,544,000, an increase of \$7,223,000 over the fiscal year 2005 enacted level of \$1,270,321, comparable for transfers proposed in the President's request.

With the continued support of this Committee, the National Institutes of Health has the unique ability to invest in complex medical studies that continue for many years. It is particularly satisfying to all of us when an investment in research cures a disease or eradicates a condition. With deep satisfaction, we report a major medical and public health achievement that the *New York Times* heralded a few weeks ago in a front page headline: *U.S. is Close to Eliminating AIDS in Infants*.

This progress came in small incremental steps that arose from a large ambitious vision: to eliminate mother-to-child HIV transmission. Just a decade ago, a pregnant woman with HIV who lived in the United States had more than a 25 percent chance of passing the virus on to her child. In the early 1990s, the NICHD and the NIAID formed the Pediatric AIDS Clinical Trials Group to test promising new anti-HIV treatments. One of the first studies showed that the drug AZT administered to the mother and newborn infant at specific times could reduce HIV transmission from 25 percent to 8 percent. Subsequent research tested a drug combination known as highly active anti-retroviral therapy (HAART) and showed that the rate of transmission could be reduced even further. Today, with an expanded array of anti-HIV

drug treatments, the chance of a pregnant woman in the United States passing the virus on to her child has plummeted to about 1.2 percent.

#### COMPOUNDS IN MOTHERS' MILK PROTECT AGAINST DIARRHEA

Human breast milk is known to protect infants from diarrhea, but the responsible components had not been known. Results of a routine investigation to understand the purpose of some complex sugar molecules found in human breast milk may lead to a way to prevent diarrheal diseases from occurring, not just in infants, but in older children and adults as well. The molecules, called oligosaccharides, are abundant in human breast milk. During the last decade, NIH-funded researchers have discovered that oligosaccharides can stop bacteria and viruses from binding to the cells in the intestinal wall, preventing diarrheal diseases from gaining a foothold.

Oligosaccharides have been found to combat *E. coli* 0157, the deadly bacterium that can infect ground beef and other common foods. They also block the Norwalk virus, which incapacitates thousands of cruise ship voyagers every year, as well as rotavirus, one of the most common causes of diarrheal diseases in children. Oligosaccharides may also provide a means to overcome the problem of bacterial resistance. They function differently than do antibiotics, and bacteria do not appear able to develop resistance to the oligosaccharides.

#### RESEARCH LEADS TO BETTER HEALTH FOR WOMEN

Fibroids, or leiomyomas, are painful noncancerous growths that develop in the smooth muscle of the uterus. Women with fibroids may have painful menstrual periods, pain during intercourse, infertility, incontinence, and bowel obstruction. Women with fibroids are also more likely to go into labor prematurely and to experience a miscarriage. The exact number of women with fibroids is not known, but between 25 and 40 percent of all U.S. women experience fibroid symptoms. Fibroids disproportionately affect African Americans. One study estimated that 80 percent of African American women have fibroids by age 60. There are few effective ways other than hysterectomy to treat these tumors. Recently, however, NICHD researchers made some basic discoveries about fibroids that may lead to effective non-surgical treatments. In one study, researchers used sophisticated gene analysis technology to learn that fibroids contained abnormally high levels of a protein known as dermatopontin. That study led to another discovery that fibroids are largely made up of abnormal strands of collagen; thus, researchers are now searching for new drug treatments directed toward the abnormal collagen.

Pregnancy and childbirth place women at higher risk for a disorder known as pelvic organ prolapse, which can be painful and disabling, and require surgical treatment. Although surgical procedures may correct the condition, many women may experience urinary incontinence as a result of such treatment, which may require a second surgery to correct. From early results of a clinical trial, NICHD-funded researchers have learned that performing an incontinence surgical procedure during the same operating room session as the prolapse repair markedly decreases the chances for incontinence, without adverse effects. Such findings not only have implications for improving the quality of life for women, but may have implications for helping to reduce the cost of care.

#### RESEARCH ENHANCES LEARNING

After more than 30 years of careful research—using the same scientific rigor we use to test a new drug or medical procedure—the NICHD has identified the instructional methods that best help children learn to read. A recent brain imaging study has shown that these scientifically proven methods actually change the brain functioning of formerly poor readers so that it resembles the brain functioning of good readers.

Unfortunately, however, many school districts still rely on instructional practices that are not based on scientific research. According to the National Center for Education Statistics, roughly 37 percent of the nation's 4th graders read below grade level. In collaboration with the Department of Education, NICHD staff is working to communicate evidence-based research findings to provide school districts around the country with new approaches to teach reading. To be competitive in the years ahead, U.S. students will also need a thorough grounding in science. A recent study has challenged current thinking on the best way to teach science. The traditional belief was that students would better remember what they learn if they discovered on their own how to conduct an experiment rather than having someone teach it to them. In fact, the researchers found just the opposite: that students learned faster and retained more information if they were given explicit instructions about ex-

perimental procedures. The finding provides teachers with important information on how best to convey scientific concepts to their students.

Our basic science laboratories continue to produce discoveries of potential clinical relevance to learning and mental retardation. NICHD scientists discovered that a single protein appears central to the formation of the long-term memories underlying all advanced learning. Two teams of NICHD scientists have discovered how the protein known by the acronym BDNF is produced in the brain and are studying whether defects in the BDNF protein system may lead to disorders of learning and memory. Other scientists have studied an animal model of the defective Rett syndrome gene that causes deterioration of cognitive and motor function in girls to learn how the gene causes anatomic and functional abnormalities. Studies also continue on the genetic and neurobiologic bases of autism.

#### KIDS MAY SAY OTHERWISE, BUT PARENTS MATTER

Several NICHD studies of child development provide strong evidence that parents can exert a direct and positive influence on the decisions that children and young adults make. For example, researchers had suspected for some time that extensive television viewing at an early age might be associated with decreased attention span in children. However, they had no data from long-term studies to support this observation. So NICHD-funded researchers designed a study to answer an important question: do children who watch increasing amounts of TV at 1 and 3 years of age have increase attention problems at age seven? The researchers analyzed data from an ongoing study involving more than 2,600 children and found that the more television very young children watched, the more likely they were at age seven to have attention problems. These findings do not mean that early television viewing is associated with clinically diagnosed attention-deficit/hyperactivity disorder (ADHD). However, the findings support the idea that parents could reduce the risk for attention problems by limiting children's television viewing in their early years.

NICHD scientists have also developed a research-based tool that parents can use to significantly reduce the risks that young, inexperienced drivers face. Insurance companies have known for some time that motor vehicle crash rates are higher for teenagers than for older drivers and are the highest during the first 1,000 miles and the first 6 months of driving. The researchers developed and tested a program in which the central feature is a contract between the parent and new driver. As part of this contract, the newly licensed driver agrees to limit driving at night, driving with other teens in the car, driving on high-speed roads, and driving in bad weather. NICHD research showed that parents can greatly reduce the risks that new drivers face.

#### REHABILITATION NETWORKS SEEK TO IMPROVE QUALITY OF LIFE

Serious illness and injury may result in life-long impairment. The Traumatic Brain Injury Clinical Trials Network will evaluate new treatments and rehabilitation techniques for children and adults with brain injury. The Pediatric Critical Care Network will evaluate new treatments for children who have suffered a serious injury or illness. The Network will study the effectiveness of short-term treatment and its relationship to the rehabilitation that patients receive and to the long-term outcomes.

#### THE BEST PHARMACEUTICALS FOR CHILDREN ACT

The NICHD, as directed by law, in consultation with the FDA and experts in pediatric drug development, has identified and prioritized the most important drugs for further study in children. Currently, children are being recruited to study lorazepam for use as a sedative and anticonvulsant, and nitroprusside for controlling blood pressure of children undergoing surgery. In cooperation with the National Cancer Institute, data pertaining to the drugs vincristine and dactinomycin are being reviewed to provide the first evidence-based look at the efficacy, toxicity, and dosing of these two drugs. The evidence from this review will provide the basis for subsequent studies that will provide specific guidance on the use of these drugs in children. Drugs on the current priority list will form the basis of solicitations in 2006.

#### THE NATIONAL CHILDREN'S STUDY

NICHD scientists working collaboratively with the NIEHS, the CDC, and the EPA continue to make progress in planning the implementation of the National Children's Study as directed by Congress in the Children's Health Act of 2000. The Study, as currently planned, will involve about 100,000 children and their families,

and can form the basis of child health guidance, interventions, and policy for generations to come. Funds in the fiscal year 2005 budget are being used to establish four Vanguard Centers that will pilot recruitment strategies and the Study protocol. A data coordinating center will be established to provide the statistical analysis and reporting of the Study results. The protocol for this Study has been drafted and 101 sites across the United States have been identified to provide a population-based representative sample. These steps bring us closer to the point at which the full study could be implemented.

#### NIH ROADMAP

The NIH Roadmap initiative is providing an important guide to help the NICHD achieve its research and programmatic goals. The initiative directed to Re-engineering the Clinical Research Enterprise is currently helping to develop future leaders in clinical research. The NICHD is leading several targeted efforts to enhance the training, development, and support of the clinical research teams of the future.

Mr. Chairman and members of this Committee, I would like to thank you for your continued support of our research to improve the health and well being of women, children and families, as well as for your support in the critical task of developing tomorrow's research leaders. I will be pleased to answer any questions.

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#### PREPARED STATEMENT OF DR. JEREMY M. BERG, DIRECTOR, NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of General Medical Sciences (NIGMS). The fiscal year 2006 budget includes \$1,955,170,000, an increase of \$11,103,000 over the fiscal year 2005 enacted level of \$1,944,067,000 comparable for transfers proposed in the President's request.

#### UNDERSTANDING DISEASE REQUIRES UNDERSTANDING NORMAL FUNCTION

As we go about our daily lives, most of us probably forget about the biological processes that make our bodies work. Our cells are constantly making new components, dividing, moving, and even dying. Complex mechanisms underlie each of these processes and elaborate networks integrate them to promote normal, healthy function. If any of these processes break down, the result can be cancer, diabetes, Alzheimer's, or a host of other diseases.

To improve our understanding of basic biological processes, we need to employ a wide range of approaches. These include conducting basic research, developing new technologies, and training tomorrow's scientists. In essence, this is the core mission of NIGMS. For more than 40 years, the Institute has focused on deepening understanding of critical life processes and the molecular underpinnings of disease. In this way, NIGMS lays the foundation for advances in the diagnosis, treatment, and prevention of many different illnesses.

#### PARADIGM-SHIFTING IDEAS AND THEIR APPLICATION

NIGMS has an impressive track record of investing in research with big payoffs. One indication of this success comes from the many prestigious awards our grantees receive for their research. In each of the last 8 years, at least one Nobel Prize has been given to an NIGMS grantee. This year continues the trend: The 2004 Nobel Prize in chemistry went to Irwin Rose, Ph.D., a biochemist at the University of California, Irvine, whose work has been supported by the Institute for several decades. He brings the number of NIGMS-supported Nobel laureates to 57.

Rose shared the prize for his studies on how cells control the breakdown of unneeded proteins. The mechanism for this controlled breakdown underlies many processes in health and disease and is now the focus of literally thousands of research studies. The discoveries flowing from this basic research are increasingly being translated into new therapies. For example, Alfred Goldberg, Ph.D., an NIGMS grantee at Harvard Medical School in Boston, initiated research that led to a new drug called Velcade®. This drug is used to treat multiple myeloma, a deadly type of bone marrow cancer. Velcade® works by targeting the proteasome—the molecular machine that breaks down unneeded proteins that Rose and his coworkers discovered. Velcade® is likely to be the first of a number of drugs based on the discovery of this process that is so fundamental to much of cell biology.

The path to new approaches for promoting health and preventing and treating diseases has several key elements. These include creatively exploring a range of biological systems, developing tools for expanding knowledge, finding appropriate ways



to integrate this knowledge into practical applications, and, of course, having a workforce of scientists who have the motivation and the knowledge to drive these advances.

#### FROM CARNIVOROUS SNAILS TO A NOVEL PAIN TREATMENT

It is tough to make a living as a carnivorous snail. A large family of such creatures, called cone snails, relies on extremely potent venom to paralyze prey almost instantly. Baldomero Olivera, Ph.D., a biologist at the University of Utah in Salt Lake City, has been studying cone snails for more than 25 years with NIGMS support, carefully separating the venom into its components and studying each one.

Remarkably, the venom components are small proteins that target structures within the neuromuscular system with exquisite specificity. Because of the roles of their targets and this great specificity, these proteins are powerful research tools and show great promise as drugs. The first drug to result from this work, Prialt®, was approved by the FDA in December 2004 to treat the chronic, intractable pain often endured by people with cancer, AIDS, or certain neurological disorders. One thousand times more powerful than morphine, this new pain medication is thought to be non-addictive.

Other recently discovered pathways are leading to new drugs as well. The process of RNA interference, first characterized in roundworms by NIGMS grantees, can specifically silence individual targeted genes. Harnessing this process has allowed scientists to precisely control genes, leading to exciting new research tools and promising new ways to treat diseases including HIV, hepatitis, and cardiovascular disease. An RNA interference-based drug to treat the blinding eye disease of macular degeneration is currently in clinical trials.

#### THE SHAPES OF THINGS TO COME

The human genome is expressed primarily through proteins, the molecules that perform virtually all of the body's activities. Based on their amino acid sequences, proteins fold into complex shapes that determine their functions, including which other molecules they bind to form complex assemblies. Powerful techniques have been developed for determining protein structures in great detail. Thousands of such structures have been determined, providing deep insights into how biological systems function in health and disease and driving the development of new drugs and other therapies. Much of this work has been performed by individual investigators working on individual proteins chosen based on their biological context. A productive laboratory might determine two to four structures per year. This approach continues to be effective, but it is too slow to keep up with the vast number of potential protein targets now accessible through genomic studies.

To complement the contributions of individual investigators, NIGMS launched the Protein Structure Initiative (PSI) in 2000 with the goal of developing technologies and processes to enable researchers to quickly, cheaply, and reliably determine the three-dimensional structures of proteins. After 4 years, the nine PSI pilot centers can produce several structures each week, and the total number of structures solved by the PSI centers has now passed the milestone of 1,000!

With the second phase of the initiative beginning this summer, the PSI will use the tools and methods developed in the pilot phase to continue technology development and to determine more protein structures, including some that were too complex to tackle during the pilot phase. Researchers will use these structures to determine and understand protein function, predict the structures of other proteins, identify targets for drug development, design molecules to fit those targets, and compare proteins from normal and diseased tissues.

An important activity related to the PSI is the structural biology component of the NIH Roadmap for Medical Research, which funded two Centers for Innovation in Membrane Protein Production to aid structural studies of this major class of proteins. Difficulties inherent in studying membrane proteins mean that we know relatively little about them, despite the fact that they represent up to a third of all proteins and are the targets for a large number of therapeutic drugs. NIGMS is actively involved in other Roadmap initiatives, as well, including those in the areas of high-risk research (specifically, the NIH Director's Pioneer Award), bioinformatics and computational biology, molecular libraries and imaging, and interdisciplinary research.

#### COMPUTERS MODEL COMPLEX SYSTEMS

Today's biomedical research has moved beyond describing the parts of living systems to focusing on the complex, dynamic interactions of those parts. One of the

best ways to approach this formidable challenge is to use computers to model and manipulate the systems.

Among the places this is happening are the five NIGMS Systems Biology Centers. Multidisciplinary teams of researchers at these centers are addressing such fundamental questions as how cells divide, differentiate, and communicate and how different kinds of environmental stress affect cell and tissue function.

At the other end of the spectrum, NIGMS-supported researchers are investigating how human systems contribute to the spread of infectious diseases. The researchers, part of the Institute's Models of Infectious Disease Agent Study (MIDAS) initiative, use computational approaches to simulate disease outbreaks, whether they occur naturally or result from bioterrorism. In much the same way as weather forecasters use computer models to predict the landfall of hurricanes, scientists can use the MIDAS models to make predictions about potential epidemics. These models will assist policymakers, public health workers, and other researchers in understanding and responding to new infectious disease outbreaks.

Responding to the medical community's growing concern that avian influenza could cause the next flu pandemic, the MIDAS network currently is simulating the outbreak of a deadly bird flu strain in a hypothetical human community. The computer models incorporate data on population density and age structure, distribution of schools, locations of hospitals and clinics, travel, and the infectiousness of the virus. The models will predict the effects of different strategies to contain the spread of infection, such as vaccinating specific groups of people or restricting travel. Preliminary results from the avian flu modeling project should be available by mid-2005.

#### DIVERSITY DRIVES DISCOVERY

To continue making rapid progress in biomedical research and improving human health, we need to ensure that the pool of biomedical scientists reflects the great diversity of our nation. This diversity can spark new research questions and offer different approaches to answering them. NIGMS promotes this diversity in a number of ways.

Through our Division of Minority Opportunities in Research, we offer programs that encourage and prepare underrepresented minority students for research careers. Other programs enhance science curricula and faculty research capabilities at institutions with substantial minority enrollments.

We require our institutional training programs to recruit and retain underrepresented minority students, as well. And we promote diversity of ideas through interdisciplinary training programs and through efforts to bring the expertise of researchers in a variety of fields, from the physical to the behavioral sciences, to bear on biomedical questions. One example is our partnership with the National Science Foundation that supports more than 30 research grants at the interface of biology and mathematics.

#### EXPANDING THE HORIZON

Our increasing knowledge of the biological processes that underpin health and disease holds great promise for new drugs and better diagnostic techniques in the future. A more complete picture of how these processes work—and don't work—may lead to new methods for preventing illness altogether.

At the same time, it is important to remember that breakthroughs are often based on years of scientific research, with each new result building on many previous ones. Each discovery pushes back the frontier and reveals intriguing new questions and avenues for future study. While we can't always predict what we'll find, we can guarantee that the journey will bring us closer to our goal of understanding human health and disease.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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PREPARED STATEMENT OF DR. FRANCIS S. COLLINS, DIRECTOR, NATIONAL HUMAN GENOME RESEARCH INSTITUTE

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Human Genome Research Institute (NHGRI). The fiscal year 2006 budget includes \$490,959,000, an increase of \$2,351,000 over the fiscal year 2005 enacted level of \$488,608,000 comparable for transfers proposed in the President's request.

Cable News Network (CNN) recently named the completion of the Human Genome Project (HGP) the number one health news story of the past 25 years. CNN reported, "Much of the marvel of medicine has to do with discovery. Mapping the human genome, the complete sequence of DNA, gave scientists a blueprint for building a person, making it the No. 1 medical story, according to a distinguished panel CNN gathered to rank the top 25 medical stories of the past quarter-century." As the leader of the HGP, the National Human Genome Research Institute (NHGRI) is very proud of this recognition, but as CNN also pointed out there is still a great deal more to learn.

#### ONGOING NHGRI INITIATIVES

##### *Analysis of the Completed Human Genome Sequence*

In October 2004, the International Human Genome Sequencing Consortium, led in the United States by the NHGRI and the Department of Energy, published a description of the finished human genome sequence in the journal *Nature*. An international team worked to convert the draft genome, published in 2001, into a highly accurate form. The new analysis reduces the estimate of the number of human protein-coding genes from 35,000 to only 20,000–25,000—a surprisingly low number for our species, considering that only a decade ago most scientists thought there would be over 100,000 genes. We now focus on the more difficult task of understanding the function of each of these genes.

##### *Use of Comparative Genomics to Understand the Human Genome*

The availability of the genome sequences of the human, the mouse, the rat and a wide variety of other organisms is driving the development of an exciting new field of biological research, comparative genomics. The NHGRI is funding research comparing the finished reference human genome sequence with that of other organisms, to identify regions of similarity and difference, thus dramatically increasing understanding of the structure and function of human genes to enable development of new strategies to combat human disease.

##### *ENCYCLOPEDIA OF DNA ELEMENTS (ENCODE) PROJECT*

With the goal of identifying the precise location and function of all sequence-based functional elements in the human genome, the NHGRI launched the ENCYCLOPEDIA OF DNA ELEMENTS (ENCODE) project in the fall of 2003. The project is an international consortium of computational and laboratory-based scientists open to all investigators who agree to abide by the project's criteria and guidelines for participation. A manuscript describing the ENCODE project appeared in the October 22, 2004 issue of *Science*, detailing the rationale and strategy behind the quest to produce a comprehensive catalog of all parts of the human genome crucial to biological function, including all protein-coding genes, non-protein-coding genes, regulatory elements involved in the control of gene transcription, and DNA sequences that mediate chromosomal structure and dynamics. All data generated for the ENCODE project are being deposited in free, public databases as soon as they are experimentally verified.

##### *Progress with the HapMap*

All diseases have a hereditary component, but for most common diseases like diabetes, heart disease, and mental illness, the gene variants responsible for the increased risk have been difficult to identify. To solve this problem, an approach to scan large regions of chromosomes to find the genetic variants (called SNPs, or single nucleotide polymorphisms) that increase or decrease the risk of disease is needed. NHGRI has taken a leadership role in the International HapMap Consortium and the development of the HapMap (haplotype map), a catalog of human genetic variations and how that is organized into haplotype "neighborhoods" across the gene. Researchers are already starting to use the HapMap to find genes and variants that contribute to many diseases; it will also be a powerful resource for studying the genetic factors contributing to variation in individual response to disease, drugs, and vaccines.

In February 2005, the International HapMap Consortium completed phase I of the project, ahead of schedule. Boosted by an additional \$3.3 million in public-private support, the NHGRI announced plans to create an even more powerful map of human genetic variation than originally envisioned. The consortium's new goal is an improved version of the HapMap about five times denser than the original plan. This "Phase II" HapMap will test another 4.6 million SNPs from publicly available databases and add that information to the map. The HapMap will be completed in the fall of 2005.

*Gene Variants May Increase Susceptibility to Type 2 Diabetes*

Understanding the genetic basis of the more common, polygenic diseases has traditionally been very difficult. But the tools of genomics, especially HapMap, are beginning to reveal many details about the risk of common diseases that had previously been unapproachable. One disease for which excellent progress has been made towards understanding its genetic cause is Type 2 diabetes. Affecting about 17 million people nationwide, it accounts for 90 to 95 percent of all diabetes cases in the United States. This past year, two international research teams, including one at NHGRI, each found variants in a gene that appears to predispose people to type 2 diabetes, the most common form of the disease. Homing in on a wide stretch of chromosome 20, the teams identified four genetic variants (SNPs) that are strongly associated with type 2 diabetes in Finnish and Ashkenazi Jewish populations and that appear to raise the risk of type 2 diabetes by about 20 to 30 percent. Translating this discovery into a treatment that benefits people with diabetes or those at risk is still years away, but this is a major step in that direction.

## NEW INITIATIVES

*Roadmap—Chemical Genomics*

The Molecular Libraries Roadmap initiative will offer public sector researchers access to libraries of novel small organic molecules that can be used as chemical probes to study the functions of genes, cells, and biochemical pathways. This marriage of chemistry and biology will provide new ways to explore the functions of major components of cells in health and disease. In June 2004, NHGRI announced the establishment of the NIH Chemical Genomics Center, and up to eight pilot extramural centers will be funded at academic institutions and other locations across the country in the spring of 2005. These will function as an integrated network, including a common publicly available database (PubChem, already activated in September 2004) which will display the results of all screens of chemical compounds.

*Human Cancer Genome Project*

The dramatic drop in costs of DNA sequencing, catalyzed by the Human Genome Project, now makes it possible to use sequencing as a major tool for medical research. Doctors and research scientists have long known that cancer is, essentially, a genetic disease. Inherited mutations or acquired genetic alterations can set a normal cell on a path of uncontrolled growth and malignancy. It is now conceivable to identify the complete universe of genes involved in every type of cancer. That is the intent of a bold new NCI/NHGRI proposal for a Human Cancer Genome Project. Such a complete inventory of cancer genes will provide powerful new ways to prevent, diagnose, and treat every major form of the disease.

*The \$1,000 Genome Project*

The ability to determine the complete genome sequence of an individual could revolutionize medical care. In October 2004, NHGRI awarded more than \$38 million in grants to spur the development of innovative technologies designed to reduce the cost of DNA sequencing dramatically. NHGRI's near-term goal is to lower the cost of sequencing a mammalian-sized genome to \$100,000, which would enable researchers to sequence the genomes of hundreds or even thousands of people as part of studies to identify genes that contribute to cancer, diabetes, and other common diseases. Ultimately, NHGRI's vision is to cut the cost of whole-genome sequencing to \$1,000 or less, which would enable the sequencing of individual genomes as part of medical care. The ability to sequence each person's genome cost-effectively could give rise to more individualized strategies for diagnosing, treating, and preventing disease. Such information could enable doctors to tailor therapies to each person's unique genetic profile.

*The U.S. Surgeon General's Family History Initiative*

The U.S. Surgeon General's Family History Initiative was launched on November 8, 2004, with the NHGRI as the lead collaborating federal agency. The purpose of this national public health campaign is to: increase the awareness of the American public and their health professionals about the importance of family history in health; provide tools to gather, understand, evaluate, and use family history to improve health; give health professionals tools to communicate with patients about family history; and increase genomic and health literacy. A web based and print tool entitled "My Family Health Portrait" was developed in both English and Spanish to facilitate collection of family history data. To date, the initiative has been highlighted in more than 1,000 media stories and over 170,000 copies of the tool have been distributed via the World Wide Web and in paper form. This public health campaign is intended to be an annual event.

*ELSI Centers for Excellence Program*

On August 31, 2004, the NHGRI's Ethical Legal and Social Implications (ELSI) research program announced the funding, with contributions from the Department of Energy and the National Institute of Child Health and Human Development, of four interdisciplinary centers as part of its Centers for Excellence in ELSI Research (CEER) program, a new initiative to address some of the most pressing ethical, legal, and social questions facing individuals, families, and communities in the genome era. Each of the centers, based at Duke University, Case Western Reserve University, Stanford University, and the University of Washington, will assemble a team of experts in several disciplines, such as bioethics, law, behavioral and social sciences, clinical research, theology, public policy, and genomic research.

## OTHER AREAS OF INTEREST

*Genetic Education for Health Care Professionals*

The NHGRI has developed numerous educational programs to prepare health care professionals for the integration of genomics into primary health care. A new effort by the NHGRI in this area in 2004 was its work with the American Academy of Family Physicians (AAFP) to develop the AAFP's 2005 Annual Clinical Focus program, which has Genomic Medicine as its theme.

*Genetic Nondiscrimination*

Possibly the greatest impediment to the advancement of genomic science and its application to human health is the fear of genetic discrimination. The NHGRI has worked for ten years to realize a federal solution to this problem. The Secretary's Advisory Committee on Genetics Health and Society has also strongly supported the need for federal legislation. On February 17, 2005 the Senate passed the Genetic Information Nondiscrimination Act of 2005 (S. 306), which would address these fears, and the Bill has now been referred to the House. The Bush Administration has also issued a Statement of Administrative Policy in support of the legislation. This issue remains a high priority for the Institute.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee might have.

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 PREPARED STATEMENT OF DR. PATRICIA A. GRADY, DIRECTOR, NATIONAL INSTITUTE OF NURSING RESEARCH

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Nursing Research (NINR). The fiscal year 2006 budget includes \$138,729,000, an increase of \$657,000 over the fiscal year 2005 enacted level of \$138,072,000 comparable for transfers proposed in the President's request.

I appreciate the opportunity to appear before you today to discuss the exciting work of the National Institute of Nursing Research (NINR) that provides important science to provide necessary improvements in the quality of patient care across the continuum of life. Unique within the NIH, our mission is structured around the science that connects health care providers to patients, their families, and caregivers.

There are many components to our society's healthcare mosaic. Care is delivered through a variety of settings: conventional healthcare sites, community-based clinics, and homes. Patients with exceptional needs—from newborns, the disabled, individuals at the end-of-life—and the underserved, from urban to rural settings, rely on quality care. Through our studies, we seek to understand and manage the symptoms of acute and chronic illness, and thus, to find effective approaches to achieving and sustaining good health.

Let me now share with you some examples of how our research is changing patient care and improving lives.

## MOTHERS AND THEIR YOUNG CHILDREN WITH ASTHMA

Asthma, a chronic and sometimes life threatening condition, is associated with high health costs related to medications, outpatient management, and emergency room visits. Especially for younger children, good asthma management requires close vigilance by the parent or caregiver. Researchers in one study interviewed working mothers of young, inner-city asthmatic children, more than a quarter of whom reported that there was a smoker in the house. While most of the children were under the care of a doctor and were prescribed appropriate asthma medications, many still experienced frequent coughing, wheezing, or shortness of breath.

The mothers often did not give medications for coughing, which can be an early sign of an asthma attack. While most were vigilant and strove to provide good asthma management, the study demonstrated that many mothers lack sufficient information on early asthma symptoms and need additional education about asthma in order to provide the best care for their children.

#### HEALTH DISPARITIES IN RURAL COMMUNITIES

The health care of rural populations is a concern because of poverty, lack of services and/or health vulnerability of the population. NINR's recently funded Rural Nursing and Health Care Research Center provides an interdisciplinary research infrastructure to conduct and disseminate nursing research to address the needs of rural populations. NINR has funded researchers who are making advances with technological interventions for the chronically ill rural populations. The Women to Women project is a computer-based communication intervention that is testing a program of health information and social support for women. The program provides educational tools for self-management skills and studies the risks of isolation and chronic illness. This project has influenced health outcomes by creating a more informed and self-managing patient population. The program may ultimately serve as a model to deliver support and education to remote or vulnerable populations.

#### CARING FOR THE CAREGIVERS

Dementia-related conditions cause a progressive decline in memory, cognition, and physical function, and affect nearly 10 percent of persons over 65 years of age. The behavior of the patient with dementia can range from forgetfulness to dangerous and aggressive activities. Family caregivers often identify the management of this behavior as a major source of distress and burden.

The Savvy Caregiver Program, an educational program for caregivers, increased the skill, knowledge, and confidence of caregivers. In addition, most caregivers reported a decreased sense of burden and improved ability to deal with dementia-related behavior of the patient. The caregivers underscored their belief in the benefits of caregiving, and stated they would recommend the program to others.

When family caregivers cannot manage the patient with dementia at home, they often must place the person in a long term care facility. The Family Involvement in Care program was developed to help family members contribute to the care of the institutionalized patient. This project tested a program for the nurses and staff on the impact of dementia for the family, and on ways to support a continued family presence. Family members reported more positive feedback to the facility, while the staff participants reported positive outcomes regarding the family caregiving role.

#### RESEARCH ON CARE AT THE END OF LIFE

The end-of-life process includes numerous challenges: physical, emotional, spiritual, and financial. There also are challenges in health care systems exacerbated by the lack of continuity among caregivers, disruption of social support networks, unshared clinical information, and multiple physical locations for care. Family members experience role changes, stress, and ultimately, bereavement as their loved one traverses life's continuum.

The NINR is charged with leading the Institutes and Centers for advancing a trans-NIH research agenda on end-of-life care. In this role, we support a broad range of studies designed to improve the management of symptoms associated with the end of life; elucidate the broad issues that affect many families across the nation such as communication among patient, family, and care providers; enhance coping with terminal illness; and examine cultural and ethnic influences on end-of-life care.

In one NINR study, researchers interviewed patients with terminal cancer and found that spiritual well-being helped reduce depression, hopelessness, thoughts of suicide, and the desire to hasten death. The investigators concluded that palliative care clinicians should assess the spiritual beliefs and needs of their terminal patients to help them cope with despair and achieve a sense of peace and meaning in their life.

In December 2004, NINR cosponsored an NIH state-of-the-science conference on end-of-life. Nearly one thousand people from around the world came to NIH to review the existing knowledge base on end-of-life and to recommend opportunities for future research. These recommendations will feature prominently in NINR's forthcoming research plans in this area.

## PALLIATIVE AND END-OF-LIFE CARE IN RURAL AND FRONTIER AREAS

Residents living in rural or frontier areas typically have limited access to health care services, particularly at end-of-life. In fiscal year 2006, NINR will initiate studies focused on understanding the scope of the problems associated with limited access to care in rural areas. These studies will examine ways to improve end-of-life care through the use of technology; develop new methods to use existing networks and services; design culturally appropriate interventions for palliative care; and identify possible alternative settings and methods for providing care and supporting family caregivers.

## BUILDING NURSING RESEARCH CAPACITY

As our nation is experiencing a shortage of nurses, we are also experiencing a shortfall in the number of nurse scientists. NINR is building research capacity with several innovative initiatives, collaborating with universities nationwide to rapidly develop baccalaureate-to-doctoral fast-track programs. The Graduate Partnership Program (GPP) in Biobehavioral Research, a new pilot training program, partners schools of nursing with the NIH intramural program to provide cutting-edge, mentored research training for outstanding doctoral students.

NINR is also supporting Centers to stimulate research and research training opportunities. One example, the *Nursing Partnership Centers to Reduce Health Disparities*, together with the National Center on Minority Health and Health Disparities, partners research-intensive universities with minority-serving institutions.

## NINR AND THE NIH ROADMAP

NINR has identified two key areas of science within the NIH Roadmap, Interdisciplinary Research Teams of the Future and Re-engineering the Clinical Research Enterprise, and integrated them within the nursing research agenda. NINR and its investigators have extensive experience in conducting interdisciplinary research projects. Currently, more than one-half of NINR-funded studies appear in non-nursing journals. This shows the promise of future interdisciplinary collaborations and the value of nursing research findings by other disciplines. In the area of improving the clinical research enterprise, most of NINR's research is clinical in nature and research questions are evaluated from the clinical researcher's perspective. Investigators translate research findings into the clinical practice of healthcare providers and develop partnerships to speed new scientific knowledge into mainstream health care.

## CONCLUSION

In conclusion, NINR strives to improve the quality of life and quality of health through every stage of life, especially for the most vulnerable in our society. We are committed to training the next generation of nurse researchers, and to continuing to fund rigorous and innovative programs of research to enhance the health of our nation.

Thank you, Mr. Chairman. I will be pleased to answer any questions that the Committee might have.

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 PREPARED STATEMENT OF DR. RICHARD J. HODES, DIRECTOR, NATIONAL INSTITUTE ON AGING

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute on Aging (NIA). The fiscal year 2006 budget includes \$1,057,203,000, an increase of \$5,213,000, or 0.5 percent over fiscal year 2005 enacted level of \$1,051,990,000 comparable for transfers proposed in the President's request.

Thank you for the opportunity to participate in today's hearing. I am Dr. Richard Hodes, Director of the National Institute on Aging, and I am pleased to be here today to tell you about our progress making and communicating scientific discoveries that will improve the health and well-being of older Americans.

There are today approximately 35 million Americans ages 65 and over, according to the U.S. Bureau of the Census, and this number is expected to rise dramatically in the coming decades. The mission of the National Institute on Aging (NIA) is to improve the health and well-being of these older Americans through research. In support of its mission, the Institute conducts and supports an extensive program of research on all aspects of aging, from the basic cellular and molecular changes that occur as we age, to the prevention and treatment of common age-related conditions,

to the behavioral and social aspects of growing older, including the demographic and economic implications of an aging society. In addition, the NIA is the lead federal agency for research related to the all-important effort to prevent and treat Alzheimer's disease (AD). Finally, our education and outreach programs provide vital information to older people across the Nation on a wide variety of topics, including living with chronic conditions, maintaining optimal health, and caregiving.

#### ALZHEIMER'S DISEASE AND THE NEUROSCIENCE OF AGING

AD is a devastating condition with a profound impact on individuals, families, the health care system, and society as a whole. Approximately 4.5 million Americans are currently battling AD, with annual costs for the disease estimated to exceed \$100 billion.<sup>1</sup> Moreover, the rapid aging of the American population threatens to increase this burden significantly in the coming decades: By the year 2050, the number of Americans with AD could rise to some 13.2 million, an almost three-fold increase.<sup>2</sup>

These statistics lend an urgency to the NIA's efforts to better understand, prevent, and treat AD, and in the past year, we have made several important steps forward. For example, a priority for the NIA is to identify risk factors for AD, as interventions that impact the effect of a risk or preventative factor could potentially delay the onset of the disease or prevent it altogether. Results from several recent studies have associated diabetes, which affects about one in five persons over age 60 years,<sup>3</sup> with increased risk of cognitive impairment, including AD, raising the possibility that prevention strategies for diabetes may also have major consequences for preventing or delaying AD.

Evidence is also mounting that lifestyle choices may affect risk of AD. In one recent study, older dogs on a regimen of regular physical exercise and mental stimulation and a diet fortified with plenty of fruits, vegetables, and vitamins performed better on cognitive tests and were better able to learn new tasks than dogs in a "control group." Although the results of this study need to be replicated in humans, they do provide evidence that diet and mental exercise may protect against late-life cognitive decline, and that they may work more effectively in combination than by themselves.

An area of some controversy has been the effects of hormonal influences on cognitive aging in women, with some studies demonstrating a decreased risk for AD among users of hormone therapy and others, notably the Women's Health Initiative Memory Study (WHIMS), showing that post-menopausal women on certain regimens were actually at higher risk for cognitive decline. The risks and benefits of hormone therapy remain under study. One new avenue of inquiry is the use of selective estrogen receptor modulators (SERMs) to prevent cognitive decline. SERMs mimic estrogen's actions in some tissues but block the action of the body's naturally occurring estrogen in others, offering the benefits of traditional hormone therapy with fewer potential health risks. In a recent study, the SERM raloxifene (Evista®), frequently prescribed for the prevention and treatment of osteoporosis, appeared to reduce the risk of cognitive impairment in postmenopausal women. More research is needed, but this is a promising area of research.

The first NIH AD prevention trial, comparing the effects of vitamin E and donepezil (Aricept®) in preventing AD in people diagnosed with mild cognitive impairment (MCI), often a precursor condition to AD, recently concluded. Preliminary data indicate that people with MCI taking donepezil were at reduced risk of progressing to AD for the first 18 months of the 3-year study when compared with their counterparts on placebo. The reduced risk of progressing from MCI to a diagnosis of AD disappeared after 18 months, and by the end of the study, the probability of progressing to AD was the same in the two groups.

NIA is currently supporting over 20 additional AD clinical trials, including large-scale prevention trials, which are testing agents such as anti-inflammatory drugs, statins, homocysteine-lowering vitamins, and anti-oxidants for their effects on slowing progress of the disease, delaying AD's onset, or preventing the disease altogether. Trials are also assessing interventions for the behavioral symptoms (agita-

<sup>1</sup>Data from the Alzheimer's Association. See also Ernst, RL; Hay, JW. "The U.S. Economic and Social Costs of Alzheimer's Disease Revisited." *American Journal of Public Health* 1994; 84(8): 1261-1264. This study cites figures based on 1991 data, which were updated in the journal's press release to 1994 figures.

<sup>2</sup>Hebert, LE et al. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* August 2003; 60 (8): 1119-1122.

<sup>3</sup>See <http://diabetes.niddk.nih.gov/dm/pubs/statistics/index.htm>. Statistics are taken from the 1999-2001 National Health Interview Survey and 1999-2000 National Health and Nutrition Examination Survey (estimates projected to year 2002).



tion, aggression, and sleep disorders) of people with AD. The Institute also supports the development of new agents for AD prevention and treatment, including chemical compounds to validate new drug targets, an activity with relevance to the "Molecular Libraries" area of the NIH Roadmap.

This year, we have moved forward with two major AD initiatives. The Alzheimer's Disease Neuroimaging Initiative, a longitudinal, prospective, natural history study of normal aging, mild cognitive impairment, and early AD to evaluate neuroimaging techniques such as magnetic resonance imaging (MRI) and positron emission tomography (PET), was funded, with funding also identified for several ancillary studies. This ambitious initiative is being implemented jointly with several other NIH Institutes, academic institutions, and industry partners, and exemplifies the potential for scientific discovery that is the goal of the NIH Roadmap component on Public-Private Partnerships.

The NIA is accelerating the pace of Alzheimer's disease genetics research with its AD Genetics Initiative, a major new program to speed the creation of a large repository of DNA and cell lines from families with multiple AD cases. The goal of this initiative is to develop the resources necessary for identifying the remaining late-onset AD (LOAD) risk factor genes, associated environmental factors, and the interactions of genes and the environment. To aid recruiting efforts, the NIA Alzheimer's Disease Education and Referral Center worked closely with the Alzheimer's Association as well as several academic partners to publicize the initiative.

In addition to AD, the NIA supports research on other neurological diseases, including Parkinson's disease, frontotemporal dementia, and prion diseases. For example, NIA investigators, along with researchers from the National Institute of Neurological Disorders and Stroke, were part of an international research team that identified a mutation that is believed to be the most common genetic cause of Parkinson's disease identified to date. This discovery could lead to the development of a test to detect the mutation in individuals at risk.

#### OTHER AGING-RELATED RESEARCH

Diseases of aging continue to affect many older men and women, seriously compromising their quality of life. Diseases and conditions currently under study at the NIA include:

*Anemia.*—Recently, NIA investigators found an overall prevalence of anemia of 11 percent in men and 10.2 percent in women ages 65 years and older, with prevalence increasing dramatically over age 85. The American Society of Hematology (ASH) has worked closely with several NIH institutes to establish a research agenda on anemia in the elderly. An ASH workshop, "Clinical Implications of Anemia in the Elderly," was held in March 2004 to establish a research agenda on anemia in the elderly; a report of this workshop will be published in the journal *Blood* in spring 2005. Program staff from NIA and several other NIH Institutes participated in the ASH workshop and will work collaboratively to identify research priorities. In addition, the NIA is developing an initiative to stimulate a broad range of research on anemia in the elderly that will inform efforts to decrease the associated functional impairment, morbidity and decreased survival.

*Obesity.*—According to the National Health and Nutrition Examination Survey, some 64 percent of U.S. adults are either overweight or obese. Excess weight and obesity are linked with an array of conditions, including diabetes, osteoarthritis, and cardiovascular disease. As we age, we tend to gain fat, which may interfere with the work of tissues in which it accumulates. For example, marrow in most bones becomes partially or wholly replaced by adipose (fat) cells, and fat accumulates around and infiltrates the bundles of muscle fibers in muscles of the limbs and trunk. The accumulation of fat in the muscle appears to be doubly dangerous, interfering with both mechanical function of the muscles and insulin sensitivity. The NIA is planning an initiative to stimulate research exploring adipogenesis in aging—i.e., the origin of the increased propensity to form fat cells, and its impact on tissues and systems. This area of research has the potential to broadly impact our understanding of both the decline in function of individual tissues in the musculoskeletal system, and the frequently seen changes in glucose metabolism and insulin sensitivity with age.

*Elder Abuse and Mistreatment.*—Many older Americans are vulnerable to mistreatment, including physical and psychological abuse, neglect, and financial exploitation. However, the scope of the problem remains unknown. The National Research Council (NRC), at the request of the NIA, established a Panel to review risk and prevalence of elder abuse and neglect. The Panel's 2003 report, *Elder Mistreatment. Abuse, Neglect, and Exploitation in an Aging America*, outlines a number of key priorities, including the development of operational definitions of elder mistreatment

and the development of reliable and valid measures of prevalence. To that end, the NIA is planning a pilot program to develop the tools to accurately assess the prevalence of elder abuse, a necessary first step in developing interventions.

A number of the NIH Roadmap initiatives are particularly relevant to aging research. For example, small molecule development, by providing chemical compounds to validate new drug targets, is crucial to the development of drugs for a variety of age-related diseases, degenerative conditions, and disabilities. Another Roadmap initiative has established a network of investigators to improve the measurement of patient-reported outcomes, and ongoing projects of particular relevance to the aged population are addressing pain, fatigue, arthritis, psychiatric symptoms, including depression, and social functioning.

#### HEALTH COMMUNICATIONS AND PROMOTION

Last year, the NIH launched NIHSeniorHealth.gov, a unique web site developed by NIA and the National Library of Medicine and geared toward the health needs of older adults. In its first year, the site was extremely successful, attracting some 380,000 unique visitors and garnering over three million page views. It was the only web site to receive an "Industry Innovators Award" from the International Council on Active Aging. A Spanish-language version of the site is currently under development.

*Meals on Wheels Initiative.*—During a 2002 Congressional hearing, it was recommended that NIA and the Administration on Aging (AoA) work together to disseminate research-based consumer education materials to the thousands of seniors who participate in the Meals-on-Wheels (MOW) program. In participation with AoA, NIA conducted focus groups with the MOW Association of America to identify the types of information of greatest interest to MOW's clients and the best ways to deliver such information. Now, a new booklet entitled "Take Your Medicines the Right Way—Everyday!" is being made available to MOW providers for their clients free of charge. The booklet is in easy-to-read language and covers important steps to help ensure safe and effective medication use.

#### DEMOGRAPHY

As the percentage of Americans over age 65 increases, profound societal changes will likely occur. NIA-supported researchers are exploring the changing demographic, social, and economic characteristics of the older population. The results of this research often have important implications for public policy. A major source of demographic data on aging is the Health and Retirement Study, a biennial survey of more than 22,000 Americans over age 50, which provides data for researchers, policy analysts, and program planners who are making major policy decisions that affect retirement, health insurance, saving and economic well-being. In 2004, the NIA added a cohort of "Early Baby Boomers" to this study; this will provide crucial information on the savings, retirement, and health behaviors of tens of millions of Americans now approaching retirement age.

Thank you for the opportunity to testify before this Subcommittee. I would be happy to answer any questions you may have.

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#### PREPARED STATEMENT OF DR. SHARON H. HRYNKOW, ACTING DIRECTOR, FOGARTY INTERNATIONAL CENTER

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's Budget for the Fogarty International Center (FIC). The fiscal year 2006 budget includes \$67,048,000, which reflects an increase of \$416,000 over the fiscal year 2005 enacted level of \$66,632,000 comparable for transfers proposed in the President's request.

Many years ago, President John F. Kennedy noted that "A rising tide lifts all the boats. And a partnership, by definition, serves both partners, without domination or unfair advantage." These words serve to remind us of the importance of working in partnership with those around the world, on equal footing, and for the common good. Congressman John E. Fogarty, for whom our Center is named, also shared this belief and worked tirelessly to champion improved health of Americans in a healthier world—through international health research and training programs.

Today, the vision of Congressman Fogarty continues to inspire the Center in building international partnerships on behalf of the National Institutes of Health (NIH) and in supporting research and training programs to advance the objectives of global health. FIC's unique mission and initiatives add value, complement NIH

international programs and build scientific capacity around the world for the benefit of Americans and the global community.

I welcome this opportunity to discuss briefly FIC's progress over the past year as well as our proposed plans for fiscal year 2006. Developed with the support and guidance of the Administration and this Committee, the Fogarty programs reflect our nation's enduring commitment to global health as well as vibrant, and equal, international collaborations.

#### GLOBAL BURDENS OF ILL HEALTH

The health challenges we face as Americans and as members of a global community are many. HIV/AIDS and tuberculosis continue to rise at alarming rates. SARS, West Nile Virus, and avian flu are constant threats to global health and economies. At the same time, as chronic diseases such as cancer, cardiovascular disease, and mental health disorders increase year after year, taking enormous tolls in human suffering and economic costs, the development and deployment of more effective preventive and treatment measures is urgent.

The Fogarty response to these challenges is to support a range of critical research and training programs, each designed to tackle specific health problems shared by United States and foreign populations. We work in partnership with universities in the United States, low- and middle-income nations, and our fellow Institutes at the NIH, the Centers for Disease Control and Prevention, the World Health Organization, and others to effect change. Fogarty supports over 20 research and training programs in more than 100 countries, involving more than 5,000 scientists in the United States and abroad. HIV/AIDS, TB, maternal and child health, environmental health and bioethics are just a few of the priority program areas in which Fogarty and its partners are making an impact.

#### IMPACT OF FOGARTY PROGRAMS

I want to share with you two examples to highlight the impact of Fogarty programs worldwide. The first is a genealogy of sorts of one scientist's career path and support by Fogarty. Dr. Lee Riley of the University of California at Berkeley traces his professional roots to Dr. Warren D. Johnson, Jr. of the Weill Medical College of Cornell University. Both have dedicated decades of their professional careers to understanding, preventing, and treating infectious diseases in the slums of Brazil. It all started in 1988 when Dr. Johnson received FIC support to train AIDS scientists in Brazil. When Dr. Riley joined the Cornell faculty in 1990, Dr. Johnson brought him into the AIDS training effort and allowed Dr. Riley to initiate additional training activities on tuberculosis diagnostics and pathogenesis. When Dr. Riley moved to the University of California at Berkeley in 1996, he competed successfully for his own training program in Brazil through Fogarty's International Training and Research in Emerging Infectious Diseases Program (ITREID). Dr. Johnson received a similar ITREID program grant at Cornell, enabling the two to coordinate and synergize their training activities. Dr. Riley's group ultimately expanded the ITREID program to other countries in Latin America as well as to Eastern Europe, and Dr. Riley competed successfully for a new FIC-supported grant on Global Infectious Disease Training and Research in Brazil.

The results and impact of these 17 yearlong partnerships have been enormous. In terms of people and publications, thirty Brazilian investigators have been trained in the United States, 29 of whom are still active researchers in Brazil; 28 articles have been published in top scientific journals; 12 Ph.D. and 3 Masters degrees in public health have been conferred; and, a large number of allied health professionals, many of whom are or were residents of slums, have received project-related training. Just one of the trainees who has returned to Brazil, Dr. Albert Ko, has trained over 50 local staff—both laboratory and field—over the last eight years, and he has now received his own FIC training award. Other trainees are applying for and are receiving funds from NIH and other research agencies.

Critically, the wealth of knowledge generated has been enormous. New understandings have emerged of the causes and treatments of leptospirosis, a disease that impacts primarily young people. Patterns of the spread of tuberculosis in crowded situations have been uncovered, and prevention strategies deployed. Training of health scientists from Brazil through the FIC AIDS training programs led to a major research grant from the National Institute of Allergy and Infectious Diseases for the study of the pathogenesis of leishmaniasis in Brazil and for a subsequent Fogarty award in infectious disease training. Training through the FIC AIDS training programs has helped Brazil evaluate the effectiveness of antiretroviral therapy programs that have served as a model and inspiration to other developing countries. The partnerships have generated millions of dollars of additional support from

Brazil, Spain, Mexico, and other nations to sustain the research and training activities. And, the relationships and partnerships that have been built over time are the ones that will allow future studies to move ahead expeditiously.

The second example is from a research project involving a 1996 pilot program in Orizaba, Mexico working to evaluate the impact of Directly Observed Therapy (Short-Course) (DOTS) in populations with drug-resistant tuberculosis. DOTS is the WHO recommended TB treatment regimen whereby TB patients are monitored daily to ensure that medications are taken properly. In this region, 21 percent of the new cases were resistant to at least one anti-tuberculosis drug and 3 percent were multi-drug resistant (MDR) over a five-year period. The data collected demonstrated that DOTS could rapidly reduce transmission and the incidence of both drug-susceptible and drug-resistant tuberculosis. The case rates of multi-drug resistant tuberculosis were also reduced; however, the fatality rate was highest (12 percent) for patients infected with resistant strains. In a developing country with a moderate rate of drug-resistant tuberculosis, DOTS can rapidly reduce the transmission of both susceptible and resistant organisms. Additional studies are now under way to expand on these initial findings.

#### FISCAL YEAR 2006 INITIATIVES

FIC will continue to support the NIH Roadmap for Medical Research in the 21st Century. Working with partners across NIH and universities around the world, FIC will foster interdisciplinary programs in clinical research training, identify novel technologies to combat global health threats, and expand efforts to bring experts from multiple disciplines together to advance NIH Roadmap goals. In keeping with the Roadmap, FIC will work in fiscal year 2006 to bring new partners into the global health enterprise. FIC will support the Framework Programs for Global Health to link multiple schools within the same university (or coupled universities) around the topic of global health, bringing business, journalism, social science, engineering, medicine, law, public health and other disciplines into the global health arena in the university setting. A second goal will be to energize the next generation of global health leaders through development of undergraduate and graduate curricula on global health. This effort will propel global health efforts forward in new ways in the United States and abroad.

FIC will enhance its two main programs to address HIV/AIDS and related TB challenges. Fogarty's AIDS International Research and Training Program builds capacity in resource poor nations to tackle the AIDS problem through science and evidence-based policies. Working through 25 U.S. universities, educational programs support post-doctoral, doctoral, Masters level work, and training for allied health professionals, including nurses, to advance research on vaccine development and microbicide development, to identify groups at high-risk for exposure and to help support the development of interventions that make sense at the local and community levels. Nearly 2,000 developing country researchers from over 100 countries have been trained in the United States, many at senior levels, and more than 50,000 through in-country workshops and courses. More than 80 percent of those trained in the United States through this program returned home to pursue research and health efforts locally. And, recognizing the need for clinical and health systems researchers for AIDS and TB, FIC launched a unique International Clinical, Operational and Health Services Research Training Award program to meet these needs. Today, under this program, experts in Uganda, Haiti, Russia, and China are working with U.S. partners to advance AIDS prevention and treatment strategies through targeted training efforts and to monitor the effectiveness of AIDS drug delivery paradigms. These programs support the goals of the President's Emergency Plan for AIDS Relief and the Global Fund and will lead to useful insights about effective drug delivery approaches in resource poor nations.

As a third emphasis area, FIC will expand in fiscal year 2006 its pilot program to support NIH Alumni Associations abroad. These Associations will serve an important role to junior scientists as they return home through support of networking activities in which to share information and expertise, and other activities. At the same time, they will allow U.S. scientists to maintain collaborative ties. Building on efforts in Brazil, Mexico, South Africa, India and China, FIC will expand this effort to include Central and Eastern Europe, Russia and Thailand.

As a fourth emphasis area in 2006, FIC will expand efforts in the neurosciences. With the exception of sub-Saharan Africa, brain disorders are the leading contributor to the years lived with disability in all regions of the world. More than 150 million people suffer from depression at any point in time and nearly one million commit suicide each year. Worldwide, about 25 million people suffer from schizophrenia and 38 million from epilepsy. FIC, in partnership with the National Insti-

tute of Neurological Disorders and Stroke and other NIH Institutes, will continue its efforts to develop new knowledge and technologies to enhance the understanding of brain disorders in resource poor settings around the world. Much of the research funded by this program could have implications for how certain brain disorders are studied, diagnosed, and treated in the United States.

#### CONCLUSION

The global health challenges we face are many, but the international partnerships supported by Fogarty and its partners are a bedrock upon which scientific progress will be made to the benefit of the American people and the global community.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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#### PREPARED STATEMENT OF DR. THOMAS R. INSEL, DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH

Mr. Chairman, and members of the Committee, I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Mental Health (NIMH). The fiscal year 2006 budget includes \$1,417,692,000, which reflects an increase of \$5,759,000 over the 2005 enacted level of \$1,411,933,000 comparable for transfers proposed in the President's request. In my statement, I will call to your attention our Nation's immense burden of mental and behavioral disorders and include a brief review of our research activities and accomplishments.

#### BURDEN OF MENTAL ILLNESS

The mission of the National Institute of Mental Health (NIMH) is to reduce the public health burden of mental and behavioral disorders. New scientific discoveries and powerful new tools are revealing the mechanisms involved in the pathophysiology of mental disorders. This is a vital step in the development of more effective strategies to manage, treat, and even prevent these debilitating disorders.

The report of the President's New Freedom Commission: Achieving the Promise—Transforming Mental Health Care in America defined the challenge. The burden of these disorders is staggering, in terms of both morbidity and mortality. Mental illness represents 4 of the top 6 sources of disability from medical causes for Americans ages 15–44 according to the World Health Organization; suicide accounts for more deaths each year than either homicide or AIDS. Recent estimates in the President's report put the economic costs of treating mental disorders at \$150 billion, with elements of these costs increasing beyond 20 percent per year. The report called for a transformation of mental health care, with recovery as a goal. NIMH is working closely with the Substance Abuse and Mental Health Services Administration (SAMHSA) as it seeks to carry out this mandate.

#### PRIORITY SETTING

This past year NIMH searched for creative ways in which to optimize its impact on public health; the Institute and its stakeholders endeavored to reevaluate priorities for funding research. To help with this process, two workgroups of the National Advisory Mental Health Council were formed: one to review the NIMH extramural clinical treatment portfolio and one to review the basic sciences research portfolio.

The goal of the clinical treatment workgroup was to help NIMH focus strategically in its support of therapeutics and interventions research. The workgroup's report describes clinical areas where more study is essential, and urges increased innovation and a sharpened focus on amplifying the impact of clinical trials on clinical practice. The report also cites the need to expand core resources and clinical trials infrastructure for NIMH to enhance its treatment development capacity.

The workgroup reviewing the basic sciences research portfolio outlined specific tools and areas of research particularly ripe for increased investment, such as the pathophysiology of mental disorders and the translation of basic science discoveries into biomarkers, diagnostic tests, and new treatments.

Translation of basic science to clinical issues and practice is now a major focus of the Institute. This past year, NIMH reorganized its extramural programs into five research divisions (from three) to focus on: basic science, translational research for adults, translational research for children and adolescents, behavioral effects on health (including HIV/AIDS spread and prevention), and psychiatric services and treatments. A key aim of the reorganization is accelerating translation of the best ideas in neuroscience and behavioral research into the clinics and out into the community.

Rapid advances in mental health research are revealing the biological and environmental components of major mental illness. We now recognize that mental disorders are brain disorders, and we now have the tools to identify the brain circuits involved. Of note is recent research on improved detection of disease with biomarkers and development of personalized treatments.

#### REVEALING THE BIOLOGICAL BASIS OF MENTAL DISORDERS

A major goal for NIMH is to identify the biological basis of mental disorders to more precisely pinpoint targets for prevention and treatment. This means understanding the neural basis of the illness at all levels, from molecular to behavioral. For instance, imaging studies suggest that ischemia (restriction of blood flow in the brain due to a narrowed or blocked artery) may significantly contribute to the development of a form of depression. In a recent clinical trial, more than half of elderly depressed participants met the criteria for this newly recognized form of depression called "ischemic depression." This realization should help improve diagnosis, and more effectively guide treatment for those with late-life depression.

A recent NIMH study shows that in people with panic disorder, a type of receptor for serotonin (a mood-regulating neurotransmitter) is reduced by nearly a third in several structures of the brain that mediate anxiety. The finding is the first in living humans to show that this specific receptor, which is pivotal to the action of anti-anxiety medications, may be abnormal in the disorder and may help explain how genes might influence vulnerability for panic and anxiety disorders.

A recent translational study on post-traumatic stress disorder (PTSD) was the first to demonstrate in humans the importance of a particular brain region in "fear extinction"—the process by which a previously learned fear is extinguished by a new form of learning, rather than the forgetting of the original fear. The brain region is associated not with emotion, but with the regulation of higher cognitive functions. This will provide important contributions to the understanding and treatment of PTSD and other anxiety disorders.

Several studies on depression have suggested that the formation of new neurons (neurogenesis) might be hindered in those with the disorder. In addition, animal studies have demonstrated that antidepressant medications are likely effective because they help increase neurogenesis. Several genes have been implicated in the susceptibility to schizophrenia and depression. In the past year, we have learned that common genetic variations bias the way the brain works, even in people who have not developed a major mental disorder. For instance, a gene variant that is especially common in people with depression is associated with a higher level of brain activation in response to threat or stress. A variant associated with schizophrenia appears to increase the amount of activity in the frontal lobe needed to perform complex attentional tasks. These kinds of studies reveal how subtle genetic variations may increase vulnerability to mental illness. Ultimately, this may provide a strategy for early detection and prevention of a psychotic or depressive episode based on identifying individuals at genetic highest risk, just as we routinely intervene in those with high blood pressure and high cholesterol to prevent a heart attack.

Autism continues to be an increasing priority for NIH. We are just beginning to see the pay-offs of cross-Institute investments in several new centers and projects. Previous studies show that on average, autism is not diagnosed in children until after the age of 6, a relatively late age considering that early intervention is critical for the best treatment response. Thus, NIMH research will help develop new tools for detecting autism early, before age two. In addition, NIMH is part of a public/private research consortium focusing on the study of infant siblings of children with autism, to help identify early features and distinguishing characteristics of autism. NIMH and other NIH institutes are collaborating with voluntary and private funding organizations and government agencies internationally to develop a new research initiative (\$21.5 million over 5 years) to identify specific gene variants that produce susceptibility to autism.

#### TREATMENTS FOR RECOVERY

The first of several large, NIMH-funded clinical studies testing various treatment options for those with serious mental illnesses was completed last summer: a 13-site trial aimed at defining the most effective and safe treatment for children and adolescents with major depressive disorder. Depression is an important risk factor for suicide, the third leading cause of death among adolescents; it is also a major risk factor for long-term psychosocial impairment in adulthood. There has been much debate about whether a class of antidepressant medications, selective serotonin re-uptake inhibitors (SSRIs) can actually increase suicidal thinking. At

present, fluoxetine (Prozac) is the only FDA-approved medication for depression in children and adolescents, and there have been conflicting results regarding its benefits and risks. The goal of the NIMH trial was to clarify the usefulness of treating adolescent depression with a type of psychotherapy called cognitive behavior therapy (CBT), or fluoxetine, or both. Results of the first 12 weeks found that a combination of fluoxetine and CBT was the most effective treatment (71 percent response rate). Of the other three treatment groups, fluoxetine alone, (60.6 percent response), but not CBT alone (43.2 percent response) was significantly better than placebo (34.8 percent response). Suicidal thinking, which was present in 29 percent of the participants at the beginning of the study, improved significantly in all four treatment groups, with those receiving medication and therapy showing the greatest reduction (below 8 percent). Soon we will know the effectiveness of these treatments over a six-month period from treatment initiation. It is critical for physicians and psychotherapists to closely monitor their young patients on antidepressant medications for signs of hurtful or suicidal behavior, particularly during the early phases of treatment.

A central focus of NIMH treatment research has been finding a more tailored, individual approach to therapy. To personalize treatments, we need to know predictors of treatment response. Recent studies have begun to reveal some predictors that will help clinicians optimize care. For instance, studies of people with major depressive disorder reveal that standard antidepressant medication may be less helpful in those with a history of trauma, or specific genetic variations, or specific patterns of brain activation as seen on imaging scans. These same patients may respond well to cognitive behavior therapy. Similarly, patients with schizophrenia who have poor attentional processing and other cognitive deficits may report less satisfaction with anti-psychotic medications, which were not designed to treat these features of the illness. Ongoing research seeks to find markers that will guide individual treatment to optimize recovery.

Other large trials to be completed within the next year will answer urgent questions about the choice of treatments in people with bipolar disorder, schizophrenia and Alzheimer's, and treatment-resistant major depression. NIMH continues its strong commitment to public dissemination of findings from these clinical trials by fostering partnerships with national and state organizations via the Outreach Partnership Program. Through this program, NIMH works with the National Institute on Drug Abuse and SAMHSA to bridge the gap between research and clinical practice.

#### BLUEPRINT FOR NEUROSCIENCE RESEARCH

The NIH Blueprint for Neuroscience is a framework to enhance cooperation among the 15 NIH Institutes and Centers that have common interests in the nervous system. By pooling resources and expertise, the Institutes and Centers can take advantage of economies of scale, confront challenges too large for any single Institute, and develop research tools and infrastructure that will serve the entire neuroscience community. The Blueprint is developing a primary set of initiatives including a gateway to existing databases that permits more effective searches; training enhancement for basic neuroscientists; and expansion of ongoing pediatric imaging, gene microarray, and gene expression database efforts.

#### NIH ROADMAP

NIMH has assumed a lead role on the Molecular Libraries and Imaging initiative of the NIH Roadmap, whose goal is to provide organic compounds called "small molecules" to scientists to use as tools to improve our understanding of biological pathways in health and disease. The potential of scientific discoveries of clinical relevance is enormous. The NIMH mission can be advanced by the identification of even one novel small molecule with biological activity in the brain, as it could provide invaluable information about brain circuits involved in mental illness and those that are altered by treatment.

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#### PREPARED STATEMENT OF DR. STEPHEN I. KATZ, DIRECTOR, NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). The fiscal year 2006 budget includes \$513,063,000, an increase of \$1,906,000 over the comparable fiscal year 2005 en-

acted level of \$511,157,000 comparable for transfers proposed in the President's request.

Improving daily life is the driving force for the research that we support and conduct at the NIAMS. Virtually every home in America is touched by diseases affecting bones, joints, muscles, and skin. We are committed to improving our understanding, diagnosis, treatment, and prevention of these diseases and disorders that are typically costly, chronic, and disabling, many of which disproportionately affect women and minority populations. I am delighted to share highlights of our research progress as well as our plans.

#### THE NIH ROADMAP FOR MEDICAL RESEARCH

The NIAMS is pleased to partner with other NIH components in the many dimensions of the NIH Roadmap, and the Institute has responsibility for the management of an initiative for a patient-reported outcomes measurement information system—or PROMIS—network. The goal of this initiative is to develop ways to measure patient-reported symptoms such as pain and fatigue and aspects of health-related quality of life across a wide variety of chronic diseases and conditions. The PROMIS initiative will develop a publicly available computerized adaptive test for the clinical research community. Many diseases that compromise daily life involve pain, fatigue, and other difficult-to-measure quality of life outcomes, and the development of a test to measure changes in these symptoms will be of benefit to patients and their health care providers.

#### RESEARCH IN CHILDREN

When arthritis and other rheumatic diseases affect children, they can significantly compromise a child's ability to enjoy an active life. NIAMS-supported researchers have launched a state-of-the-art genomics project, and the goal of this project is to take full advantage of the tremendous progress that has been realized in genetics and genomics, and to uncover gene expression patterns (groups of genes that are "turned on" or "turned off") that contribute to the development of pediatric arthritis. The NIAMS and a chapter of the Arthritis Foundation and the Schmidlapp Trust are supporting this study of children newly diagnosed with a variety of pediatric diseases such as juvenile rheumatoid arthritis, juvenile ankylosing spondylitis (or spinal arthritis) and other related immune disorders. Identifying the gene expression patterns for different types of arthritis in children will help to improve diagnosis as well as to predict the severity of disease for affected children.

In other studies supported by the NIAMS, the promise of genetic studies was underscored by the identification of a gene variant that increases susceptibility to juvenile arthritis. The NIAMS and the Arthritis Research Campaign funded researchers from around the world who worked collaboratively in collecting DNA samples from children with juvenile rheumatoid arthritis and their parents. Research findings suggest that there may be distinct genetic profiles for the disease that result in differences in age of onset as well as disease severity.

#### BIOMARKERS OF DISEASE

Progress in identifying the onset and progression of disease is a challenge in many chronic diseases, and the NIAMS has taken the lead in three initiatives to address this challenge: the first is the Osteoarthritis Initiative—a public-private partnership that the NIAMS, the National Institute on Aging, several other NIH components, and three pharmaceutical companies support that is working to develop clinical research resources for the discovery and evaluation of biomarkers and surrogate endpoints for clinical trials on osteoarthritis (the most common form of arthritis). Data and images collected will be available to researchers around the world to speed the pace of research in biomarker identification, and this consortium is expected to serve as a model for initiatives in the future that involve public and private partnerships. We have already enrolled 1,900 individuals to participate in this Initiative. The second initiative is the creation of the Osteoarthritis Biomarkers Network involving institutions in the United States and Sweden. This Network facilitates the sharing of clinical, biological, and human resources to more rapidly and more effectively identify biomarkers for osteoarthritis. In the third biomarker initiative, the NIAMS supports the Autoimmune Biomarkers Collaborative Network which includes efforts to identify and validate biomarkers for lupus—a serious and potentially fatal autoimmune disease that occurs with greater frequency and intensity in African American women, and that affects many organ systems of the body.



## ARTHRITIS AND OTHER RHEUMATIC DISEASES

Rheumatoid arthritis is an autoimmune disease, and affected individuals often must be treated with powerful drugs that may help to keep the disease better controlled, but also suppress the immune system—leaving patients particularly vulnerable to infection. NIAMS-supported researchers have identified a potential treatment that will suppress the abnormal, autoimmune response that causes the rheumatoid arthritis, but does not diminish the patient's ability to fight bacteria and viruses. The treatment is a synthetic peptide (a chain of amino acids) called dnaJP1—a particular section of a protein that has the same characteristic amino acid sequence as that found in patients with rheumatoid arthritis. In initial studies a synthetic version of the dnaJP1 peptide was given to patients with rheumatoid arthritis with the goal of blocking the immune response, and the immune system responses were normal in these treated patients. The NIAMS partnered with the National Institute of Allergy and Infectious Diseases, the Royal Netherlands Academy of Arts and Sciences, and the Dutch Organization for Scientific Research in funding this study. A new larger study will be undertaken to pursue studies of this promising synthetic peptide for people with rheumatoid arthritis.

Fibromyalgia is a disease that affects many systems of the body, affects women far more commonly than men, and is characterized by low pain thresholds at specific tender points in the body. NIAMS-supported researchers have furthered our understanding of fibromyalgia in recent studies that determined that fibromyalgia was strongly aggregated in families, and that the number of tender points as well as total muscle pain scores were strongly associated with fibromyalgia in families. In addition, there was an increase in the presence of mood disorders in relatives of fibromyalgia patients. This aggregation of fibromyalgia in families suggests that genetic factors may play an important role in this disease. The NIAMS supported a workshop in November 2004 that reviewed the state of the science and a view to future studies in fibromyalgia.

## BONE AND MUSCULOSKELETAL DISEASES

Osteoporosis is characterized by bone thinning that results in increased susceptibility to fracture. A particular clinical challenge has been that often the first indication of osteoporosis is when a person (most often a woman) has a bone fracture, and by then the bone has already thinned. Better methods are needed to screen for osteoporosis and for those who are at high risk for fractures. Researchers have recently learned that bony regions of conventional dental x-rays may be useful in evaluating both the current micro-architecture of bone as well as following changes in bone over time. Bone quality plays a critical role in osteoporosis and other bone diseases, and the NIAMS has partnered with the American Society for Bone and Mineral Research in sponsoring a meeting in May 2005 to evaluate the current status of assessment methods to serve as surrogates for fracture and bone fragility, as well as to determine the next steps that must be taken to validate these methods and incorporate them into clinical trials. In other studies with relevance for osteoporosis, basic scientists have identified a particular gene (*Alox15*) that is strongly associated with changes in bone mineral density—a measure of vulnerability for osteoporosis. Researchers had previously identified the involvement of *Alox15* in fat metabolism, so the identification of its role in bone links metabolic pathways and bone changes, and also provides a new drug target for osteoporosis.

## MUSCLE DISEASES

One of the most active and productive areas within the Institute's research portfolio is in the muscular dystrophies—a group of genetic diseases characterized by progressive weakness and degeneration of the skeletal or voluntary muscles which control movement. NIAMS research has made progress in defining the genetic mutations and in overcoming the current barriers to effective gene therapy of Duchenne muscular dystrophy, Facioscapulohumeral dystrophy, and other muscle diseases. For example, scientists supported by the NIAMS and the Muscular Dystrophy Association recently reported that a particular method of gene therapy was able to reach all damaged muscles in a muscular dystrophy (MD) mouse, with implications for delivering genetic therapy for MD and perhaps other diseases of the muscle or heart. Previous work showed that MD could be prevented from occurring in a mouse model of the disease by replacing the gene for dystrophin, which is defective in people with the Duchenne form of the disease with a corrected copy of the gene. However, until now, no one had found a way to deliver a new gene to all muscles of an adult animal, including muscles that had already developed MD.

The NIAMS has teamed with the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Child Health and Human Development (NICHD) to bring a strong focus to basic and clinical studies of MD. Activities include the efforts related to the new Muscular Dystrophy Coordinating Committee (MDCC), and the Muscular Dystrophy Research and Education Plan for the NIH that was developed by the MDCC and released in September 2004. In addition, in fiscal year 2003, the NIAMS, along with NINDS and NICHD, each funded a Muscular Dystrophy Cooperative Research Center for which additional funding was provided by the Muscular Dystrophy Association. In fiscal year 2004, the three institutes re-issued the solicitation for centers—now known as Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, and expect to fund two to three additional meritorious centers in fiscal year 2005.

The NIAMS, NINDS, NICHD and the Centers for Disease Control and Prevention sponsored a workshop on the burden of muscle diseases in January 2005. The participants in this workshop identified existing data on the costs and scope of muscle diseases, with a focus on the muscular dystrophies, and recommended strategies for developing new information sources.

#### SKIN DISEASES

Skin diseases significantly compromise daily life for millions of Americans, both physically and psychologically. Researchers supported by the NIAMS have made great progress in our understanding of basic skin biology as well as understanding the bases for skin diseases.

A particular area of focus in the NIAMS portfolio is on the roles of genes in skin diseases, and scientists have advanced our understanding in a number of areas, including identifying two genes on chromosome 17 which are associated with psoriasis. Other studies have identified susceptibility genes for keloids, which are an abnormal form of scarring that disproportionately affects people of color. Investigators studying the physiologic basis for keloid formation were able to determine that a blood vessel growth factor was likely to be associated with keloid formation. This suggests that it may be possible to suppress keloid formation by topical application of an inhibitor of this molecule. In a third area of genetics research, investigators have identified a new mouse model of alopecia areata that has allowed genetic susceptibility studies to be undertaken, and two new regions on chromosomes 8 and 15 were identified. The availability of this new animal model will allow better identification of the genetic basis of alopecia areata as well as provide a basis for testing potential interventions.

#### CONCLUSION

Significant progress has been made in our understanding of fundamental life processes and how they go awry in diseases of bone, joints, muscles, and skin. We are proud of the advances that scientists supported by the NIAMS have achieved, and we are excited about initiatives that we have launched. Our goal remains, as always, to improve the health of the American public—to reduce the burden of disease and to enrich the quality of life for all Americans.

I will be happy to answer any questions that you may have.

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#### PREPARED STATEMENT OF DR. TING-KAI LI, DIRECTOR, NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute on Alcohol Abuse and Alcoholism (NIAAA). The fiscal year 2006 budget includes \$440,333,000, which reflects an increase of \$2,056,000 over the fiscal year 2005 enacted level of \$438,277,000 comparable for transfers proposed in the President's request. The Centers for Disease Control and Prevention last year ranked alcohol the number-three preventable cause of death in the country. This finding echoed a report issued by the World Health Organization, which listed alcohol as the third leading preventable cause of healthy years lost to death and disability in developed nations during 2002. The high rate of death and disability associated with alcohol is the result not only of injury, but also of organ damage, including brain damage. Alcohol's biological actions are widespread in the body, and, when used in excess, it has the potential to contribute to conditions such as cancer and liver disease. Every age group is at risk of alcohol-related problems, from fetuses exposed to alcohol in the womb to the elderly. In the United States, the estimated annual cost of alcohol-use disorders (al-

cohol abuse and alcohol dependence), including indirect costs, such as lost productivity, is \$185 billion.<sup>1</sup>

#### MEDICATION DEVELOPMENT

Development of more widely effective medications for alcohol-use disorders and organ damage is among NIAAA's highest priorities; it is among the 28 research outcome goals listed in the NIH Government Performance and Results Act report. Medications help prevent or reduce drinking by acting on one or more of the many brain systems through which alcohol exerts its actions. For example, some medications reduce craving for alcohol. We are testing promising compounds for treatment of alcohol-use disorders, by themselves and in combination with behavioral therapies, and for treatment of liver damage.

Recent advances in science and technology have enabled remarkable progress in our understanding of neurobiological mechanisms that underlie behavior, and are revealing new molecular targets for medications for alcohol-use disorders. Likewise, advances in our understanding of organ injury are providing new opportunities for developing medications. These advances are reflected in unprecedented progress in NIAAA's medication development initiative.

A special challenge for our initiative is to develop strategies that will increase translation of promising medications identified by NIAAA research into clinical applications. The pharmaceutical industry has been reluctant to develop medications for alcoholism, and the medical community has been reticent to use new pharmacotherapeutic modalities as an adjunct to traditional behavioral therapies for the treatment of this disease. For example, only 3 to 13 percent of patients treated for alcoholism receive a prescription for the medication naltrexone, although it has yielded positive results in NIAAA-funded studies published in medical journals. We need to increase the likelihood that compounds we identify as effective and safe will reach the market and that they will reach patients who can benefit from them. Research is underway to identify barriers and strategies to remove them.

Our recently established collaboration with the Food and Drug Administration (FDA) will help to expedite progress. Together, NIAAA and FDA are developing standards for clinical trials of medications to be tested as alcoholism treatments. This will help ensure that NIAAA-supported trials are in line with regulatory requirements, enabling them to proceed.

Our two highest priorities for accelerating our medication program are (1) to develop animal models and human research paradigms that can predict the clinical success of potential medications. Having these predictive models in place will prevent spending time and money on more elaborate testing of compounds that would ultimately fail to be effective. (2) Another priority is to establish a network of sites for early stages of human testing of medications, to reveal whether or not a drug should be pursued in larger, more expensive trials. Medications in this system will be on a fast track, in which scientific elements of safety testing, etc., remain, but elimination of unnecessary administrative roadblocks will expedite the process.

#### IN THE PIPELINE

Human trials of two particularly promising medications are underway. Among the studies being conducted is a collaboration with the National Institute on Drug Abuse (NIDA), to test the antiseizure drug topiramate's effectiveness in treating people addicted to both alcohol and cocaine. Antiseizure drugs act on neurotransmitter systems that modulate brain-cell activity, to restore their natural balance. Alcohol causes an imbalance in the glutamate and GABA neurotransmitter systems (among others) and topiramate's actions on these receptors are thought to ease some of the symptoms of alcohol withdrawal. The drug rimonabant is directed at a different neurotransmitter system (the cannabinoid system) and has shown considerable promise in animal studies. Several other kinds of medications that have shown promise in research settings are in various phases of clinical studies, including several collaborations with other NIH Institutes.

<sup>1</sup>Harwood, H.; Fountain, D.; and Livermore, G. (2000). The Economic Costs of Alcohol and Drug Abuse in the United States 1992 (updated for 1998). Report prepared for the National Institute on Drug Abuse and the National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Department of Health and Human Services. NIH Publication No. 98-4327. Rockville, MD: National Institutes of Health. NIAAA's mission is to develop prevention and treatment interventions that reduce alcohol-use disorders and their consequences. To achieve this goal, we must understand the underlying biological, behavioral, and environmental factors and identify populations at risk. NIAAA research initiatives in four areas, in particular, are essential to this effort: medication development, neuroscience, metabolism, and youth.

Some populations are at particular risk, and we also are conducting studies specific to them. We are testing medications in youth, who have high rates of alcohol abuse. This group poses special challenges, since the biological changes that occur in the brain during adolescence might compromise the pharmacologic actions of medications used for adults.

People with co-occurring alcoholism and psychiatric conditions are another high-risk group. Our studies of this population include collaborations with the National Institute of Mental Health. In a recent trial, a drug already used as an anticonvulsant and to treat bipolar disorder showed promise in treating alcoholism in bipolar people, who are generally resistant to current medications for alcoholism.

A collaboration with the National Cancer Institute and NIDA is helping researchers to understand the biological interactions that occur between alcohol and nicotine, and to develop treatments for alcoholic smokers. Studies suggest that addiction to alcohol and nicotine involves some common underlying mechanisms.

In addition to developing medications to treat alcohol-use disorders themselves, we are developing treatments for alcoholic liver disease. Alcohol is among the leading causes of death from liver disease in the United States.

Pharmaceutical companies put aside many of the medications they develop. Even though they may be safe, they may not be optimally effective for treating the diseases or conditions for which they were developed. These medications are potentially useful for treatment of other diseases, and some act on neurotransmitters that we have identified as promising targets for treatment of alcoholism. We are encouraging pharmaceutical companies to collaborate with us in developing these compounds as potential alcoholism treatments.

#### NEUROSCIENCE AND METABOLISM

The biology of the brain contributes to how we make decisions—to the choices we make in life and the behaviors in which they result. Neuroscience research is essential for understanding the biological basis of alcohol-related behaviors and for identifying molecular targets for therapeutic compounds that can alter alcohol's actions in the brain. Many different biological systems in the brain influence how people respond to alcohol, and chronic, heavy exposure results in brain adaptations that form the underpinnings of alcoholism.

NIAAA-funded scientists are making important discoveries about genes and proteins active in these brain systems, whose variant forms increase or decrease the risk of alcohol-use disorders. For example, recent studies suggest that a gene that produces an appetite-regulating protein fragment, neuropeptide Y, also affects tolerance to alcohol, a predictor of alcoholism and a factor in its development.

In 2006, NIAAA will take part in the NIH Blueprint for Neuroscience, a collaboration of 15 Institutes. We are particularly interested in the Blueprint's cross-training programs for the next generation of researchers and clinicians in neuroscience. One component trains physicians and scientists to work together toward translating neuroscience findings into clinical practice; others provide training in computer and neuroimaging technologies that offer unprecedented research capabilities. The Blueprint's project to target all of the genes in the mouse genome, to discover which of them are critical players in health or diseases of the nervous system, will benefit NIAAA research.

Metabolism also has a profound effect on people's responses to alcohol. Variations in the genes and proteins involved in alcohol metabolism can, like those involved in brain function, increase or decrease risk of alcoholism. NIAAA's metabolism initiative is making progress in identifying these gene/protein variations and their impact on alcohol-related behaviors, particularly in regard to enzymes in alcohol-metabolism pathways. The NIH Roadmap Initiative on National Technology Centers for Networks and Pathways is contributing valuable information to the effort. Like our neuroscience research, our metabolism research is helping us to identify potential targets for therapeutic compounds.

#### YOUTH AT RISK

Last year, we reported that new epidemiology data called for a major scaling up of efforts to prevent underage drinking. The data revealed that youth is the age of greatest risk of alcoholism; people 18-to-25 years old have much higher rates of alcoholism than any other age group in the Nation. Previous studies had shown the extent to which youth engage in risky patterns of drinking, such as occasionally or frequently drinking too much, too fast. Alcohol is the largest contributor to unintentional injury, the leading cause of death of Americans under age 21. People who begin drinking earlier in adolescence have a much higher risk of alcoholism as adults, as compared with late starters. Children are beginning to drink at earlier

ages, and youth from secondary-school age to college age have substantial rates of risky drinking. In the military, more than 26 percent of underage personnel engage in “binge drinking” (five or more drinks in a row), according to a recent Department of Defense report. These and other epidemiology data indicated to us that (1) the problem of underage drinking required renewed emphasis and coordination in the research and service communities, and (2) we should approach alcoholism as having a developmental trajectory that begins in childhood and adolescence. In a recent report, *Reducing Underage Drinking: A Collective Responsibility*, the Institute of Medicine called for strategies to ameliorate these problems. Last year, NIAAA announced the addition of a major new initiative to its ongoing research on youth.

#### YOUTH INITIATIVE

Research shows that brain development and maturation occur over a longer period than previously thought. A key question we are asking is: What brain systems differ in adolescents and adults such that youth tend to binge drink? The brain receives and sends chemical messages that influence when an individual has “had enough” and stops drinking. Are the brain systems that regulate these “stop mechanisms” not yet mature in the adolescent brain? Does alcohol alter their development? A collaboration with NIDA is stimulating studies on consequences of alcohol exposure and drug abuse on development of the brain and behavior.

NIAAA has formed a steering committee that includes both scientists and policy and communication experts. The former chairman of the IOM committee on underage drinking is a member, as are two of the 60 current and former governors’ spouses leading a national NIAAA-sponsored prevention campaign. In addition, the NIAAA sits on the newly established Interagency Committee on Prevention of Underage Drinking. This Committee cuts across agencies, from research to service, including the Substance Abuse and Mental Health Services Administration, in a major coordination of effort.

Our initiative also is reaching out to health-care systems and communities. An area in critical need of attention is the response of health care systems to underage drinking. NIAAA’s youth initiative is beginning to address this need, in part, with a project called *Underage Drinking: Building Health Care System Responses*. Rural academic health centers will use existing services and clientele to conduct the studies.

The youth initiative is responding to crisis levels of risky drinking on college campuses, as well. It includes fast-track approval of grant applications in response to campuses that request help, a recommendation issued in the NIAAA Task Force on College Drinking—a collaboration between scientists and college presidents. Seven approved and funded projects are underway; another application is nearing approval, and others are under review. The Task Force is about to release an updated report, which will reflect the latest research findings. Another new program under the youth initiative, the Mississippi River Delta Project, is examining whether a prevention strategy recommended for college students by the Task Force is effective for rural adolescents.

One major question that must be addressed regarding underage drinking and its consequences is whether enforcement of existing laws can reduce these problems by reducing youths’ access to alcohol. We recently began collaborating with the Office of Juvenile Justice and Delinquency Prevention to address this question in rural communities. NIAAA’s role in this joint effort is to provide the research required for evaluation of the effectiveness of the 3-year program. Four projects are underway; three more are nearing approval.

The leadership of the youth initiative is discussing collaborations with other potential partners. In Spring 2005, we will meet with leaders in the radio and television media about the effects of alcohol portrayal on youth behaviors. Navy leaders have requested a meeting with NIAAA, also to be held in Spring 2005, to discuss prevention and treatment strategies. We have begun discussions with the Department of Agriculture about the possibility of conducting research and outreach through the 4-H Club organization.

#### AT THE CROSSROADS

The results of our research will be useful to the public to the extent that clinicians and communities apply them. We are at a crossroads, in which we are able to identify new medications, for example, while the pharmaceutical and medical communities are relatively unresponsive to new findings in alcohol research, and prevention and treatment are not reimbursed adequately by private insurers.

At this juncture, a high priority for our Institute is to develop strategies that will increase the likelihood that clinicians, communities, and health-care systems will

adopt findings from our investigations. Efforts are underway. Thank you Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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PREPARED STATEMENT OF DR. STORY C. LANDIS, DIRECTOR, NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

Mr. Chairman and Members of the Committee I am Story Landis, Director of the National Institute of Neurological Disorders and Stroke (NINDS). I am pleased to present the fiscal year 2006 President's budget request for NINDS. The fiscal year 2006 budget includes \$1,550,260,000, an increase of \$10,812,000 over the fiscal year 2005 enacted level of \$1,539,448,000 comparable for transfers proposed in the President's request.

The mission of the NINDS is to reduce the burden of neurological disorders by finding ways to prevent or to treat these diseases. This mission is extraordinarily important and extraordinarily difficult. It is important because the burden of neurological disorders is immense, affecting all segments of society. Diseases of the nervous system kill people of all ages, disrupt essential bodily functions, cause pain and discomfort, and disturb all aspects of human ability, from perception and movement through emotions, memory, language, and thinking. It is difficult because hundreds of diseases affect the brain, spinal cord, and nerves of the body, each presenting unique challenges. Compounding the challenge, the brain and spinal cord are difficult to access, sensitive to intervention, reluctant to regenerate following damage, intricate in structure, and elusive in their normal workings.

Despite these challenges, we are making progress. Prevention of stroke and of nervous system birth defects is having a major impact on public health. Better drugs and surgical treatments help relieve symptoms for people with Alzheimer's disease, Parkinson disease, epilepsy, chronic pain, multiple sclerosis, and other diseases. Improvements in genetic testing and brain imaging also enhance physicians' ability to diagnose disease and guide therapy for nervous system disorders.

To continue this progress, the NINDS supports basic studies to understand the nervous system in health and disease, translational research to move from the laboratory toward the clinic, and clinical research, including clinical trials to test the safety and efficacy of treatments and preventive interventions. The Institute supports most research through extramural grants and contracts to physicians and scientists throughout the country. NINDS intramural investigators also conduct research on the NIH campus in Bethesda, Maryland.

To complement investigator-initiated research, the Institute directs initiatives to public health needs, unusual scientific opportunities, or issues that Congress highlights as critical. NINDS initiatives for fiscal year 2006 focus on tuberous sclerosis, Rett syndrome, muscular dystrophy, neuro-AIDS, transmissible spongiform encephalopathies (TSEs), stroke, and Parkinson disease, as well as on cross-cutting issues including counterterrorism, neurological emergencies, and stem cells. Increasingly, NINDS initiatives and other programs are in cooperation with other components of the NIH.

CLINICAL RESEARCH

The NINDS currently supports more than 1,000 research projects that involve human subjects, with more than 300,000 people expected to participate. For example, epidemiological studies are examining risk factors for stroke with special attention to Blacks and Hispanics; genetic studies have recently helped identify genes related to Parkinson disease, ALS, dystonia, Joubert syndrome, and cerebrovascular disease; and brain imaging research is revealing how the brain develops throughout childhood and adapts after damage. Among the findings this year are brain imaging data that will identify which stroke patients might benefit from emergency treatments to unblock blood vessels and preliminary indications that vitamin D might help prevent multiple sclerosis in women, a finding which researchers are following up.

Of the NINDS clinical research studies, approximately 125, with more than 25,000 expected participants, are clinical trials of interventions to prevent or treat neurological disorders. Projects range from planning and pilot trials to large multicenter trials. In notable results this year, a small intramural clinical trial of multiple sclerosis patients who did not respond to interferon, the standard therapy, found that administering the genetically engineered antibody daclizumab improved outcome substantially. An extramural clinical trial found that ultrasound may improve the effectiveness of t-PA (tissue plasminogen activator) in breaking up clots and restoring blood flow to the brain. T-PA has been the only FDA-approved ther-

apy for acute ischemic stroke since NINDS clinical trials demonstrated its effectiveness in the 1990's.

In other clinical trials activities this year, the innovative Neuroprotection Exploratory Trials in Parkinson Disease (NET-PD) program is selecting drugs that show promise for slowing the course of Parkinson disease and testing them through a clinical trials network. From 59 drug candidates proposed by 42 scientists from 13 countries, 4 drugs were selected for testing in phase II clinical trials, with results expected in the next few months. If results warrant, larger trials will follow quickly. To enhance drug selection in the future, the NINDS is establishing a contract animal testing facility. The NINDS Pilot Studies Network (NPTUNE) is also underway to expedite pilot trials of new treatments for rare neurological disorders, for which the lack of clinical trials infrastructure often blocks moving therapies forward. NPTUNE chose testing of phenylbutyrate for spinal muscular atrophy (SMA) as the first trial. Development of the Clinical Research Collaboration (CRC) has also begun, which will extend the reach of the NIH into more communities across the United States. The CRC will engage hundreds of community practice and academic neurologists to speed trials; minimize costs; make trials more accessible to patients; recruit a diverse spectrum of participants; facilitate trials of rare diseases; and improve transfer of research results to clinical practice in community settings. Complementing the CRC, the NINDS is building a network to develop emergency treatments for neurological disorders. Stroke, seizures, and traumatic injury are just a few of the neurological disorders that often require emergency treatment. This program brings together specialists in emergency medicine with experts in neurological disease and in clinical trials. Finally, the NINDS is fully engaged in Roadmap initiatives to address clinical research and trials issues that cut across all of medical science.

#### TRANSLATIONAL RESEARCH

Translational research encompasses the many steps that move basic research findings to a therapy that is ready for testing in clinical trials. In 2002, the NINDS began a comprehensive translational research program that can apply to all diseases within its mission. The program solicits investigator-initiated proposals, evaluates them according to peer review criteria tailored to the needs of translational research, and monitors progress with milestone-driven funding, as is common in industry. The first major project in this program, the Parkinson's Gene Therapy Study Group, met critical milestones this year with the creation of a stable colony of parkinsonian non-human primates for testing therapies and the development of modified viral vectors that can deliver therapeutic genes under tight control.

Complementing the broad translational research program and relevant Roadmap initiatives in areas such as molecular libraries are several specific NINDS efforts. In one such program, the Institute, working with academia and voluntary disease organizations, formed a consortium of 26 laboratories to screen a set of 1,040 known drugs with laboratory tests for potential use against neurodegenerative diseases. Most of the drugs in this set have been approved by the U.S. Food and Drug Administration (FDA) for other uses, and so might move more quickly toward clinical trials. Several drugs from this program have shown promise against neurodegeneration and moved forward to testing in more definitive mouse models of human diseases. One drug, ceftriaxone, has already proceeded to testing in a clinical trial for ALS early this fall.

Because of the state of the science and the impact of SMA on children and families, the NINDS chose this disease as the focus of an innovative approach to expedite therapy development. The SMA Project uses a performance-based contract mechanism to accelerate all steps from recognition of a research need, through solicitation, review, and funding of targeted research subprojects. In its first year, the Project quickly developed detailed plans for SMA drug development and solicited targeted research subprojects. A September 2004 workshop engaged SMA researchers, clinicians, and voluntary health organizations on clinical trials. As the Project proceeds, the NINDS is evaluating whether the approach might be applied to other disorders. The NINDS continues to support teams of researchers focused on developing therapies for neurological diseases through several other programs. These programs emphasize basic, translational, or clinical research, as appropriate to the state of science for each disorder. Examples include the Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, the Morris K. Udall Centers of Parkinson's Disease Research, the Facilities of Research Excellence in Spinal Cord Injury, and the Specialized Programs of Translational Research in Acute Stroke.

## BASIC RESEARCH

Preventing and treating neurological disorders relies on understanding the normal workings of the nervous system and what goes wrong in disease. The emerging new modalities for combating disease highlight this: Stem cells and growth factors arose from fundamental studies of nervous system development. Deep brain stimulation, which shows promise for Parkinson, dystonia, Tourette syndrome, and other diseases, relies upon research techniques developed to monitor the activity of single nerve cells in the brain, and on basic knowledge of anatomical circuits that control movement. Studies of how the brain learns are leading to behavioral therapies that may enhance “brain plasticity” to repair damage and giving new insights into what causes chronic pain, epilepsy, and dystonias. Most current drugs for nervous system diseases target molecules identified for their role in normal brain function. Gene therapy, new understanding of the molecular basis of diseases, diagnostic tests, and animal models for testing therapies are among the many fruits of fundamental studies in neurogenetics.

Basic neuroscience research is continuing to advance rapidly, and Roadmap initiatives in areas such as protein structure, computational biology, and nanomedicine will help to accelerate that pace. Among the many basic neuroscience findings this year are studies that give insights into what controls stem cells in the brain and how they might be used therapeutically, the role of estrogen in autoimmune disease, strategies to transfer therapeutic genes into muscles to treat dystrophies, insights into the molecular targets of nicotine, better understanding of how genes and experience interact in brain development, and a new approach to silencing harmful genes in diseases such as Huntington’s and spinocerebellar ataxias.

## THE NIH BLUEPRINT FOR NEUROSCIENCE RESEARCH

Over the last several years, the NIH Institutes and Centers that have an interest in the nervous system have increasingly joined forces, driven by advances in neuroscience that have revealed common issues that intersect their unique missions. The NIH Blueprint for Neuroscience is a framework to enhance that cooperation. Just as the NIH Roadmap addresses the roadblocks that hamper progress across all of medical science, the NIH Blueprint for Neuroscience takes on challenges in neuroscience that are best met collectively. By pooling resources and expertise, the 15 NIH Institutes and Centers that make up the Blueprint can take advantage of economies of scale, confront challenges too large for any single Institute, and develop research tools and infrastructure that will serve the entire neuroscience community. The Blueprint is developing an initial set of initiatives focused on tools, resources, and training that can have a quick and substantial impact because each builds on existing programs. These initiatives include an inventory of neuroscience tools funded by the NIH and other government agencies, enhancement of training in the neurobiology of disease for basic neuroscientists, and expansion of ongoing pediatric imaging, gene microarray, and gene expression database efforts. For fiscal year 2006, Blueprint initiatives focus on genetically engineered mouse strains to study the nervous system, neuroscience training programs, and specialized “core” resources that can be shared across many laboratories.

Thank you, Mr. Chairman. I would be pleased answer questions from the Committee.

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 PREPARED STATEMENT OF DR. DONALD A.B. LINDBERG, DIRECTOR, NATIONAL LIBRARY OF MEDICINE

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President’s budget request for the National Library of Medicine (NLM). The fiscal year 2006 includes \$318,091,000, an increase of \$2,945,000 over the fiscal year 2005 enacted level of \$315,146,000 comparable for transfers proposed in the President’s request.

In a world that is increasingly digital, the National Library of Medicine plays a pivotal role in facilitating research, supporting safe and effective health care, and promoting healthy behavior. In addition to maintaining the largest physical collection of health science literature in the world, the Library builds and makes freely available immense databases of scientific information, identifies and organizes free Web-based consumer health information produced by the NIH institutes and other authoritative sources, and connects all of these resources in novel ways that increase their value to scientists, health care practitioners, and the general public. Each day, almost a million people access the National Library of Medicine’s digital resources. By making the results of research—from DNA sequences to published sci-



entific articles to patient and consumer health information—readily available, the Library magnifies the positive impact of NIH's investment in the creation of new knowledge.

The Library is a key player in a number of important NIH and HHS initiatives that have current implications for the scientific community, health care providers, and the general public. These are described later, but briefly they are: the new policy to encourage the depositing of peer-reviewed articles supported by NIH grant in an archive maintained by the Library; the creation of PubChem, a new resource for scientists that is part of the NIH Roadmap Initiative; the movement to widen the registration of clinical trials in ClinicalTrials.gov, an NIH/NLM database; and the dissemination of standard vocabulary for electronic health records and research data within NLM's Unified Medical Language System (UMLS).

#### INFORMATION FOR SCIENTISTS AND HEALTH PROFESSIONALS

The Library's services have never been more central to the scientific enterprise. No scientist would think of embarking on an experiment without a careful review of the literature. Researchers rely on NLM databases for this. They search the Medline/PubMed collection of 15 million journal article records, or perhaps utilize the GenBank collection of 40 million DNA sequences and associated molecular data. Research articles and biological databases are interlinked through NLM's Entrez retrieval system that provides seamless searching of a vast information space all from a user's desktop computer.

The original role of the Library, to provide access to the published literature of the health sciences, remains the foundation of NLM's services, and the physical collection continues to expand steadily. Medline/PubMed is a Web-accessible database that now contains more than 15 million references and abstracts to articles in biomedical journals from the 1950s to the present. For most of the records now being entered, it is possible to link from the reference to the full text of the article. More than half a million records, from journals in many languages, are added each year. Medline/PubMed is free on the Web and in fiscal year 2004 there were 678 million searches done on the system.

PubMedCentral, which was created by NLM's National Center for Biotechnology Information (NCBI), is a database that is a key in one of the special NIH initiatives mentioned earlier—archiving the full text of articles that represent work supported by the NIH. Today's technology has led to research that frequently generates an enormous amount of data that is associated with the publication of an article. To maximize the usefulness of such articles, the full text needs to be stored, with ancillary data, and with links to associated resources, in a data repository such as PubMedCentral. Under a new NIH policy, peer-reviewed research articles are submitted electronically to PubMedCentral. There are now more than 350,000 current and retrospective articles available free of charge in this archive.

NLM's NCBI also hosts over 40 databases providing researchers and students with easy access to molecular biology information—sequences, genome maps, 3-D protein structures, and gene functions. The integration of all these data coupled with Web-based analysis tools offers a virtual desktop laboratory to the 50,000 researchers and students who visit daily over the Internet.

With the completion of the NIH genome project, an important new opportunity to explore the interactions of chemical substances with biological systems has opened. The Molecular Libraries component of the NIH Roadmap aims to exploit this opportunity by developing chemical probes that modulate biological processes. A new database created by the NCBI, called PubChem (the second major initiative noted earlier), integrates data from a variety of sources to enable researchers to link diverse information about chemicals and biological processes. For example, PubChem links chemicals to PubMed, so that users may investigate the relationship of screening-center results and biological activities reported in the biomedical literature. As such, PubChem is a research tool for expediting discovery of the biological basis of disease and the development of new therapeutic approaches.

A new information system was introduced by NLM in 2004: the Wireless Information System for Emergency Responders (WISER). Available for downloading over the Internet, the system uses a hand-held PDA device to provide on-the-spot information for emergency personnel who first respond to situations where hazardous materials have been released into the environment. WISER extracts data from NLM's extensive electronic file of peer-reviewed hazardous substances information and makes it instantly and conveniently available.

## INFORMATION SERVICES FOR THE PUBLIC

The Library was first prompted to create information services for the general public in 1997, when it became apparent that consumers were in fact using the Medline/PubMed database of the scientific medical literature heavily. The following year the NLM Board of Regents formally recommended that the Library expand its mandate to include serving the public. Since that time, NLM has created a series of highly successful Web-based information services aimed at consumers.

Foremost among these is MedlinePlus.gov. This service, begun in 1998, has become a much-consulted information resource for the public, patients, and their families. Some 6 million people use MedlinePlus each month, viewing more than 60 million pages of health information written especially for consumers. Much of the data comes from the NIH institutes, a reliable source of authoritative health information for the public. Other HHS health agencies, professional societies, voluntary health agencies, and academic organizations are also sources of the information carried on MedlinePlus. Many users come to the site for access to extensive information on prescription and over-the-counter medications, a medical encyclopedia, directories of physicians and hospitals, and "health tutorials" on common medical topics and procedures.

With help from the medical library community and from the National Institutes of Health, MedlinePlus continues to expand its coverage. A "Go Local" function has been introduced so that users of MedlinePlus can link directly to organizations and agencies in their locality to request needed health services. North Carolina and Missouri are now connected locally, and more states will soon be joining Go Local. Another popular service is MedlinePlus en español. This was introduced in 2002 and has grown rapidly to reach virtual parity with the English version. Both English and Spanish language MedlinePlus scored the highest marks of any Federal Web site in a recent evaluation by the American Customer Satisfaction Index.

One popular feature of MedlinePlus is the ability to link from any of the health topics to the database, ClinicalTrials.gov. In the past, information about clinical research was not readily available to the public. Patients typically learned about studies only from their doctors. ClinicalTrials.gov, which now contains extensive information on more than 12,000 studies, is a one-stop Web site for patients, families, and members of the public. Each record includes the locations of a study, its design and purpose, criteria for participation, contact information, and further information about the disease and intervention under study. One of the special NIH initiatives mentioned at the beginning of this statement is about the need for a broad registry to track all trials and their results. Because ClinicalTrials.gov provides an established system for collecting, organizing, and displaying study information, expansion of its role is being considered.

In addition to MedlinePlus and ClinicalTrials.gov, the Library in recent years has introduced a number of specialized information resources for different segments of the public. NIHSeniorHealth.gov, for example, created with the National Institute on Aging, has information in a format that is especially usable by seniors on topics they are concerned with, such as Alzheimer's, arthritis, hearing loss, exercise for older adults, and so forth. There are other information resources created by NLM especially for people living with AIDS, American Indians, those living in the Arctic, and Asian Americans.

The public will also find useful NLM databases that contain health and safety information about the content of everyday household products, consumer information about genetic conditions and the genes or chromosomes responsible for those conditions, and the potential environmental hazards in ordinary communities ("Tox Town"). The newest database of interest to the public is TOXMAP, a system that allows the user to specify a chemical, or a location, and to create a map that shows the distribution of that chemical in a geographic area.

The usage of the Library's databases, both those for scientists and for the public, continues to climb. NLM pursues a number of outreach projects to spread the word that these resources are available to everyone, free and without registration. The more than 5,000 member institutions of the National Network of Libraries of Medicine are valued partners in this endeavor. They hold workshops at public libraries and other community organizations, demonstrate NLM databases to the public, and exhibit at meetings and conventions on behalf of NLM, thus providing the personal element that can be so important to reaching populations affected by health disparities. Another special outreach project is the "Information Rx" program, a collaboration with the American College of Physicians (ACP) Foundation. This is a project to encourage physicians to make information referrals to MedlinePlus. Since patients trust their physicians to recommend good health information, the idea is to promote MedlinePlus as the "Web site your doctor prescribes." NLM is also now

working with the American Medical Association Foundation in a similar project for its members.

#### RESEARCH TO IMPROVE INFORMATION PRODUCTS AND INFRASTRUCTURE

In addition to the work of the National Center for Biotechnology Information, described earlier, NLM also sponsors research and development through the Lister Hill National Center for Biomedical Communications. This organization conducts advanced communications research projects in such areas as high-quality imagery, medical language processing, high-speed access to biomedical information, developing intelligent database systems, multimedia visualization, data mining, and machine-assisted indexing. One prominent area of research has been the Visible Human Project. The project consists of two enormous (50 gigabytes) data sets, one male and one female, of anatomical MRI, CT, and photographic cryosection images. These data sets are available through a free license agreement. More than 2,000 individuals and institutions in 47 countries have licensed the data and are using them in a wide range of educational, diagnostic, treatment planning, virtual reality, artistic, and industrial applications. An "Insight Toolkit" makes available a variety of open source image processing algorithms for computing segmentation and registration of medical data. The Visible Human Web site is one of the most popular of NLM's Web offerings.

Another initiative of the Lister Hill Center is the Scalable Information Infrastructure program. Its purpose is to encourage, through 3-year research contract awards, the development of health-related applications of scalable, network aware, wireless, geographic information systems, and identification technologies in a networked environment. The initiative focuses on situations that require, or will greatly benefit from the application of these technologies in health care, medical decision-making, public health, large-scale health emergencies, health education, etc.

The Library has a program of grant assistance for research, training and fellowships, medical library assistance, improving access to information, and publications. For more than 30 years NLM has supported medical informatics research and the training of medical informaticians at universities across the nation. NLM funding has been instrumental in the development of pioneering electronic health record systems now considered models for the nation and for the training of generations of leaders in the field of informatics. Today the training programs also emphasize opportunities for training in bioinformatics, the field of biomedical computing for the large datasets characteristic of modern research. At present, NLM provides 18 grants to biomedical informatics training at 26 universities, supporting 250 trainees. A new initiative to expand the scope of these training programs is a collaboration between the NLM and the Robert Wood Johnson Foundation that is establishing public health training tracks at several of these sites. In this post 9/11 era the sophisticated use of public health information—whether for timely detection of disease outbreaks or rapid dissemination of information to clinicians and the public in an emergency—is a subject of great importance.

An important contribution of NLM to the infrastructure of medicine is the Unified Medical Language System. This project develops and distributes multi-purpose electronic "Knowledge Sources" and associated lexical programs for system developers. The purpose of these UMLS databases and programs is to help computer systems behave as if they "understand" the meaning of the language of biomedicine and health. The UMLS Metathesaurus, the heart of the UMLS Knowledge Sources, contains more than 1 million concepts and 4.5 million unique concept names from more than 100 different biomedical vocabularies and classifications, including the three principal clinical vocabulary standards: SNOMED CT (Systematized Nomenclature of Medicine—Clinical Terms), LOINC (Logical Observation Identifiers, Names, Codes), and the RxNorm clinical drug vocabulary. NLM has been instrumental in making these standards freely available through U.S.-wide licensing contract support, or direct development.

These resources are especially important to the Federal government's plans to achieve always-current, always-available electronic health records (EHRs) for most Americans within a decade. The lack of common, readily available electronic medical terminology standards has been a major obstacle to the widespread deployment and effective use of EHRs. NLM is playing an important role in remedying this situation with the national licensing of SNOMED CT and its uniform distribution with other clinical and administrative standards within the UMLS. It is now possible for software vendors, health care providers, hospitals, insurance companies, public health departments, medical research facilities, and others to incorporate uniform terminology into their information systems much more readily. This is an important step toward establishing interoperable electronic health records that can be made avail-

able wherever and whenever patients need treatment. In addition to improving the safety and quality of health care, standard electronic health data will assist in detecting and responding to public health emergencies and provide one of the key building blocks for a cost-effective national research infrastructure.

In summary, the National Library of Medicine has a central part to play on today's health care scene. It continues to be a freely accessible archive of the world's published biomedical literature and collection of genomic data, relied on by scientists and health professionals around the world. Millions of people view the Library as a source of trusted consumer health information and access the MedlinePlus and other NLM resources for the public. And the U.S. health care system, as it evolves to take advantage of new information technologies, will rely on infrastructure advances made by the NLM in the area of standard and widely shared terminology.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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PREPARED STATEMENT OF ELIZABETH G. NABEL, M.D., DIRECTOR, NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's Budget request for the National Heart, Lung, and Blood Institute (NHLBI). The fiscal year 2006 budget includes \$2,951,270,000, an increase of \$10,069,000 over the fiscal year 2005 enacted level of \$2,941,201,000 comparable for transfers proposed in the President's request. I come to you with pride on behalf of the NIH component that is responsible for much of the gain in life expectancy that we have enjoyed over the past three decades in the United States, as shown in this chart. At the same time, however, I come with deep concern because the diseases under NHLBI responsibility still comprise three of the four leading causes of death in this country—heart disease, stroke, and chronic obstructive pulmonary disease (COPD). Clearly, we have come a long way, but we have far to go.

A VISION FOR THE FUTURE OF THE NHLBI

As the NHLBI's first new director in 22 years, I would like to take this opportunity to share with the Committee my vision for the Institute. This vision is based upon a fundamental set of values—excellence, integrity, innovation, respect, and compassion—that will permeate all activities in the NHLBI. I believe that scientific discovery provides the basis for progress and that the NHLBI is uniquely positioned to catalyze changes that must be made to transform our new scientific knowledge into tangible benefits for the people of this country. Within this framework, let me articulate four themes that will guide priority setting of our research agenda.

THEME ONE: DISCOVERY

The first theme—stimulating basic discoveries of the causes of diseases—is vital to developing new, critically needed treatments. Basic research provides the foundation of the NHLBI portfolio and has been one of its great strengths. The typical model of investigation—research conducted by single investigators or small groups of investigators on projects of their own inspiration—accounts for most of the unanticipated and major scientific discoveries in this country. I believe strongly that we must protect and nurture investigator-initiated research. The NHLBI will continue to invest in the most talented scientists conducting the highest caliber research. Innovation and creativity using the most advanced biomedical technologies will be our goal.

We have an exciting opportunity to support emerging new scientific fields. Major strides are being made in computer sciences, bioengineering, material sciences, chemistry, and other areas of study that vastly benefit medical research, and the pace of discovery in these disciplines should be accelerated. One approach is to develop funding mechanisms (e.g., for support of high-risk research) that encourage innovative thinkers to turn their attention to the major current challenges in heart, lung, and blood diseases.

Another objective is to generate large, publicly available sets of reagents and data that could function as a "tool kit" for NHLBI investigators. Gene sequences and maps, cell lines, knockouts and knockdowns of genes in selected animals, reference sets of proteins, protein affinity reagents, and libraries of small molecules are examples of resources that will provide our investigators with the technologies required for innovative discoveries.

## THEME TWO: TRANSLATION

Our second task is to speed translation to clinical applications so that people can benefit as quickly as possible from the basic research enterprise. Clinical research, and more specifically, translational research (“bench to bedside”) are vital to our mission, so that we can translate basic discoveries into the reality of better health for our country.

The NHLBI must further develop the infrastructure for clinical research so that it serves the evolving field of scientific discovery and provides a foundation for evidence-based clinical decision-making. Clinical research is critical to ensuring that new products and techniques are safe and effective before they are widely applied. However, clinical research is often time-consuming and inefficient, and is increasingly burdened by regulatory hurdles. Our challenge is to expand clinical research to complement the exciting basic science discoveries, while making it more efficient and cost-effective.

We intend to develop a translational research agenda supported by clinical trials, clinical networks, and clinical workforce training. Key components will focus on increasing interactions between basic and clinical investigators and easing the movement of new tools from laboratories to clinics. We will build upon our rich experience with clinical trials and networks to develop new partnerships among organized patient communities, community-based physicians, and academic researchers. We will work on improving bioinformatics and clinical databases, standards for clinical research protocols, measures of clinical outcomes, and quality assessment. Translational research requires the expertise of many fields and should include analysis of health education, outcomes, health-care delivery, and health-care economics. This focus fits well with the Re-engineering the Clinical Research Enterprise of the Roadmap.

The NHLBI must cultivate a cadre of clinical researchers who have skills commensurate with the complexity and needs of our research enterprise. Clinicians must be trained to work in the interdisciplinary, team-oriented environments that characterize today’s research efforts. We further anticipate that specific training will be required in an array of disciplines important to clinical research, including genetics, epidemiology, biostatistics, and behavioral medicine.

At the core of this vision is the need to develop new partnerships of research with organized patient communities, community-based health care providers, and academic researchers. We will rely on our partnerships to facilitate the conduct of this clinical research, to train our clinical investigators, and most important, to achieve our common goals of improved health for the public.

## THEME THREE: INTERACTIONS

The third theme is facilitating communication between scientists and physicians so that new ideas can be generated, shared, and advanced.

Today’s science is far more complex than that of yesteryear. Research, whether basic or clinical, is now commonly done by teams of scientists wherein each individual brings specific talents and expertise to the overall effort. We will stimulate and facilitate the conduct of interdisciplinary research, so that advances can be made more quickly. Principal-investigator status will be granted not to just one investigator, as is the norm, but to all key members of the research team. Integrated reviews of grants will take into account the melding of various disciplines to address the problem at hand, and interdisciplinary teams will be encouraged to evolve in both directed and unexpected ways.

An essential component of our efforts in research collaboration will be community-based clinical trials, which enhance the conduct of clinical research at academic medical centers. An outstanding example is our ALLHAT (Antihypertensive and Lipid-Lowering to Prevent Heart Attack Trial), in which physicians from many types of medical settings—a total of 623 sites in 47 states, Puerto Rico, the United States Virgin Islands, and Canada—successfully enrolled over 42,000 patients and followed them for 6 years. The physicians participated because they believed in the importance of the scientific questions being addressed with regard to patient care and because of the direct benefits of participation to their patients, including free medications. These community-based physicians conducted the trial at very high standards—follow up was over 97 percent. As part of our plan to disseminate the ALLHAT results, participating community physicians are now working with other doctors in their local communities to treat patients with high blood pressure.

## THEME FOUR: COMMUNICATION

Our fourth task is to effectively communicate our research advances to the public to improve understanding of new, promising science.

The NHLBI has an outstanding history of outreach in the areas of high blood pressure, cholesterol, asthma, heart attack, obesity, sleep disorders, and women's cardiovascular health, and new efforts are under way with respect to COPD and peripheral arterial disease. I wholeheartedly support these programs that serve the mission of our Institute and the Nation. Education of our patients and the public regarding prevention and treatment of heart, lung, blood, and sleep disorders is one of my highest priorities.

We will continue to work collaboratively with our colleagues in the DHHS, including the CDC and the FDA, to support prevention and control programs. We also have an unprecedented opportunity to build upon our partnerships with professional organizations, who have a large stake in developing and implementing practice guidelines and monitoring their effectiveness, and with patient advocacy groups. One of our most gratifying partnership programs has been The Heart Truth, which is successfully raising awareness nationwide that heart disease is the leading cause of death among American women. The "reach" of this campaign continues to expand as we forge additional fruitful partnerships with entities in the public and private sectors.

Disparities in health status constitute a significant global issue. Research is essential to understand the diverse contributions of genetics, health behavior, diet, socioeconomic status, culture, and environmental exposures in the genesis of health disparities in heart, lung, and blood diseases and to formulate, evaluate, and disseminate well-conceived, focused intervention programs. This work will necessarily entail a vigorous effort to increase the representation of minorities in the ranks of NHLBI researchers. We are also cognizant of the need to improve and expand programs to prevent, manage, and treat diseases and conditions that disproportionately affect U.S. minority and underserved populations, such as cardiovascular disease and asthma, and to evaluate the effectiveness of our research, treatment, and education programs. A full resolution of the health disparities problem will occur only through committed and sustained efforts by many in our government, health centers, and society.

## SUMMARY

The realization of this vision will require the efforts of many. We are engaged in a special form of public service, that is, the promotion of patient and public health. I will work diligently to preserve public trust in the Institute, the NIH, and the biomedical research enterprise, and to ensure that the NHLBI serves the public with the highest level of integrity. This trust is essential for meeting our common goals of making important new scientific discoveries and translating them to improve health in this country.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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 PREPARED STATEMENT OF DR. KENNETH OLDEN, DIRECTOR, NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Environmental Health Sciences (NIEHS). The fiscal year 2006 budget includes \$647,608,000, an increase of \$3,103,000 over the fiscal year 2005 enacted level of \$644,505,000 comparable for transfers proposed in the President's request.

## INTRODUCTION

"Genetics loads the gun, but environment pulls the trigger."—Judith Stern, University of California, Davis

The Nation needs better information to promulgate evidence-based environmental health regulatory policies and to prevent or cure most chronic diseases. This paucity of information has an enormous impact on the world's economy, both in terms of costs associated with health care and with regulatory compliance. In large measure, this situation exists because we still do not understand what role the environment plays in human health and disease. The application of knowledge and technologies developed through the pursuit of the Human Genome Project offers great promise for elucidating mechanisms of gene-environment interactions in the development of complex diseases.

For years, the environment was considered to have a minor role in the etiology of human illness. But, in recent years, the thinking has shifted in favor of gene-environment interactions. For example, recent studies show that no more than one-third of the cancer burden can be attributed to the action of genes alone (Verkasala, et al., 1999, *Int. J. Cancer* 83:743-749; Lichlenstein, et al., 2000, *NEJM* 343:78-85), only 15 percent of Parkinson's Disease (Tanner et al., 1999, *JAMA*, 281:341-346), and about a third of autoimmune diseases (Powell, et al., 1999, *Env. Health Pers.* 107 (Suppl. 5), 667-672). A more recent study reported that 90 percent of individuals with severe heart disease have at least one or more of four classic risk factors captured in the current definition of the environment (Khat et al., 2003, *JAMA* 290:899-904). Because of these and other findings, it is now generally accepted that more informative, cost-effective, high-throughput methods for assessing and predicting risk resulting from environmental exposures will need to be developed. Otherwise, we will not be able to prevent or cure most chronic diseases, and the costs associated with health care and environmental regulatory compliancy will continue to escalate.

Starting in 1997, NIEHS developed several new research initiatives to respond to this urgent need. Such programs include: the Environmental Genome-Project (Kaiser, 1997, *Science* 278:569-570; Brown and Hartwell, 1998, *Nat. Genet.* 18:91-93), the National Center for Toxicogenomics (Kaiser, 2003, *Science* 300:563), and the Mouse Sequencing Project (*Nature* 432: 5, 2004). While the results from these three initiatives will provide information relevant to most chronic diseases, other research programs have been developed to address specific diseases such as breast cancer, Parkinson Disease, and autism. Today, I will briefly describe several of these initiatives and their implications for human health and disease.

#### GENETIC DIFFERENCES IN SUSCEPTIBILITY TO DRUGS AND ENVIRONMENT

Individuals vary, often significantly, in their response to environmental agents. This variability provides a high "background noise" when scientists examine human populations to identify environmental links to disease, often masking important environmental contributors to disease risk. Fortunately, the Human Genome Project created tools that can help identify the genetic variations in environmental response genes that can lead to such wide differences in disease susceptibility. NIEHS developed the Environmental Genome Project (EGP) to catalogue these genetic variants (polymorphisms) and to identify the ones that play a role in human susceptibility to environmental agents. This information is already being used in epidemiological studies to better pinpoint environmental contributors to disease. Also, several important variants have been discovered that are associated with risk for chronic illnesses such as leukemia, cardiovascular disease, and neuronal dysfunction.

#### ANIMAL MODELS PREDISPOSED TO ENVIRONMENTAL RISK

The usefulness of the susceptibility data generated in the EGP is enhanced by the availability of animal models with the exact sequence variations discovered by resequencing of the human environmental response genes. Therefore, NIEHS developed a university-based Mouse Genomics Centers Consortium to create mice with such variations and provide them to the scientific community. To date, approximately 20 well-characterized mouse models have been developed. These models represent a variety of disease endpoints, including: Werner's syndrome (aging disorder), diabetes, mammary cancer, gastrointestinal and bladder cancer, prostate cancer, and skin cancer.

#### EFFORT TO IMPROVE RELEVANCE OF ANIMAL MODELS

Environmental health scientists often use mice to predict how environmental agents might affect people. Although mouse studies can indicate the potential of an exposure to cause cancer and other diseases, there is no way to precisely extrapolate these study results to the risk in humans. Information on the similarities and differences in homologous genes between human and mouse is important to improve accuracy in predicting human risk. While laboratory mice might look alike, the 100 different strains used in medical research differ significantly in their behavior, physiology and susceptibility to drugs and environmental agents (e.g., carcinogens), and scientists are eager to discover the differences in the genetic sequences that underlie these traits, with the goal of finding counterparts in humans. NIEHS initiated a mouse sequencing project to decipher the genomes of the 15 mouse strains used most frequently in research to predict human risk. Such data will improve environmental risk assessment decisions and will help researchers in choosing the most appropriate strain for studying toxicity.

## SISTER STUDY OF BREAST CANCER

A unique study exploring gene-environment interactions in breast cancer development has begun nationwide recruitment. It will look at how genes, activities of daily life, and environmental exposures affect breast cancer risk. To get the information quickly, this study is recruiting 50,000 symptom-free women who have a sister that had breast cancer. These women are at increased risk of breast cancer, share many genes with their affected sibling, and would have experienced many of the same exposures. For these reasons, it is expected that a sufficient number of women will develop breast cancer within 10 years and their genes and exposures can be compared with those of women in the study who did not develop the cancer. A broad range of exposures will be examined, including personal care and household products, workplace exposures, and dietary factors, along with genetic analysis. The principal investigator has the active support of the American Cancer Society, Sisters Network, Inc., the Susan G. Komen Breast Cancer Foundation, and the Y-ME Breast Cancer Organization.

## PARKINSON'S DISEASE

A major impediment in Parkinson's Disease (PD) research has been the lack of rapid communication between epidemiologists, laboratory researchers, and clinicians which prevents the type of multidisciplinary approach this field needs. To encourage advances in this important area of study, NIEHS developed a multidisciplinary Collaborative Centers Program for Parkinson's Disease Environmental Research. This multi-institutional approach is designed to accelerate the identification of genetic and environmental factors leading to PD. Collectively, the three centers have expertise in basic neurosciences, human genetics, clinical research, and epidemiology, as well as long-standing interactions with patient groups. Accomplishments to date include: efforts to discover new PD susceptibility genes; development of a registry in California to track the disease; development of mouse models with specific alterations in genes suspected of playing a role in PD, and efforts to develop a primate model of PD that exhibits the most prominent clinical features of the disease.

## AUTISM

Autism is a devastating behavioral disorder that most likely arises from underlying genetic susceptibilities interacting with specific environmental exposures during pre- or post-natal development. A number of people have suspected that the mercury-containing compound thimerosal, used to preserve childhood vaccines, could be an environmental trigger for autism development, based on the established neurotoxicity of higher doses of mercury. Extensive epidemiological studies, however, have failed to provide any association between vaccines and autism. It is possible, however, that only a subset of children are susceptible to mercury effects, perhaps when coupled with an immunological challenge. Preliminary animal studies have provided an intriguing clue to possible susceptibilities that NIEHS is now pursuing. In these studies, different mouse strains were exposed to thimerosal at ages and doses that corresponded to the standard protocol for childhood vaccinations. Only the immunologically deficient strain of mouse exhibited a response. In these mice, behavioral effects were reported and morphological changes were observed in the brain. However, this study did not have sufficient power to be definitive. Fortunately, the NIEHS already had two Children's Environmental Health and Disease Prevention Research Centers devoted to autism. Thus, the Institute provided a supplement to one of these Centers to do more extensive testing of thimerosal in autoimmune-prone (SJL) mice. This Center has expertise in evaluating critical social behaviors, as well as the ability to conduct state-of-the-art stereology to measure brain effects such as volume changes and changes in cell number occur. This more extensive look at thimerosal-immune co-contributors to brain damage may provide better insight into this disorder than previous studies have. In addition, the same Center is recruiting a cohort of 700 autistic children, and appropriate control subjects, to further examine the role of gene-environment interactions in the etiology of autism.

## OBESITY AND THE BUILT ENVIRONMENT

Obesity is a major contributor to human disease and rising health care costs. NIEHS is collaborating with the Robert Wood Johnson Foundation to examine how community design influences physical activity. This so-called Active Living Design Program is working with local governments to influence city planning and land use decisions. The program's impact on physical activity, obesity, and other health indicators will be assessed. The Institute is also encouraging research to evaluate the role of "in utero," neonatal, and pre-puberty exposures to environmental estrogens



and other compounds in the onset and development of obesity, as well as examining gene-environment interactions that favor weight gain.

#### NANOTECHNOLOGY

Nanotechnology is an exciting area of research with broad implications for multiple industries, including medicine and communication. For example, nanoscale devices have the potential to deliver therapeutic and imaging agents to specific cells and tissues in ways not presently possible. However, when bulk material is converted to ultrafine nanoparticles, its physical, chemical, and biological properties can be altered in ways that might adversely affect health. So, while many laboratories are focused on exploiting the rich potential of these agents, there is little activity to assess their toxicological properties. NIEHS, under the auspices of the National Toxicology Program (NTP), has initiated a program to evaluate the toxicological properties of the major classes of nanoscale materials and will investigate fundamental questions such as: How are nanoscale materials absorbed, distributed in the body, and taken up by cells? Are there novel toxicological interactions? What are the appropriate detection and quantification methods for nanoscale particles?

#### NIH ROADMAP AND ENVIRONMENTAL HEALTH RESEARCH

The ability to investigate and understand issues in environmental health requires collaboration between many scientific disciplines: epidemiology, toxicology, molecular biology, clinical sciences, and many others. Thus, Roadmap initiatives such as the Interdisciplinary Research Planning Centers will greatly enhance NIEHS' work. Examples include: the use of geographic/spatial methodologies to address combined genetic, social, and environmental factors on child health and development, and an effort to redefine computational genomics with emphasis on gene-environment interactions in alcoholism, atherosclerosis and breast cancer. Both projects have strong ties to other significant NIEHS-funded programs at the same institutions.

Thank you for the opportunity to comment on the important work supported by the NIEHS. I will be happy to answer any questions you might have.

#### PREPARED STATEMENT OF DR. JOHN RUFFIN, DIRECTOR, NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Center on Minority Health and Health Disparities (NCMHD). The fiscal year 2006 budget includes \$197,379,000, an increase of \$1,220,000 over the fiscal year 2005 enacted level of \$196,159,000 comparable for transfers proposed in the President's request.

The NCMHD has just entered its fourth year of operation. Much has been accomplished during this time. However, much remains to be done. Racial and ethnic minorities and other health disparity populations continue to suffer a disproportionate burden of illness, disability and premature death. Health disparities cover a broad spectrum of health conditions and diseases that include cancer, mental illness, infectious diseases, autoimmune diseases, endocrine diseases, vascular diseases, infant mortality, diabetes, HIV/AIDS, obesity and nutritional deficiencies. There are many factors that contribute to health disparities such as genes, biology, culture, race, environment, socioeconomic, and health behavior. Due to the interaction of these complex factors, the elimination of health disparities requires a multifaceted approach.

#### NIH HEALTH DISPARITIES STRATEGIC PLAN

The Congress has charged the NCMHD to lead the Federal effort in health disparities research, research capacity building, and outreach. The NCMHD guides the NIH efforts in collaboration with NIH Director, the other NIH Institutes and Centers, and the NCMHD's Advisory Council in revising the *NIH Health Disparities Strategic Plan* annually. The plan represents the trans-NIH health disparities vision and strategy to eliminate health disparities through research, research infrastructure, capacity building, and community outreach.

The NIH Institutes and Centers (ICs) are committed to educating minority patient populations on disease management and quality care. Several of the ICs plan to increase the number of culturally relevant health educational materials and to develop and expand linkages with minority organizations and professional societies to increase dissemination of research advances to minority-serving institutions, and racial and ethnic minority and health disparity communities. For example, the National Institute of Allergy and Infectious Diseases (NIAID) will produce a series of low-literacy fact sheets on sexually transmitted infections, HIV/AIDS, and tuber-

culosis. The NINDS expanded its health education program, *Know Stroke. Know the Signs. Act in Time.*, to populations at high risk for stroke—African Americans, Hispanics, and seniors—in communities that have the health care systems in place to treat them. The National Center for Complementary and Alternative Medicine (NCCAM) will employ multimedia technology, such as web chats, teleconferences, and minority-focused media to disseminate information about complementary and alternative medicine.

The National Cancer Institute (NCI) is achieving significant progress toward understanding and addressing the needs of the Hawaiian and Pacific Basin populations through a five-year cooperative agreement with Papa Ola Lokahi, a Native Hawaiian owned-and-operated community-based health organization. Through this agreement, the NCI funds a variety of culturally competent cancer awareness, research, and training activities.

The National Heart, Lung and Blood Institute (NHLBI) is initiating a new program to address the substantial and growing burden of Cardiovascular Disease (CVD) in American Indians and Alaska natives. This initiative will develop and test culturally appropriate interventions to promote the adoption of lifestyles and behaviors that are known to reduce biological and CVD risk factors, such as high blood pressure and cholesterol levels, obesity, glucose intolerance, and diabetes.

#### NCMHD HEALTH DISPARITIES IMPACT

In addition to developing the NIH Strategic Plan, the NCMHD has focused attention on the pressing need to establish its programs. The national reach of the NCMHD extends to more than 100 institutions and more than 500 individuals that have received awards to train for health professions careers, conduct health disparities research, build research capacity and advance outreach efforts.

The NCMHD Health Disparities Centers of Excellence (Project EXPORT) program currently funds seventy-one institutions in 29 states engaged in multidisciplinary research. Priority research focus areas include cancer, cardiovascular disease, stroke, diabetes and the health of mothers and their infants.

Communities nationwide in states such as Alabama, New York, Pittsburgh, Montana and Hawaii are being encouraged and equipped for participation in clinical studies and for partnering in the conduct of evidence-based disease prevention and intervention activities. The Clemson University-Voorhees College Project EXPORT partnership has three studies focused on obesity. Using a network of community-based partners, each study examines diet and/or physical activity levels of rural residents or students. The objectives of the studies are to identify the socio-cultural factors influencing choices and determine how environmental effects and knowledge of nutrition and physical activity impact choices about diet and exercise.

Culturally competent health care is an essential component in defeating health disparities and requires a distinct sense of urgency. In a recent study on cultural competence among physicians treating Mexican Americans who have diabetes, supported by a NCMHD-Center of Excellence, scientists determined that physicians can increase cultural competence and effective care by becoming self-aware of their knowledge, views, and attitudes about cultures and ethnic groups, and by engaging in culture-focused educational activities. Recognizing that culturally appropriate actions can be predicted, based on a provider's awareness that culture is relevant to medical care and that negative preconceptions can hinder the effectiveness of health care delivery, is an important finding for improving cultural competence and reducing health disparities.

The NCMHD Research Endowment Program, unique within the NIH, is best described as inclusive and diverse. Fourteen institutions receive NCMHD endowment funds to enhance research capacity and infrastructure for research and training. The activities of the institutions involve strengthening teaching programs in the biomedical and behavioral sciences; establishing endowed chairs and programs; obtaining state-of-the-art equipment for instruction and research; and enhancing the recruitment and retention of student and faculty from health disparity populations. A NCMHD Endowment Program award to the University of Kansas has enabled the university to develop a K-12 pipeline to recruit students through summer programs; retain and graduate 95 percent of underrepresented minority medical students; increase underrepresented minority faculty members from 24 to 39; and provide opportunities for 48 underrepresented minority students to participate in health disparity research over the summer.

The NCMHD supports two loan repayment programs—the Health Disparities Research Loan Repayment Program (HDR) and the Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds (ECR), to promote a diverse and strong scientific workforce by alleviating the financial bar-

riers that often discourage many talented health professionals from health disparity, medically underserved and disadvantaged communities from pursuing a research career.

The NCMHD funds are supporting the deployment of 466 emergent researchers to 42 states and the District of Columbia to conduct health disparities research. These programs are the foundation for developing a lasting relationship with talented and committed health disparities scholars. Fifty-six percent of the awardees in the HDR program are members of a health disparity population. The loan repayment programs exemplify the multidisciplinary approach needed to address health disparities. For example, epidemiology, pharmacology, linguistics, etiology, ethnography, health policy, and behavioral science are among the program's research disciplines. Research includes: identifying barriers to health care access; race and long-term diabetes self management in an HMO; a comparison of androgen receptor for polymorphism in African American and Caucasian women with breast cancer; and reducing HIV/STI risk in young adult minority populations.

The number of participating institutions in the Research Infrastructure in Minority Institutions (RIMI) Program has tripled since 2001. Program accomplishments include faculty seminar series on health disparities research; research on the health and developmental impact of methamphetamine production in New Mexico children, and the establishment of a Natural Toxins Research Center. The NCMHD will continue to build upon the RIMI program by exploring partnerships among tribal colleges, community/junior colleges, and non-research intensive four-year institutions with major research-intensive colleges and universities.

The Minority Health and Health Disparities International Research Training Program (MHIRT) positions the NCMHD in collaboration with the NIH Fogarty International Center, to extend its health disparities research and training capacity across borders. The MHIRT program enables students and faculty from health disparity populations to participate in international research training opportunities in countries such as South Africa, Sweden, Italy, Mexico, Bulgaria, Thailand, Trinidad, China, Australia, Brazil, and Senegal. Research efforts include cancer epidemiology, reproductive biology, parasitology, malaria, ethnopharmacology and neurobiology.

#### COMMUNITY-BASED PARTICIPATORY RESEARCH AND OUTREACH

The NCMHD recently established an Office of Community-Based Participatory Research and Outreach, and launched a new program that will support collaborative partnerships between academic institutions and community-based organizations for research studies looking at the interface of physical and psychological environments and their health impacts on communities of color and the medically underserved; methodology research looking at effective methods of measuring racism and community level outcomes; evaluation of outcomes; and impact of the research. This program will build on the NCMHD existing community-based research and outreach initiatives through its Project EXPORT program.

#### FEDERAL RESEARCH COLLABORATIONS

In addition to its core programs, the NCMHD has continued to fund a broad range of collaborations with the other NIH Institutes and Centers, the Department of Health and Human Services, and other Federal agencies. Recently, the NCMHD launched a new initiative to support research relevant to the Mississippi Delta Region and its medically underserved populations. This endeavor involved the collaboration of eight NIH Institutes and Centers with the NCMHD supporting approximately \$8 million in research projects.

#### CONCLUSION

Working with our many research partners, the top priority of the NCMHD is to build a solid and diverse national biomedical research enterprise of individuals, institutions, and communities dedicated to eliminating health disparities. The NCMHD will sustain and expand its primary strategies. Research capacity building will extend beyond academia to involve community and faith-based organizations, individuals, and business at local and grassroots levels. Training and the diversification of the health, scientific, and technological workforce will remain key areas of focus in developing innovative projects. Prevention, treatment, cultural competency, and health care delivery for urban and rural communities will be approached more aggressively. We will continue to strive for an America in which all populations will have an equal opportunity to live long, healthy, and productive lives.

## PREPARED STATEMENT OF DR. PAUL SIEVING, DIRECTOR, NATIONAL EYE INSTITUTE

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Eye Institute (NEI). This budget includes \$673,491,000, an increase of \$4,421,000 over the fiscal year 2005 enacted level of \$669,070,000 million comparable for transfers proposed in the President's request. As the Director of the NEI it is my privilege to report on the progress laboratory and clinical scientists are making in combating blindness and visual impairment and about the unique opportunities that exist in the field of vision research.

## GLAUCOMA AND OPTIC NEUROPATHIES

Glaucoma is a group of eye disorders that causes optic nerve damage that can lead to severe visual impairment or blindness. Elevated intraocular pressure (IOP) is frequently, but not always, associated with glaucoma. Glaucoma is a major public health problem and published studies find it is the most common cause of visual impairment and blindness in African Americans.

The prevalence of glaucoma is three times higher in African Americans than in non-Hispanic whites.<sup>1</sup> Additionally, the risk of visual impairment is much higher and the age of onset is earlier than in Whites. An NEI-supported follow-up study to the Ocular Hypertension Treatment Study (OHTS) found that early treatment of elevated IOP reduces the risk of developing glaucoma in African Americans. Of the participants in the treatment arm of the study, 8.4 percent developed glaucoma whereas 16.1 percent in the observation group developed the disease. Additionally, the OHTS follow-up study found that certain biological characteristics of the eye including corneal thickness are helpful in predicting who will likely develop glaucoma and who will benefit from therapy. This study provides important treatment and prognostic information for clinicians in caring for this at risk population.

## RETINAL DISEASES

Retinal diseases are a diverse set of sight-threatening conditions that include age-related macular degeneration, diabetic retinopathy, retinopathy of prematurity, retinitis pigmentosa, Usher's syndrome, ocular albinism, retinal detachment, uveitis (inflammation) and cancer (choroidal melanoma and retinoblastoma). This year, NEI supported laboratory researchers made great strides in developing therapies for these diseases. For example, a recent NEI study found that eye injections of bone marrow stem cells from adult animals prevented vision loss in two rodent models of retinitis pigmentosa (RP). These findings raise the possibility of a therapy in which patients could receive an injection of their own bone marrow stem cells to preserve vitally important central vision.

Age-related macular degeneration (AMD) is a leading cause of blindness and visual disability in older age Americans. The inability to prevent the development of AMD and its complications is largely due to an imprecise understanding of the pathologic mechanisms of the disease. Genetic and environmental factors have previously been implicated in the disease. A recent NEI supported study in animal models has found evidence that inflammation may also play a role. These animal models suggest that the immune system contributes to the disease and offer new insights into possible mechanisms of the disease. The availability of animal models of the disease will also allow for the testing of new intervention strategies.

## CORNEAL DISEASES

The cornea is the transparent tissue at the front of the eye. Corneal disease and injuries are the leading cause of visits to eye care professionals, and are some of the most painful ocular disorders.

The epithelial cells of the cornea form a surface barrier that protects the underlying tissues from the external environment. When this layer is damaged, the epithelial cells normally respond quickly to close the wound and reform the barrier. In some cases, however, this response is defective, leading to the formation of persistent and painful corneal ulcers. Development of more effective treatments for this condition has been hampered by the limited information about the cellular and biochemical events that regulate corneal wound closure. This year, scientists at the NEI discovered that an enzyme called Cdk5 plays a central role in regulating the migration of epithelial cells to close corneal wounds. More importantly they discovered that drugs which inhibit Cdk5 promote cell migration and wound closure.

<sup>1</sup>The Eye Diseases Prevalence Research Group: Prevalence of open-angle glaucoma among adults in the United States. *Arch Ophthalmol* 122:532-538, 2004.

These findings suggest a new therapeutic approach for treating persistent corneal ulcers and other conditions that impair wound healing. Animal studies are in progress to determine whether inhibitors of Cdk5 can safely be used in the eye to enhance wound healing.

#### CATARACT

Cataract, an opacity of the lens of the eye, interferes with vision and is the leading cause of blindness in developing countries. It is also a major public health problem in this country. Throughout life, the lens carries out a process of continued growth with epithelial cells dividing and differentiating into fiber cells. As epithelial cells differentiate into fiber cells they become denuded of certain cell components so they will not interfere with vision or cause cataracts. NEI supported scientists have recently discovered that the epithelial cells “borrow” enzymes involved in programmed cell death, or apoptosis, to mediate the destruction of these cell parts. Apoptosis is a normal biologic process that guides an orderly destruction of cells that are no longer functional or needed. This study defines a critical step in how fiber cells are formed and will spark further investigation into whether alterations in apoptotic enzymes play a role in cataract formation.

#### STRABISMUS, AMBLYOPIA AND VISUAL PROCESSING

Developmental disorders such as strabismus (misalignment of the eyes) and amblyopia (commonly known as “lazy eye”) are among the most common eye conditions that affect the vision of children. In addition, published data estimates that more than 3 million Americans suffer from visual processing disorders not correctable by glasses or contact lenses.

It is estimated that 20 percent of preschool children ages 3–4 have a treatable eye condition.<sup>2</sup> While many states are developing guidelines for preschool screening programs, none of the commonly used vision tests have been evaluated in a research-based environment to establish their effectiveness. Initial results from the NEI-sponsored Vision in Preschoolers (VIP) Study found that 11 commonly used screening tests vary widely in identifying children with symptoms of common childhood eye conditions such as amblyopia, strabismus, and significant refractive error. When the best tests are used by highly skilled personnel in a controlled setting, approximately two-thirds of children with one or more of the targeted disorders were identified. These better tests were able to detect 90 percent of children with the most severe visual impairments. The ongoing VIP study will continue to provide state and local agencies with data to select the most effective vision screening exams that are currently available. The VIP study will also help ensure that more children are detected and treated at an early stage when therapy is most effective.

A fundamental issue in neuroscience has been the inability of nerve cells to regenerate. If researchers could develop therapies that overcome this limitation, the deleterious effects of many neurologic diseases and central nervous system (CNS) injuries might be reversed or greatly improved. NEI-supported researchers provoked nerve cell regeneration in rodents by activating a nerve cell’s natural growth capacity and using gene therapy to suppress the effects of growth-inhibiting factors. Although vision was not restored, this combined approach stimulated nerve cell regeneration three times greater than prior attempts. Regeneration of the mature CNS would provide an opportunity to treat blindness and other neurologic diseases.

#### HEALTH DISPARITIES

Census 2000 data indicate that 12.5 percent of residents in the United States, or 35 million people, are Latino. Based on these data, it is estimated that by the year 2025, 61.4 million Latinos will live in this country, making this the fastest growing minority population. However, there is little available data to ascertain the prevalence and severity of major eye diseases in this population. Results from the NEI-sponsored Los Angeles Latino Eye Study (LALES) suggest that Latinos have some of the highest rates of visual impairment and blindness in the United States. The prevalence of visual impairment and blindness in Hispanics increased with age and women were more frequently affected than men. From a socio-economic perspective, Latinos who were unemployed, divorced or widowed, or less educated had increased rates of visual impairment and blindness. The prevalence statistics, coupled with the socio-economic data from LALES concerning the factors that negatively influ-

<sup>2</sup> Comparison of preschool vision screening tests as administered by licensed eye care professionals in the Vision in Preschoolers Study. *Ophthalmology* 111(4): 637–50, 2004.

ence access to health care, will aid the NEI, through its public education programs, to devise strategies that better target these at-risk populations.

#### NIH ROADMAP

A major theme of the NIH Roadmap, Re-engineering the Clinical Research Enterprise, is aimed at accelerating and strengthening the clinical research process. This Roadmap theme is consonant with the NEI's own goal of supporting the highest quality clinical research. The NEI and vision research community have anticipated these opportunities by creating networks such as the Pediatric Eye Disease Investigator Group (PEDIG) and the newly launched Diabetic Retinopathy Clinical Research Network. Continuation and expansion of these initiatives should facilitate and hasten the translation of research discoveries from the laboratory to the clinic for the benefit of those afflicted with a range of eye disorders and diseases.

#### NIH NEUROSCIENCE BLUEPRINT

The NIH Neuroscience Blueprint was launched in 2004 to further enhance cooperation among 15 NIH Institutes and Centers that support research on the nervous system. Blueprint participants are developing an initial set of initiatives focused on tools, resources, and training that can have a quick and substantial impact because each builds on existing programs. Among the Blueprint initiatives for fiscal year 2006, NEI will participate in the systematic development of genetically engineered mouse strains for research on the nervous system and training in neuroimaging and computational biology. NEI will also participate with other Institutes in an initiative to provide specialized neuroscience resources such as animal model, imaging, gene sequencing and screening facilities.

Mr. Chairman, this concludes my prepared statement. I would be pleased to respond to any questions you or other members of the committee may have.

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#### PREPARED STATEMENT OF DR. ALLEN M. SPIEGEL, DIRECTOR, NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) a sum of \$1,872,146,000, which includes \$150,000,000 for the Special Appropriation for Research on Type 1 Diabetes through Sec. 330B of the Public Health Service Act. The NIDDK transfers some of these funds to other institutes of the NIH and to the Centers for Disease Control and Prevention (CDC). Adjusted for mandatory funds, this is an increase of \$8,562,000 over the fiscal year 2005 enacted level of \$1,863,584,000 comparable for transfers proposed in the President's request.

I appreciate the opportunity to testify on behalf of the NIDDK. Our Institute supports research to combat a wide range of debilitating chronic health problems, including diabetes and other endocrine and metabolic diseases; digestive diseases; kidney and urologic diseases; blood diseases; and obesity. Through vigorous support of investigator-initiated research and Institute-initiated efforts, the NIDDK will continue to elucidate the fundamental biology underlying health and disease and to explore new strategies for disease diagnosis, treatment, and ultimately, prevention.

#### FROM THE LABORATORY BENCH TO THE PATIENT'S BEDSIDE

In recent years, ever-advancing technologies have led to an explosion of biomedical knowledge. It is imperative that scientists harness new discoveries to improve medical care. Thus, in addition to supporting critical basic and clinical research, the NIDDK is also bolstering "translational" research, to accelerate the progression of scientific discovery from basic to clinical studies to directly benefit patients. In one stage of translational research, insights gained at the laboratory "bench" spur the design of new strategies for prevention or intervention, which investigators then test in clinical studies—at the patient "bedside." In a second stage of translational research, investigators explore ways to bring successful interventions and lifesaving knowledge from the clinical research setting into the realm of healthcare practice.

With the goal of directing NIDDK translational research investments to enhance efforts on multiple diseases, I established a Trans-NIDDK Translational Research Working Group to identify research obstacles and opportunities. The Working Group charted the progression from basic to clinical research to medical practice for a number of health conditions to identify common themes for future research. These anal-

yses were considered by NIDDK's National Advisory Council; external advice was also received at other scientific meetings.

By way of example, translational research relating to the assessment of blood sugar (glucose) levels has greatly benefited diabetes care. Scientists discovered that levels of a variant of the red blood cell protein hemoglobin, called hemoglobin A1c (HbA1c), correlate with blood sugar levels. In the 1990s, a landmark NIDDK-supported clinical trial demonstrated that people with type 1 diabetes can reduce the risk of eye, kidney, and nerve complications by lowering their HbA1c levels through intensive treatment of blood sugar. As a result of this research, target levels for HbA1c were set, thus improving patient care by encouraging medical practitioners to use a combination of methods to better control blood sugar. This research further led to the FDA's acceptance of the HbA1c level as an end-point sufficiently robust to define clinical benefit in clinical trials. "Biomarkers," such as the level of HbA1c, can facilitate clinical trials and thus stimulate the development of new therapeutic agents. Many new drugs for diabetes have now been FDA-approved based on HbA1c as an outcome.

In another example of successful bench-to-bedside research, NIDDK-supported investigators elucidated the biological defect responsible for the devastating inherited metabolic disease, MPS I; discovered a naturally-occurring dog model for the disease; and tested a potential therapy in dogs. Following clinical testing, this therapeutic agent is now produced by industry and available on the market to treat this disease. These two examples illustrate the critical role of NIH investment in research from bench-to-bedside. Both also spanned several decades from the initial basic research discoveries to clinical application. Thus, a critical goal of NIDDK's new translational research efforts is to accelerate this process.

In one planned translational research effort, the NIDDK will pursue the development of new biomarkers. Examples of diseases or conditions for which such biomarkers would be valuable include acute kidney failure, liver and kidney fibrosis, type 1 diabetes, and insulin resistance—which is associated with type 2 diabetes. The NIDDK will also foster research on biomarkers for interstitial cystitis, including the evaluation of a potential diagnostic marker that emerged from prior NIDDK-funded research.

Among other translational research efforts, the NIDDK will strengthen research to bring new non-invasive imaging techniques from the laboratory to the clinical setting to enhance clinical research on liver, pancreatic, kidney, and urologic diseases. The Institute will also encourage the development of new animal models suitable for preclinical testing of diagnostic, preventive, or therapeutic interventions for diseases within NIDDK's mission. Although a wealth of information about human biology has been and continues to be gleaned from studies of mice and other animals, in many cases existing animal models are insufficient for preclinical testing. Other translational research efforts are capitalizing on fundamental knowledge about how proteins assume their proper structures. This approach, informed by a recent NIDDK-sponsored conference, will help propel the search for therapies for cystic fibrosis and certain liver and kidney diseases, which are caused by defects in protein "folding" or "processing." Translational research promoted by the NIH Roadmap will synergize with these NIDDK efforts to accelerate progress.

Insights gained from clinical observations can open new avenues for basic research studies, which, in turn, will spur new clinical research endeavors. Several NIDDK initiatives are fostering increased collaboration between basic and clinical researchers, including support for ancillary studies to major ongoing NIDDK clinical trials. Such studies will also maximize the Institute's investment in these trials. As part of our new efforts to enhance our research centers programs, the NIDDK will encourage basic and clinical research partnerships to take advantage of the opportunities of research centers.

In addition to the bench-to-bedside research just described, the NIDDK is pursuing strategies to best translate successful clinical research results from patient study volunteers to the public. These efforts include, for example, translating the results of the Diabetes Prevention Program (DPP) clinical trial, which demonstrated that people at high risk for type 2 diabetes can dramatically reduce risk of disease onset through modest weight loss and exercise. To promote these positive findings, the NIDDK launched its campaign, "Small Steps. Big Rewards. Prevent Type 2 Diabetes," with tailored messages and materials developed for ethnic groups at high risk for type 2 diabetes, older adults, and a general audience. In parallel, the Institute is supporting research demonstration and dissemination projects to explore new strategies for effectively translating the DPP results, from clinical trial to community. This research includes testing programs that target different age groups and minority populations.

New translation efforts to combat kidney disease are building upon the recent finding that even modestly-impaired kidney function increases risk of cardiovascular disease and premature death. Avoiding these devastating outcomes requires early awareness of kidney disease and appropriate treatment. Critically important is detection of deterioration in the kidneys' filtering capacity, the glomerular filtration rate (GFR). While GFR is difficult to measure directly, it can be estimated from routinely measured serum creatinine. The NIDDK's National Kidney Disease Education Program (NKDEP) is thus encouraging laboratories that measure serum creatinine to provide clinicians with GFR values. The NKDEP recently launched an education campaign emphasizing the importance of early detection and treatment, and targeting this message to primary care providers and those at high risk for kidney disease.

#### EXAMPLES OF BASIC AND CLINICAL RESEARCH ENHANCEMENTS

Underscoring a growing health crisis among our Nation's children, this past year a NIDDK-supported pilot study of middle school students uncovered high levels of the "metabolic syndrome," which is a cluster of health problems associated with obesity and increased risk for diabetes and cardiovascular disease. To address the health threats posed by obesity, we developed and published a Strategic Plan for NIH Obesity Research. Informed by extensive input from scientific and lay experts, the Strategic Plan was developed by the NIH Obesity Research Task Force. Since its inception by the NIH Director, I have had the privilege of co-chairing the Task Force with the NHLBI Director, with the aims of synergizing and accelerating obesity research across the NIH. Consistent with the goals of the Strategic Plan, the NIDDK is pursuing a multifaceted obesity research agenda, from basic molecular investigations to novel intervention studies to translational research. For example, the NIDDK is spearheading a new trans-NIH initiative to study how factors such as maternal weight during pregnancy can lead to obesity in offspring. This research has important implications for public health.

In the area of digestive diseases, the *Action Plan for Liver Disease Research* has now been published. It was developed through NIDDK-led efforts with broad external input from the research, professional, and patient-advocacy communities. Examples of the many areas addressed by the Action Plan include developing or improving therapies for hepatitis C; developing tools for early liver cancer detection; and research on living donor liver transplantation. The Action Plan will direct new liver disease research; the NIDDK will also continue major ongoing clinical studies on hepatitis C; biliary atresia, a disease that strikes children; and non-alcoholic steatohepatitis, a fatty liver disease.

The *Action Plan for Liver Disease Research* is part of a larger planning process for research on digestive diseases, which have an enormous burden on the U.S. population. For inflammatory bowel disease, external advice received in previous planning efforts will continue to inform the NIDDK research agenda. New planning efforts will aim to strengthen research on irritable bowel syndrome and other functional gastrointestinal disorders, which are debilitating and highly prevalent but not well understood. Following focused planning efforts relevant to gastroparesis, the NIDDK will establish a new clinical research consortium to study this debilitating syndrome of nausea, vomiting, bloating, and other symptoms which complicates diabetes and other diseases.

In the areas of kidney and urologic diseases, in addition to the efforts described earlier, the NIDDK will encourage partnerships to pursue promising new therapies for polycystic kidney disease, and will launch a new clinical intervention study of children with vesicoureteral reflux, a bladder condition which can impair kidney function.

I have highlighted today examples of NIDDK's many and diverse research plans and efforts. These reflect our strong commitment to improving human health.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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#### PREPARED STATEMENT OF DR. STEPHEN E. STRAUS, DIRECTOR, NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2006 President's budget request for the National Center for Complementary and Alternative Medicine (NCCAM). The fiscal year 2006 budget includes \$122,692,000, an increase of \$587,000 over the fiscal year 2005 enacted level of \$122,105,000 comparable for transfers proposed in the President's request.



In 2004 NCCAM celebrated its first 5 years by reflecting on its contributions to the science of complementary and alternative medicine (CAM) and crafting a second strategic plan that articulates the Center's plans for 2005–2009. The plan is a collaborative effort that was developed with extensive input solicited from the public, CAM practitioners, and experienced scientific investigators; it articulates NCCAM's agenda for researching CAM healing practices, training CAM researchers, and conducting outreach.

It is noteworthy that an independent analysis released in January 2005 of the major scientific and policy issues surrounding CAM use, which was undertaken by conventional and CAM investigators for the Institute of Medicine (IOM) of the National Academies, identified many of the same research and training priorities as had NCCAM in its strategic planning process. The IOM report emphasized that evidence-based science must inform all health care practices, both conventional and CAM.

In accord with the philosophy articulated by the IOM, scientific rigor has been and will remain the foundation upon which NCCAM advances its research agenda. In its first 5 years, NCCAM funded more than 1,200 projects at some 260 CAM and conventional research institutions. The results of these projects are being published in leading medical journals, affording the public and their health care providers better data on which to base decisions on CAM use. The following are a few highlights of NCCAM's recent scientific advances, ongoing activities, and plans that illustrate the Center's progress and future directions.

#### UNDERSTANDING WHO USES CAM AND WHY

Understanding who uses CAM and why they do so informs NCCAM's research goals, initiatives, and collaborations. In 2004, NCCAM reported results based on survey data collected in partnership with the Centers for Disease Control and Prevention from more than 31,000 Americans. The data revealed that 62 percent of survey respondents used CAM in 2002. Back pain was the single most common reason respondents used CAM, followed by respiratory infections. To track trends in CAM use, NCCAM and the CDC have agreed to undertake a followup survey in 2007. Additional NCCAM-funded survey analyses are also under way to examine in greater detail CAM use in diverse minority populations.

#### DETERMINING THE EFFECTS OF ACUPUNCTURE

Acupuncture is among the top ten most popular CAM practices in the United States. In spite of its venerable traditions as a therapeutic practice in Asia, scientific research on acupuncture and how it might work is a relatively recent phenomenon. The recent report on the efficacy of acupuncture for osteoarthritis demonstrates the power and promise of the research strategies developed and implemented by NCCAM.

More than 20 million Americans have osteoarthritis, a frequent cause of pain and disability among aging adults. In 2004, NCCAM-funded investigators, building on the results of previous smaller studies, reported the results of the largest randomized, controlled Phase III clinical trial of acupuncture ever conducted. This study of 570 patients demonstrates that acupuncture is an effective complement to conventional treatments in patients with osteoarthritis of the knee.

#### EXPLORING MIND-BODY MEDICINE

Recognizing the important role of social and behavioral factors in illness and health, NCCAM's new strategic plan describes further growth in the Center's investments on mind-body medicine for a range of diseases. One such study already under way is a clinical trial examining the use of meditation to achieve weight loss and enhance overall health and well-being among obese men and women. Also, in 2004 NCCAM funded a mind-body center as part of its research centers program.

To further stimulate the field of mind-body medicine research, NCCAM is co-funding an initiative with the NIH Office of Behavioral and Social Sciences Research to encourage interdisciplinary collaborations to elucidate processes underlying mind-body interactions and health and to develop health promotion and disease prevention and treatment interventions.

#### INVESTIGATING DIETARY SUPPLEMENTS AND FOODS

As reported in the NCCAM/CDC survey, herbal products are among the most popular CAM therapies. Although many believe these products to be safe because they are "natural" or have been used for centuries, few of these products have undergone sufficient study of their safety and effectiveness. Research on botanicals is a priority

area, and NCCAM funds numerous studies ranging from basic laboratory investigations to large Phase III clinical trials, to gather data on the nature, safety, and efficacy of popular herbal remedies.

For example, NCCAM supports several interrelated studies of cranberries for preventing urinary tract infections (UTIs), which afflicts approximately 25 percent of women at least once in their lifetime. These include Phase II clinical trials to identify the optimal cranberry formulation, dose, and treatment duration in studies on UTI prevention as well as other smaller studies on the basic mechanisms, pharmacokinetics, and renal clearance of cranberry's major chemical components.

Another priority for NCCAM's dietary supplement research portfolio is chronic liver disease, which claimed the lives of more than 20,000 Americans in 2002 and disproportionately affects minorities. Through the Small Business and Innovative Research program, NCCAM supports development of a standardized milk thistle product, the most promising CAM therapy for liver disease. In collaboration with the National Institute of Diabetes and Digestive and Kidney Diseases, NCCAM will undertake early phase studies of safety and tolerability of milk thistle to determine if a Phase III trial is likely to be successful, and if so, the optimal research design for its implementation.

NCCAM grantees are also examining the potential therapeutic properties of foods such as soy—especially as it relates to alleviating menopausal symptoms and promoting bone health. Last year NCCAM-supported scientists reported that in a study of pain induced by bone cancer, soy-fed mice experienced less pain than those in a control group. A better understanding of how dietary constituents and plant-based nutrients moderate pain may yield further treatments to help patients with chronic pain.

Benefiting NCCAM's botanical research agenda is its partnership with the NIH Office of Dietary Supplements (ODS). This year NCCAM and ODS have renewed their partnership in funding Botanical Research Centers to promote interdisciplinary collaborative studies on dietary supplements.

#### MEETING THE DIVERSE NEEDS OF SELECTED POPULATIONS

NCCAM has a broad-based research portfolio, reflecting the diversity of individuals who use CAM for help in managing an array of diseases and conditions. For example, understanding how racial and ethnic minorities use CAM is a focus of the Center's research agenda in health disparities. Initiatives are under way to examine the interplay of race, ethnicity, age, gender, and locale to understand how they affect minorities' use of CAM to manage chronic illnesses such as diabetes or asthma. Examining these practices will help direct future research to answer why specific populations use certain CAM practices—for cultural reasons, because of access issues, for economic reasons, or for effectiveness—which in turn will help health care providers better meet the needs of these groups.

Diseases and conditions predominately affecting the elderly are major targets of ongoing investments. For example, NCCAM is supporting the largest randomized Phase III clinical trial to date of Ginkgo biloba to prevent dementia in the elderly. Cardiovascular disease (CVD), the leading cause of death in the United States, is also a research priority for NCCAM. Investigations are ongoing of the ability of green and black tea extracts (*Camellia sinensis*) to reduce cholesterol absorption and biosynthesis in postmenopausal women and patients at high risk for CVD.

In 2004, NCCAM grantees reported results from a clinical trial in children affected with upper respiratory infections (URI). In the trial, over 400 healthy 2- to 11-year-olds received a placebo or an echinacea product, an herbal identified by the NCCAM/CDC survey as widely used, to determine objectively whether it would reduce the severity of URIs over the 4-month study period. The researchers observed no differences between the two groups in the duration, severity, number of days with fever, and rate of adverse events except for an increased incidence of rashes in children receiving echinacea. Given the widespread use of this product, NCCAM is following up on this research, focusing on prevention of infection, which is how echinacea is usually taken, and studying the mechanisms by which echinacea may have health effects.

In the wake of the Women's Health Initiative, NCCAM is developing a diverse research portfolio to explore use of CAM in treating menopausal symptoms, including hot flashes and osteoporosis. Some studies are examining the safety and efficacy of a range of CAM modalities women now use to treat these symptoms; others address more basic science questions, such as a therapy's mechanism of action. NCCAM's research portfolio also addresses other important health conditions exclusive to women—endometriosis and premenstrual syndrome (PMS)—as well as those that af-

fect more women than men, such as UTIs, osteoporosis, fibromyalgia, osteoarthritis, breast and other cancers, and cardiovascular disease.

#### PARTICIPATING IN TRANS-NIH INITIATIVES

NCCAM co-chairs a critical component of the NIH Roadmap for Medical Research Activity, Reengineering the Clinical Research Enterprise, to develop a more effective and cost-efficient model of translational research to move basic research into safe, well-designed clinical trials. In addition, NCCAM is actively involved in the NIH Neurosciences Blueprint, a trans-NIH initiative to accelerate the efficiency and pace of neurosciences research. Also, as part of the Trans-NIH Obesity Initiative, NCCAM is co-sponsoring efforts on childhood obesity and obesity prevention and treatment.

#### CHARTING NCCAM'S FUTURE

NCCAM has accomplished much in its first 5 years. The first NCCAM-supported large-scale clinical trials are nearing completion; these findings are appearing in the nation's leading medical journals. NCCAM also has developed a comprehensive communications program to inform the public and health care professionals about CAM research findings. And the Center has created new opportunities in CAM research training for young scientists and has forged linkages between CAM institutions and conventional research centers. With its second strategic plan as a guide, NCCAM looks forward to making ongoing contributions as the nation's lead CAM research agency.

Thank you Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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#### PREPARED STATEMENT OF DR. LAWRENCE A. TABAK, DIRECTOR, NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Dental and Craniofacial Research (NIDCR) for fiscal year 2006. The fiscal year 2006 budget includes \$393,269,000, an increase of \$1,440,000 over the fiscal year 2005 level of \$391,829,000 comparable for transfers proposed in the President's Request.

#### THE ROAD AHEAD: MERGING SCIENTIFIC VISION AND TECHNOLOGY DEVELOPMENT

Many of the opportunities that now face our nation's oral health researchers have never been more exciting or scientifically challenging. For the first time, we can envision a day when early stage tooth decay will be reversible with remineralizing solutions that patch the tooth and halt the disease process before a filling is required. Researchers will soon begin to learn how to engineer teeth and their constituent parts in the laboratory and transplant them into the mouth to replace a missing tooth or damaged tissue. The day also is approaching when saliva will be a reliable diagnostic fluid to detect systemic diseases, providing a rapid, non-invasive alternative to blood-based tests. These are but a few of the many opportunities that await us. And yet, as important as these visions of the future are in setting the course toward improved public health, it is abundantly clear that the road ahead will be blocked unless we develop new tools and technologies for working within the complex microenvironments of the human body. It is this merging of scientific vision with technology development that the NIDCR is fostering within our nation's oral research community and which I would like to highlight.

#### EARLY DIAGNOSIS TO PREVENT DENTAL CARIES

Let me begin with one of the examples just mentioned. Despite dramatic reductions in tooth decay in the United States over the last half century, dental caries remains a significant public health problem, particularly among disadvantaged population groups. Dental decay also is an unexpected impediment to timely deployment of military personnel. At a time when our nation remains at war, dental readiness has been cited in testimony by the Reserve Officers Association as the number one deployment problem for National Guard and Reserve members. In a 2002 Department of Defense study, 34 percent of military personnel required dental care before they could be deployed, compared to only 16 percent in 1998.

The NIDCR will soon launch an initiative to evaluate the ability of emerging technologies to accurately and reproducibly measure extremely subtle changes in dental enamel that signal the earliest phases of dental caries. While this initiative may sound highly technical, its outcome could play an essential role in transforming den-

tal care. Treatments with the potential to remineralize tooth surfaces in the very earliest stages of decay, long before a filling is needed, are emerging. In anticipation of the required clinical trials to rigorously evaluate these treatments, NIDCR will soon launch an initiative to ensure that microscopic changes in a tooth's mineral content can be measured accurately and reproducibly. Through this enabling research, the evaluation of these treatments will be firmly grounded in science, ensuring the greatest possible benefit to the public.

#### BIOENGINEERING: BUILDING A TOOTH

Tooth loss has been a public health problem in the United States since the days of George Washington and Thomas Jefferson. Despite revolutionary advances in oral health over the last half century, tooth loss remains a problem, particularly among disadvantaged groups. In addition, tooth agenesis—the lack of one or more permanent teeth—is the most common congenital malformation in humans. While dental implants or dentures are often effective replacements, science has progressed to the point that it may be possible to generate replacement teeth from scratch, which would mark a truly historic advance in oral healthcare and in our understanding of human biology.

Whereas just a few years ago tooth regeneration was far beyond the reach of science, which is no longer the case. An historic opportunity now awaits dental science to learn to seed and reproducibly control the complex, tightly orchestrated cellular and molecular interactions involved in producing a tooth and its supporting structures. The crucial first steps will be to: identify existing gaps in our knowledge of tooth formation; pursue viable solutions from throughout the biological and physical sciences to bridge these gaps; and, based on these comprehensive analyses, formulate blueprints for a complete tooth. Relying on the best of these blueprints, interdisciplinary teams of scientists will begin the process of engineering replacement teeth. It is likely that these investigations will initially yield viable replacement parts, such as enamel, dentin or periodontal ligament, but the ultimate goal is complete tooth regeneration.

#### LAB ON A CHIP: SALIVARY DIAGNOSTICS

Another particularly exciting area of research is salivary diagnostics. Scientists have long recognized that our saliva serves as a “mirror” of the body's health, in that it contains the full repertoire of proteins, hormones, antibodies, and other molecular substances that are frequently measured in standard blood tests to monitor health and disease. Saliva is easy to collect and poses none of the risks, fears, or “invasiveness” of blood tests. The problem has been that the needed technologies have not existed to adequately develop salivary diagnostics on a large scale.

The Institute continues to support a major research effort that will further develop these needed technologies and create the first comprehensive baseline catalogue of all proteins found normally in oral fluids. This is the initial step in building the needed scientific infrastructure required to expand salivary diagnostics. Already, scientists have begun to evaluate which of the myriad gene products in saliva correlate with various disease processes.

The NIDCR envisions that this basic research could one day translate into miniature, hi-tech tests, or so-called “labs” on a silicon chip, which rapidly scan oral fluids for the presence or absence of multiple proteins linked to various systemic diseases and conditions. Given the ease of sample collection and the breadth of protein markers that could be arrayed on the silicon chip, salivary tests have the potential to revolutionize how diseases are diagnosed. Physicians and dentists would continue to diagnose diseases. But they would be in the position for the first time to monitor a patient's health, producing a comprehensive molecular print out of that individual's health status that can be assessed over time.

Salivary diagnostics will have benefits far beyond medicine and dentistry as well. Law enforcement agencies could employ saliva tests in the field to determine rapidly whether a person is intoxicated or has recently used illegal drugs. These tests may also be beneficial in determining exposures to environmental, occupational, and biological substances, such as anthrax.

#### ORAL CANCER: EARLY DETECTION IS KEY TO SAVING LIVES

The field of salivary diagnostics recently yielded exciting early findings related to oral cancer detection. According to the American Cancer Society and the Centers for Disease Control and Prevention, oral cancer is the seventh most common cancer among U.S. males and ranks fourth among African American men. Unfortunately, survival rates have not improved significantly in decades. A patient's chance of survival is improved significantly with early detection and treatment. A team of

NIDCR-supported scientists at the University of California at Los Angeles recently reported that they could measure elevated levels of four distinct cancer-associated molecules in saliva and distinguish within 91 percent accuracy between healthy people and those diagnosed with oral squamous cell carcinoma. This “proof-of-principle” study marks the first report in the scientific literature that distinct patterns of “messenger RNA” are not only measurable in saliva, but can indicate a developing tumor. These initial results highlight the potential clinical value of saliva and hold out exciting possibilities for development of commercially available tests capable of delivering early, reliable, non-invasive detection of developing tumors.

#### PAIN: TRANSLATING TARGETS INTO TREATMENTS

Sizeable gaps exist in our understanding of some of the most basic cells involved in the pain process. Prime examples are the glial cells. For decades, scientists assumed that glial cells primarily played a supportive role in the central nervous system and had no direct influence on the transmission of sensory signals to the brain. But, as more powerful analytical molecular tools have emerged in recent years, scientists now realize that glial cells play a far more important role in pain than was previously appreciated. With this new awareness, it becomes imperative to better define the biology of these cells and their roles in regulating certain aspects of nervous system function.

The NIDCR will launch an initiative that will stimulate needed research into the basic biology of glial cells and their interactions with neurons in causing orofacial pain disorders, such as temporomandibular joint disorders. The initiative will encourage multidisciplinary studies in a variety of areas to define more broadly than ever important aspects of the pain process. Based on this broad investigative approach, key aspects of the pain process will be more clearly defined, pointing the way to unique and highly specific molecular targets for drug development. Without identifying these additional targets, it will be impossible to ever adequately control or treat pain, particularly among the estimated 10 percent of Americans who suffer from chronic pain.

#### NIH ROADMAP

The NIH Roadmap themes are synergistic with NIDCR research initiatives and provide added impetus to the efforts of oral health researchers. For example, the theme *Re-engineering the Clinical Research Enterprise* is particularly relevant to the development of NIDCR-sponsored dental Practice Based Research Networks. Similarly, the goals of the initiative *Building Blocks, Biological Pathways and Networks* are closely linked to NIDCR’s own bioengineering initiative, “Building a Tooth.” *Research Teams of the Future* provides an opportunity to further integrate dentists into the new clinical research structure, and highlights NIDCR’s longstanding efforts to encourage multi- and interdisciplinary approaches to research questions.

With the above-mentioned examples and other research progress, such as in salivary gene transfer, defining the oral biofilm, and the molecular targeting of oral cancer, NIDCR has never faced more exciting opportunities. By merging our vision of the future with technology development, the road ahead will lead this nation to a new generation of progress and improved oral health.

Thank you, Mr. Chairman. I would be pleased to answer any questions that the Committee may have.

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#### PREPARED STATEMENT OF DR. JACK WHITESCARVER, DIRECTOR, OFFICE OF AIDS RESEARCH

Mr. Chairman and Members of the Committee, I am pleased to present the fiscal year 2006 President’s budget request for the NIH AIDS research programs, a sum of \$2,932,992,000, which is an increase of \$12,441,000 above the comparable fiscal year 2005 appropriation.

#### WORLDWIDE PANDEMIC

AIDS is the deadliest pandemic of modern times. More than 20 million people have already died of AIDS, and more than 60 million people around the world have been infected with HIV. AIDS is the leading infectious cause of death worldwide, surpassing tuberculosis and malaria.<sup>1</sup> Its impact is profound, affecting families,

<sup>1</sup> Report on the Global HIV/AIDS Epidemic: July 2002, (UNAIDS/WHO, Geneva, Switzerland, 2002).

communities, agriculture, business, healthcare, education, military preparedness, and economic growth. The United Nations General Assembly's Declaration of Commitment on HIV/AIDS states . . . "the global HIV/AIDS epidemic, through its devastating scale and impact, constitutes a global emergency and one of the most formidable challenges to human life and dignity, as well as to the effective enjoyment of human rights, which undermines social and economic development throughout the world and affects all levels of society—national, community, family, and individual."<sup>2</sup> According to a U.N. report, "The misery and devastation already caused by HIV/AIDS is enormous, but it is likely that the future impact will be even greater . . . The HIV/AIDS epidemic has erased decades of progress in combating mortality and has seriously compromised the living conditions of current and future generations."<sup>3</sup> A CIA report estimated that by 2010, five countries of strategic importance to the United States—Nigeria, Ethiopia, Russia, India, and China—collectively will have the largest number of HIV/AIDS cases on earth.<sup>4</sup> *Foreign Affairs* magazine stated: ". . . HIV/AIDS is set to be a factor in the very balance of power within Eurasia—and thus in the relationship between Eurasian states and the rest of the world."<sup>5</sup> Dramatic increases in HIV infection also are occurring in Eastern Europe, Central Asia, Latin America, and the Caribbean.

#### THE U.S. EPIDEMIC

In the United States, according to CDC, the decline in death rates observed in the late 1990s, due largely to expanded use of new antiretroviral therapies (ART), has now leveled off. The use of ART has now been associated with a serious side effects and long-term complications that may have a negative impact on mortality rates. HIV infection rates are continuing to climb among women, racial and ethnic minorities, young homosexual men, individuals with addictive disorders, and people over 50 years of age.<sup>6</sup> This means that the overall epidemic is continuing to expand.<sup>7</sup> <sup>8</sup> <sup>9</sup> CDC reports that approximately one quarter of the HIV-infected population in the United States also is infected with hepatitis C virus (HCV). HIV/HCV co-infection is found in 50 to 90 percent of injecting drug users (IDUs). HCV progresses more rapidly to liver damage in HIV-infected persons and may also impact the course and management of HIV infection, as HIV may change the natural history and treatment of HCV.<sup>10</sup>

For the past several years, we have cautioned in our testimony that the appearance of multi-drug resistant strains of HIV presents an additional serious public health concern.<sup>11</sup> <sup>12</sup> <sup>13</sup> <sup>14</sup> <sup>15</sup> In just the past few weeks, we have had a new warning about that potential. The New York City Health Department reported the possibility of a more virulent and aggressive multi-drug resistant HIV strain<sup>16</sup> focusing attention again upon the nature of the infection, the associated immune decline, and the behaviors linked to HIV transmission. It is too early to determine if this is some newly virulent form of HIV. A series of highly sophisticated tests is now underway to examine how the virus replicates in cells, as well as the efficiency and mechanisms of viral attack. The fact that the individual infected by this virus progressed more rapidly to immune decline may be reflective of a number of factors, some unrelated to the viral strain, such as host factors, native immune system function, or genetics. We have much more to learn about this case. However, it highlights a number of lessons about the active and ongoing U.S. HIV epidemic. HIV infection

<sup>2</sup>The Impact of AIDS (Department of Economic and Social Affairs, United Nations, 2004).

<sup>3</sup>The Impact of AIDS (Department of Economic and Social Affairs, United Nations, 2003).

<sup>4</sup>Intelligence Community Assessment: The Next Wave of HIV/AIDS: Nigeria, Ethiopia, Russia, India, and China. (CIA, 2002).

<sup>5</sup>The Future of AIDS, Foreign Affairs, November/December 2002.

<sup>6</sup>Characteristics of Persons Living with AIDS and HIV, 2001, HIV/AIDS Surveillance Supplemental Report (CDC, 2003).

<sup>7</sup>Year-End HIV/AIDS Surveillance Report for 2002 (CDC, 2003).

<sup>8</sup>Centers for Disease Control and Prevention HIV Prevention Strategic Plan Through 2005, (CDC, 2001).

<sup>9</sup>Cases of HIV Infection and AIDS in the United States 2003, HIV/AIDS Surveillance Report (CDC, 2004).

<sup>10</sup>Frequently Asked Questions and Answers about Co infection with HIV and Hepatitis C Virus (CDC, 2002).

<sup>11</sup>N. Loder, *Nature* 407, 120 (2000).

<sup>12</sup>H. Salomon et al., *AIDS* 14, 17 (2000).

<sup>13</sup>Y.K. Chow et al., *Nature* 361, 650 (1993).

<sup>14</sup>M. Waldholz, Drug Resistant HIV Becomes More Widespread, *Wall Street Journal*, 2/5/99.

<sup>15</sup>World Health Report on Infectious Diseases: Overcoming Antimicrobial Resistance, (WHO, Geneva, 2000).

<sup>16</sup>"New York City Resident Diagnosed with Rare Strain of Multi-Drug Resistant HIV that Rapidly Progresses to AIDS," New York City Health Department Press Release 2/11/2005.

does not occur in a vacuum or in isolation—it occurs in the context of behaviors, including alcohol and drug use (the use of crystal methamphetamine in the New York City case), that require a contextually appropriate and interwoven response. This case underscores the importance of access to quality care that may need to include HIV resistance testing, and closer monitoring for immune decompensation in the setting of appropriate treatment. Most importantly, this case is a wake-up call, a reminder that the ability to interrupt HIV transmission, as well as the cycle of pain and suffering associated with HIV disease, is directly related to the robustness of HIV care, treatment and research infrastructure in the communities impacted by this disease. This expanding and evolving U.S. epidemic continues to present new and complex scientific challenges.

#### ROADMAP FOR NIH AIDS RESEARCH

In response to this worldwide crisis, NIH is the world's leader in the magnitude and quality of our AIDS research effort—a comprehensive program of basic, clinical, and behavioral research on HIV infection, its associated co-infections, opportunistic infections, malignancies, and other complications. No other disease so thoroughly transcends every area of clinical medicine and scientific investigation, crossing the boundaries of nearly all of the NIH Institutes and Centers. The Office of AIDS Research (OAR) plays a unique role at the NIH, establishing a roadmap for the AIDS research program. OAR coordinates the scientific, budgetary, and policy elements of the NIH AIDS program, prepares an annual comprehensive trans-NIH strategic plan and budget for all NIH-sponsored AIDS research; facilitates NIH involvement in international AIDS research activities; and identifies and facilitates multi-institute participation in priority areas of research. These legislative authorities are critical to identify and ensure support for the areas of highest scientific priority.

#### COMPREHENSIVE AIDS RESEARCH PLAN AND BUDGET

The OAR planning process is inclusive and collaborative, involving the NIH Institutes, eminent non-government experts from academia, industry, foundations, and AIDS community representatives. The Plan serves as the framework for developing the annual AIDS research budget for each Institute and Center, for determining the use of AIDS-designated dollars, and for tracking and monitoring those expenditures. The planning process also serves to monitor and assess scientific progress. The Plan establishes the NIH AIDS scientific agenda in the areas of: Natural History and Epidemiology; Etiology and Pathogenesis; Therapeutics; Vaccines; and Behavioral and Social Science; Microbicides; Racial and Ethnic Minorities; Women and Girls; Prevention Science; International Research; Training, Infrastructure, and Capacity Building; and Information Dissemination.

In consultation with the Director of NIH, the OAR determines the total annual AIDS research budget. The Institutes and Centers submit their AIDS budget request to OAR, and the OAR establishes their AIDS research budgets, in accordance with the priorities of the Plan, at each step of the budget development process.

#### FUNDING FOR HIGHEST PRIORITY RESEARCH

To develop the fiscal year 2006 request, OAR initiated a comprehensive trans-NIH review of all grants and contracts supported with AIDS-designated funds to ensure that these projects represent the highest scientific priorities and opportunities. OAR carefully reviewed the mix of investments in key priority areas of research in view of the current epidemic. This budget request reflects OAR's redirecting of AIDS funds to the highest priority projects and new scientific opportunities in fiscal year 2006.

This budget request places highest priority on the discovery, development, and testing of additional HIV vaccine candidates, including funding to move promising vaccine candidates into large-scale clinical trials to evaluate the potential for efficacy. The NIH priority in AIDS vaccine research to date has resulted in approximately 70 clinical trials of nearly 40 vaccine candidates. The evaluation of an AIDS vaccine will require extensive testing in the United States and in international settings where there is a high incidence of HIV.

In the area of therapeutics research, current drug regimens have resulted in extended survival and improved quality of life for many HIV-infected individuals in the United States and Western Europe. However, a growing proportion of patients receiving therapy are demonstrating treatment failure, experiencing serious drug toxicities and side effects, and developing drug resistance. The increasing incidence of metabolic disorders, cardiovascular complications, major organ dysfunction, and physical changes associated with current antiretroviral drugs underscores the critical need for new and better treatment regimens. Improved regimens also are need-

ed to treat HIV co-infections such as hepatitis B and C, as well as other opportunistic infections to reduce drug interactions and problems with adherence to complicated treatment regimens. The goal of this research is to develop new, safe, less toxic, less expensive, and more effective therapeutic agents and regimens.

OAR spearheaded a multi-IC inter-disciplinary collaboration to formalize plans for the restructuring of the NIH clinical trials networks for HIV therapeutics, vaccines and prevention. This effort resulted in a set of principles to guide the development of the Request for Applications (RFAs) for the re-competition of these essential multi-IC supported clinical programs in fiscal year 2006, designed to ensure that they operate effectively and cooperatively, making the best use of research dollars.

Our prevention research priorities include the development of vaccines, topical microbicides, strategies to prevent mother-to-child transmission, including a better understanding of risk associated with breast-feeding, management of sexually transmitted diseases (STDs), and behavioral research strategies, including interventions related to drug and alcohol use. Efforts continue to identify the most appropriate intervention strategies for different populations and sub-epidemics in the United States and around the world.

#### INTERNATIONAL AIDS RESEARCH

NIH bears a unique responsibility to address the global epidemic, with priority on the urgent need for more affordable and sustainable prevention and treatment approaches that can be implemented in resource-limited nations. The high incidence of Hepatitis B and C, malaria, and TB in many of these nations further complicates the treatment and clinical management of HIV-infected individuals. NIH international AIDS research includes: development of HIV vaccine candidates and chemical and physical barrier methods, such as microbicides; behavioral strategies; strategies to prevent mother-to-child transmission; therapeutics for HIV-related co-infections and other conditions; and approaches to using ART in resource-poor settings. NIH supports international training programs and initiatives that help build research infrastructure and laboratory capacity.

#### WOMEN AND MINORITIES

In the United States, the rate of diagnoses for African Americans was almost 10 times the rate for whites and almost 3 times the rate for Hispanics. The rate of AIDS diagnoses for African American women was 25 times the rate for white women.<sup>17</sup> Women experience HIV/AIDS differently than men. NIH research has demonstrated that women progress to AIDS at lower viral load levels and higher CD4 counts than men. Women also experience different clinical manifestations and complications of HIV disease. These findings may have implications for care and treatment of HIV-infected women, particularly with ART. NIH is exploring research questions about specific characteristics of women and girls that might play a role in transmission, acquisition, or resistance to HIV infection during different stages of the life course.

We are focusing on the need for comprehensive strategies to decrease HIV transmission in affected vulnerable populations, and improve treatment options and treatment outcomes, including interventions that address the co-occurrence of other STDs, hepatitis, drug abuse, and mental illness; and interventions that consider the role of culture, family, and other social factors in the transmission and prevention of these disorders in minority communities. NIH continues to make significant investments to improve research infrastructure and training opportunities for minorities and will continue to ensure the participation of minorities in AIDS clinical trials, as well as in natural history, epidemiologic, and prevention studies.

#### SUMMARY

The NIH's leadership role in the response to the AIDS pandemic is fundamental and unprecedented, and we have established a research program that is complex, comprehensive, multi-disciplinary, inter-disciplinary, and global. Further, this research investment is reaping even greater dividends, as AIDS-related research is also unraveling the mysteries surrounding many other infectious, malignant, neurologic, autoimmune, and metabolic diseases. The legislative authorities of the OAR allow NIH to pursue a united research front against the global AIDS epidemic. NIH is enhancing collaboration, minimizing duplication, and ensuring that research dollars are invested in the highest priority areas of scientific opportunity that will

<sup>17</sup>HIV/AIDS Surveillance Report 2003, Vol. 15 (CDC, 2004).



allow NIH to meet its scientific goals. We are deeply grateful for the continued support the Administration and this Committee have provided to our efforts.

Senator SPECTER. Well, that is a good juncture to discuss that, Dr. Zerhouni. My colleagues look at the increases in the NIH budget and compare them with what is done generally or in other research lines, the National Academy of Sciences. NIH has gotten a much greater increase than anyone, and I think that's because this subcommittee has taken an interest in the subject and we have seen what you can do.

How can you quantify the good use of the money? Because many of my colleagues say, well, we don't know the details of NIH, but they've gotten too much money too fast to be efficient. Are you efficient?

Dr. ZERHOUNI. Well, this is—

Senator SPECTER. I know what the answer's going to be, but tell me why it's yes.

Dr. ZERHOUNI. I'm going to give you very simple numbers, sir. I believe in facts. Are we efficient? Do we have too much—have we received too many resources? \$96 per American per year is what we invest in research and development and knowledge faced to a \$5,500 per year spending in health care, rising at a much faster rate than inflation.

This ratio is really the key. We need to accelerate our knowledge so that we can change the paradigm of how we treat patients today. It would be more effective if we could develop methods of intervening years before the disease develops, rather than do what we do today, which is intervene after the disease has struck.

Senator SPECTER. Give me an illustration of that.

#### RESULTS FROM ACCELERATING OUR KNOWLEDGE

Dr. ZERHOUNI. A good illustration of that, I showed you the statistics on heart disease. You've seen how the mortality has dropped. That's because we've used as a preventive measure drugs that reduce high blood pressure and drugs that reduce cholesterol. Those two actions have led to a half of the reduction in mortality. That's a good example.

In stroke, we've reduced the mortality of stroke by 50 percent, just because we've used methods to reduce the impact of high blood pressure.

In cancer, screening for cancer, in colon cancers, is responsible for the majority of the reduction in mortality from colon cancer. So there are things we can do as we learn more about the genetics—

Senator SPECTER. Would you amplify your response on cancer?

Dr. ZERHOUNI. Well, in cancer you can see, for example, in breast cancer—I'll give you one example in breast cancer—with the use of tamoxifen and the use of new drugs, we've reduced the occurrence, the reoccurrence of breast cancer by 50 percent. We believe that in high risk populations, as we can identify them, and the National Cancer Institute is working on these factors, we'll be able to ultimately reduce the number of patients altogether who develop cancer. The same is true in colon cancer.

Senator SPECTER. How will you do that?

Dr. ZERHOUNI. Primarily by understanding—

Senator SPECTER. Why haven't you done it before now?

Dr. ZERHOUNI. I think we did not know the genetics of breast cancer or colon cancer until 10, 15 years ago. We started to know it, and our knowledge has accelerated over the past 5, 6 years with the completion of the human genome. We are continuing our efforts with the understanding of the genetic map and the continuing efforts and investments that NCI has put in understanding the genetics of cancer. That's the knowledge that allows us to do that.

Senator SPECTER. On this subject, we have with us today Dr. Andrew von Eschenbach, who's the director of the National Cancer Institute. Dr. von Eschenbach, would you step forward?

I might comment on the number of witnesses we had here because I had set at the outset that we have not followed the customary practice of having all of the directors where we couldn't possibly question more than 20 people who work in attendance. But Dr. Zerhouni and Dr. von Eschenbach are presidential appointees, and Dr. Zerhouni requested bringing Dr. Anthony Fauci and Dr. Allen Spiegel because of questions which might arise, and then we have added in, as I said earlier, Dr. James Battey because of the currency of an issue which has arisen on the application of the new ethics rules.

Dr. von Eschenbach.

Dr. VON ESCHENBACH. Yes, sir.

#### THE WAR ON CANCER

Senator SPECTER. You have the largest allocation in the National Institutes of Health, coming close to almost \$5 billion. President Nixon declared war on cancer in 1970. Thirty-five years have passed and we've won some wars, but not that one. What will it take to win that war?

Dr. VON ESCHENBACH. Well, Mr. Chairman, first of all, the wisdom and the support that we have received at the National Cancer Institute from the Congress in providing the resources has led us to a point where in 1971 when we began this effort we did not understand cancer. We didn't understand that it was a spectrum of diseases, and we certainly didn't understand the basis of that disease. But today—

Senator SPECTER. A spectrum of diseases?

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. How many roughly?

Dr. VON ESCHENBACH. Well, there are certainly a large number of cancers, but what we're learning even today is that even when we think of one cancer like breast cancer or lymphoma, or even colon cancer, there are subsets of those cancers because of the fact that there are unique, different changes in the genes and the molecules that cause and drive that cancer—

#### LYMPHOMA

Senator SPECTER. How many subsets of lymphoma? I have a special interest.

Dr. VON ESCHENBACH. There are two major subsets of Hodgkin's and non-Hodgkin's lymphomas. But even within those groups, even as we speak, we are learning that there are subsets—

Senator SPECTER. Subsets within Hodgkin's lymphoma?

Dr. VON ESCHENBACH. Correct, sir, and especially in non-Hodgkin's lymphomas. For example—

Senator SPECTER. But how about subsets in Hodgkin's lymphoma? You'll pardon my special interest.

Dr. VON ESCHENBACH. Yes, sir. If you allow me, one of the ways that we're beginning to understand even what we think is a single disease of Hodgkin's lymphoma is to recognize that in different patients that lymphoma may have different molecules or proteins on the surface of the cell that cause it to behave differently and respond differently to different therapies or interventions.

For example, a recent drug that has been created is a drug that can attach itself to those proteins on the surface of the cell. One of those proteins is CD-20, an antibody. So if we can look at a Hodgkin's tumor and determine whether the antibody is present or not, we can then design and apply specific therapy for that specific patient.

#### RETURN ON INVESTMENT

To follow up on the question of the return on investment, this investment in cancer research that has led us to a point today where we're beginning to understand cancers at the molecular and genetic and cellular level is influencing our selection of therapy and moving us to personalized medicine and personalized oncology.

We're sparing patients unnecessary treatments that we can predict will not help them, while at the same time making certain we're giving patients the specific and exact therapy that we can predict and know at the molecular level will help them.

This drug I alluded to that's recently been released, Bexxar, combines the knowledge of that antibody, of CD-20, in a group of other lymphomas, non-Hodgkin's lymphomas, called follicular lymphoma. By identifying that antibody and coupling to it a radioactive material, we can target those lymphoma cells, and patients who were previously considered incurable now have a 75 percent complete response rate in elimination of their tumor.

Senator SPECTER. Before yielding to Senator Cochran, the distinguished chairman of the full committee I want to ask you one more question, Dr. Zerhouni, and you one more question, Dr. von Eschenbach. If we have a flat-level funding for NIH this year, how many grants will you have to reduce because of inflationary factors and other factors, contrasted with what you could do if we were able to get the extra \$1.5 billion which is in the budget resolution?

#### SUCCESS RATES

Dr. ZERHOUNI. The total number of grants will decrease by about 400 total. As I said, we were going to make a special effort to increase the number of grants for new investigators or what we call competing investigators so that—

Senator SPECTER. With the extra \$1.5 billion, then what?

Dr. ZERHOUNI. We could reestablish—you know, one of the things you said that is very important that we hear a lot is NIH has too much money, it cannot spend any more money. The best statistics I can give you is we are getting more and more ideas we cannot fund, and our success rate is actually dropping. I'll show you some statistics here that you can see, and we were at about 32 percent

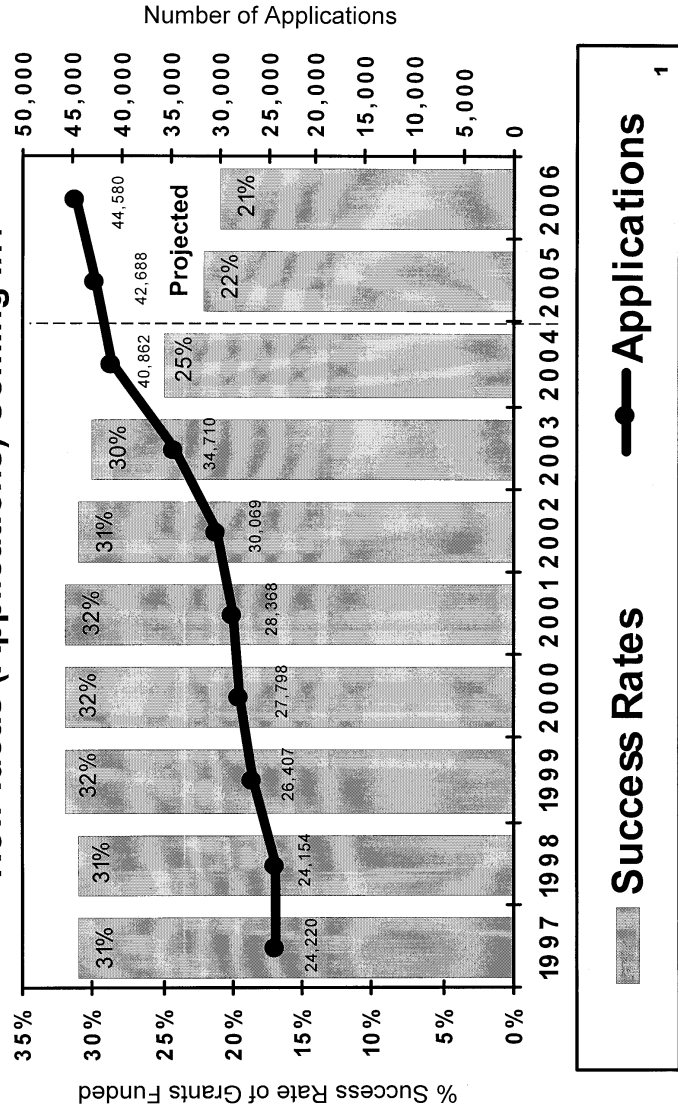
a few years back to 30 percent to 25, 22, and eventually we will reach 21 percent in 2006. With—

Senator SPECTER. Of grants on applications, percentage that you grant?

[The information follows:]



### How Does the % of Grant Applications Funded (or "Success Rate") Compare with the Number of New Ideas (Applications) Coming In?



Success Rates      Applications

Dr. ZERHOUNI. By those number of scientists we can fund when they apply, one in five, or a little bit above that. So clearly anything we could do to reestablish the ability of fulfill and satisfy the scientific demand would be helpful. However, we recognize as you did the very, very difficult fiscal times we're in.

FUNDING THE WAR ON CANCER

Senator SPECTER. Dr. von Eschenbach.

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. With sufficient funding, can we win the war on cancer in the reasonably near future?

Dr. VON ESCHENBACH. Senator, we have made a commitment at the National Cancer Institute to eliminate the suffering and death that results from cancer, to eliminate the outcome of cancer, and to bring that about as early as 2015 in this Nation. We have made that commitment because we believe that this investment that has been made in cancer research has led us to a point today where we can build on our understanding of cancer and use that knowledge to develop new and more effective interventions that can in fact achieve the goal—

Senator SPECTER. Do you have sufficient funding to reach that goal by 2015?

Dr. VON ESCHENBACH. The funding that we have we are applying as effectively and as efficiently as possible to achieve that trajectory. Obviously, with increase resources we have increasing opportunities to even further accelerate that pace of progress.

Senator SPECTER. If your funding were increased, could you reduce that date to 2010?

Dr. VON ESCHENBACH. We certainly could accelerate the pace of progress, and how quickly and how soon we could bring that about, I could not absolutely predict.

Senator SPECTER. I would like you to give that some thought and provide the subcommittee with a projection as to what kind of funding you would require to reduce the figure to 2010. A lot of people are going to have a lot of suffering in those other 5 years.

Dr. VON ESCHENBACH. Yes, sir.

Senator SPECTER. Really in the 5 years from now until 2010.

[The information follows:]

NATIONAL CANCER INSTITUTE

What would it take to accelerate the achievement of the NCI's 2015 goal to eliminate suffering and death due to cancer from 2015 to 2010?

You have requested information on the amount of money necessary for the National Cancer Institute (NCI) to achieve its 2015 goal by 2010. It should be noted, though, that these funding estimates for additional resources were developed without taking into consideration overall fiscal constraints and other competing priorities of NIH, HHS, or the rest of the Federal government over this five-year time period. The current annual NCI budget is nearly \$5 billion, and the resources discussed below would be in addition to this base.

NCI has established an ambitious goal of eliminating the suffering and death due to cancer by 2015 by sustaining and integrating progress in the discovery, development, and delivery of more effective interventions based on molecular mechanisms of cancer. We estimate that expenditure of an additional \$4.2 billion above the NCI base of nearly \$5 billion over the next five years could accelerate progress. While the elimination of suffering and death due to cancer may not be fully achievable by 2010, there would be significant progress toward narrowing the gap between 2015 and 2010.

This \$4.2 billion estimate reflects an additional up front allocation of \$2.5 billion to be expended over five years for a National Advanced Technology Initiative for cancer (NATiC) to accelerate the emerging disciplines of molecular oncology, nanotechnology, and bioinformatics for use in creating a pipeline of new personalized cancer diagnostics and therapeutics. This would also reflect an annual increase of \$171 million over current base NCI levels for five years to deploy a modern integrated cancer clinical trials infrastructure and an annual increase of \$164 million for five years to expand and integrate the NCI-designated Cancer Centers program from 60 existing centers to 75. In addition to resources, additional legislative authorities related to exemptions from specific parts of current procurement, grant review and processing, and licensing and patenting rules would also help speed progress toward an accelerated cancer goal.

Three decades ago there were 3 million U.S. cancer survivors; today that number has increased to over 10 million. Today, each minute of every hour of every day, one American dies from cancer: 570,280 lives will be lost this year due to this disease. Despite this fact, there has been remarkable progress in understanding the cancer process and applying that knowledge. Today, 65 percent of patients diagnosed with cancer can expect to survive. If we had the ability to apply what we know today to every cancer patient, we could have an immediate impact on survival, largely through the NCI Cancer Centers. Incremental improvements in survival will continue toward our 2015 goal, but we can accelerate these gains. Even improving the overall survival rate to 90 percent by 2010 could mean an additional 850,000 lives saved. The impact of this strategy could produce annual changes in the first two years of around 2–3 percent, with larger increases occurring in 2008–10.

For most cancer patients, survival is greatly influenced by early detection. The rapid deployment of advanced imaging, nanotechnology supported early detection platforms and targeted therapies will change the face of diseases such as ovarian cancer, lung, colon and breast cancers; where survival is low because we can not currently detect them before they spread. Ovarian cancer, which is very difficult to detect and diagnose in its early stages, has over 25,000 new cases diagnosed annually and over 14,000 deaths; the mortality rate is nearly 85 percent. Imaging and detection techniques presently under development and broadly applied could reverse that mortality rate to be an 85 percent survival rate. Lung cancer, with approximately 170,000 expected deaths this year, would see a significant reduction in the number of deaths if the application of new technologies combined with other interventions could be universally applied in an accelerated manner.

The challenge to achieving the goal of eliminating the suffering and death due to cancer by 2010 is daunting, but with the authorities and appropriations commensurate with the task, the pace of progress could be accelerated, and the gap between 2015 and 2010 narrowed. The following reflects a brief overview of how such funds, if available, could be applied.

- Rapid Deployment of a National Advanced Technology Initiative for cancer—\$2.5 billion one time appropriation with commensurate authorities.
- Deployment of a Modern Integrated Clinical Trials Infrastructure—\$171 million addition to the NCI base budget.
- Expansion and Integration of the Cancer Centers Program—\$164 million addition to the NCI base budget.
- Mechanisms and Flexibilities—streamlined procurement and review processes to acquire materials and services; coordination of licensing and patenting activities.

A National Advanced Technology Initiative for cancer (NATiC) could provide a linkage between the National Cancer Program and R&D initiatives being developed in selected National Laboratories and advanced technology facilities located in more than 40 states and regions. Connected in real time through a common bioinformatics grid, NATiC as a “network of networks” of science, technology, and treatment, could serve to accelerate the emerging discipline of molecular oncology to create a pipeline of new personalized cancer diagnostics and therapeutics from bench concept to bedside and community delivery. In the next few years, such an initiative could:

- Accelerate the implementation of a nationwide high-end information technology grid for bioinformatics that could be uniquely adapted for real time data sharing. NCI’s pilot version, called caBIG, is currently being implemented among 50 cancer centers, the Food and Drug Administration (FDA), and other organizations.
- Develop a comprehensive biomarker discovery and validation program.
- Foster the application of emerging technologies, such as nanotechnology, and integrate molecular agents with advanced imaging devices.

- Accelerate a nationwide “real time” medical information electronic system for research and medical data sharing using technologies and devices currently employed by the banking industry and large-scale commercial enterprises.
- Enhance the discovery and validation of new targets of genes and proteins critical to cancer development.

NCI could deploy a more modern and integrated infrastructure for cancer clinical trials. This clinical research infrastructure could:

- Strengthen collaborations with industry, FDA, Centers for Medicare and Medicaid Services, and other public, private, academic, and patient advocacy organizations to oversee the conduct of cancer clinical trials.
- Develop new infrastructure and procedures to standardize, coordinate, and track clinical trials development and accrual across all NCI-supported clinical trials.
- Increase utilization of imaging tools in screening and therapy trials, evaluate new imaging probes and methodologies, enable access to the imaging data from trials in an electronic format, and facilitate evaluation of image-guided interventions.
- Expand access and improve the timeliness for completion of the highest priority clinical studies.
- Foster the development of a cadre of established clinical investigators who could work between bench and bedside.
- Pilot new approaches and develop prototypes for clinical trials networks that could improve the efficiency, coordination, and integration of our national efforts.
- Develop a common clinical trials informatics platform that could be made available to the full range of investigators working within the cancer clinical trials system.

NCI could accelerate the expansion and integration of the NCI designated Cancer Centers program, including the addition of 15 new cancer centers, increasing the number of centers from the current 60 to 75. The Cancer Centers program could:

- Implement progressive bioinformatics and communication systems to achieve horizontal integration.
- Fund additive programs in collaborative, multidisciplinary research, and require integration and sharing of results.
- Broaden the geographic impact of the centers, networks, and consortia and vertically integrate them with community and regional health care delivery systems.
- Improve the access of minority and underserved populations to state-of-the-art research and resources.
- Create and strengthen partnerships with government agencies and community organizations.
- Broadly provide expertise, and other resources to caregivers, patients and families, and appropriate health agencies.

In addition to appropriations, flexible legislative authorities related to exemptions from specific parts of current procurement, grant review and processing, and licensing and patenting rules could also help accelerate progress. A streamlined procurement process could facilitate the acquisition of materials and services to support the R&D activities. Technology development could also be enhanced by sufficient flexibility and integration to enable interactions among a wide array of laboratories and other entities. Expedited review procedures and workflow processing could help to award funds in sequence as needed. This might include direct solicitation from known laboratories or other sources of technology, and capability to terminate funding instruments at the convenience of the government with limited appeal processes so that funds could be redirected from low performing consortia to the more productive venues.

Coordination of the licensing and patenting activities among grantees, contractors and the intramural program could also be useful for many of the multi-component technology platforms that could be created through this effort. An accelerated process for Determination of Exceptional Circumstances (DEC) and deviations from appropriate Federal Acquisition Regulation (FAR) clauses, when deemed valuable to the broad research enterprise, could be utilized.

Senator SPECTER. Senator Cochran, thank you for joining the subcommittee.



## STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Mr. Chairman, thank you very much. We appreciate you chairing this hearing and also inviting Dr. Zerhouni and selected members of the National Institutes of Health staff who can help us understand the budget request and do our best to identify the areas that need emphasis in this budget. We appreciate your leadership on this subcommittee and on the full committee as well.

I notice that the budget request is \$144.5 million over last year's appropriate level for the National Institutes of Health. I'm hopeful that that will permit the NIH to continue its research into health disparities, examining why a disproportionate number of African-Americans, for example, suffer from heart disease than the rest of the population. I think taking the research to the underserved areas of our country is beneficial. I hope you can let us know what your reaction to that initiative is at this point and what you foresee in terms of the needs for funding will be.

I think I'll stop at that point and let you respond, and I then have a couple of other questions.

## STRATEGIC GOALS AND OBJECTIVES

Dr. ZERHOUNI. Those points are absolutely on target, Senator. As you know, we have five major goals that we have outlined in our strategic plans. One is aging of the population, the change from acute to chronic diseases. The third one is health disparity, not in any particular order. Those are amongst the five. And then we have biodefense and emerging and re-emerging diseases, including, for example, obesity.

We're acutely aware of the disparate impact of these conditions on the American population. As you know, we have the vanguard study in the Jackson heart study that in fact studies how to do this better. As part of the Roadmap for Medical Research, we are also developing the idea of a community-based corps of clinical researchers that will be included within the underserved areas of the country and connected through a better information system, so that more patients in those communities can participate.

A good example of that, Senator, was the ALLHAT study, which was the study of hypertension conducted in over 600 practices. A great majority of the practices were in African-American communities and showing which drugs were the most effective in those populations.

So we will continue that. I think the investment needs to be continued, Senator. This is not an easy problem to tackle, but we need to look forward to more activities that will integrate the main research that we do with the research that needs to be done in those communities.

## COMPLEMENTARY AND ALTERNATIVE MEDICINES

Senator COCHRAN. One other interesting new area of inquiry for the National Institutes of Health is in the area of dietary supplements and herbal products. There is a growing number of Americans using these supplements and products. The National Center for Complementary and Alternative Medicines is playing a role in

helping us understand the effects of that activity and the use of those products.

What are the current research needs or priorities in terms of this budget request that we need to consider when we are reviewing the request and deciding on the amounts to appropriate?

Dr. ZERHOUNI. First and foremost is your statement about the increasing use of dietary supplements across our population is real. Herbal products are becoming very popular. One of the things we need to do as scientists is to figure out whether or not these products are of equal effectiveness across their compositions. So we need to have more research done in exactly how to make these herbal products reliable and safe.

We are doing that at NCCAM. We verify the purity of these herbal products. We also have trials verifying their effectiveness. This year NCCAM and the Office of Dietary Supplements are going to fund five new botanical research centers across the country. There is a request for applications that has gone out. We've received the applications. So we'll have at least an infrastructure now of five centers that will look exactly at these issues of how do you really make sure that when you buy a particular product it's effective for what you think it is effective for.

Senator COCHRAN. My final question has to do with the role for new technologies in the detection and treatment of disease. For example, the National Institute for Biomedical Imaging and Bioengineering was created specifically to enhance research on these technologies across the NIH Institutes. What budget levels are needed for this work to be done and to improve the rate of discovery in biomedical research across the Institutes and increase the development of new tools for diagnosis and treatment in clinical practice?

NATIONAL INSTITUTE FOR BIOMEDICAL IMAGING AND BIOENGINEERING

Dr. ZERHOUNI. This is newest Institute, as you all know, that is essentially going through its strategic first steps. It is the only Institute that has for a mission the interaction of technologies, physical sciences, biological sciences, in the context of bioengineering or biomedical imaging. In that regard, it is very important to continue to invest, because as we see, you know, when we look at detection, for example, of new diseases, new technologies to do research, it's becoming very apparent that we need to make specific investments in those areas if we are going to make progress in both detection and therapy.

For example, nanotechnology is a good example whereby you can through nanotechnology techniques concentrate energy inside a tumor and treat a tumor in a way that you couldn't otherwise. NIBIB is key to that interface. It's taken a role, a lead role, in matching physical sciences and biological sciences at NIH, works with the National Institute of General Medical Sciences.

Obviously, the budgetary environment is such that they have to make very tough choices in terms of prioritization. But from my standpoint, Senator, emerging research technologies, I see that and we've identified in the Roadmap for Medical Research, as a major area of investment. In the past, biomedical researchers tended to

wait for technology to be developed and then used it off the shelf, whether it be computers or robotics or other technologies.

In the future, as we are going to areas of research that are only specific to medical research, no one in the free market is going to develop an off-the-shelf technology that will have just application to medicine. And therefore, NIBIB's strategic role has to increase over time, and all of NIH's investment in that area.

Senator COCHRAN. Thank you very much. I appreciate your leadership in these areas that I've touched on and generally at NIH. I think you're doing a great job and we appreciate your service.

Dr. ZERHOUNI. Thank you, Senator.

Senator SPECTER. Thank you very much, Senator Cochran. I'm now going to yield to the distinguished ranking member, Senator Harkin. I'm going to go vote and I will return promptly so we can maintain the continuity of the hearing.

Senator HARKIN [presiding]. Thank you very much, Dr. Zerhouni.

Dr. ZERHOUNI. Good morning.

Senator HARKIN. I apologize for being a little late for your presentation. Obviously we all have a lot of committees we have to go to. But I just wanted to make a brief opening statement and welcome you back and the others back.

As you know, Dr. Zerhouni, both Senator Specter and I have been very strong supporters of NIH and funding. We've partnered in doubling the funding for NIH over 5 years. We got that job done. It was one of my proudest moments as a Senator to actually get that accomplished.

Yet as I look at the President's budget for 2006, it's with a sense of disappointment. We didn't double the funding for NIH to then have the bones cut out of the funding. But that's what it seems is happening. This budget would provide the smallest percentage increase since 1970, .5 percent. The total number of grants would drop by 402. Most importantly, the success rate for new and competing grants would fall to 21 percent. I have the table here. I guess you put it up here. I missed it, but my staff told me you put it up here. Twenty-one percent, that's the lowest since 1970, and that's as far back as our records go, 21 percent. This is very disturbing.

Our scientists have just mapped the human genome. We should be entering a golden age of medical research. Scientists should be flocking to this field. It's the wrong time to hold this budget flat.

I'm also troubled by other developments. Top researchers are leaving NIH. Recruitment is suffering because of new conflict of interest regulations. While I strongly support restrictions on outside compensation, I am concerned that the new regulations go too far, Dr. Zerhouni, especially when it comes to requiring employees to divest stocks that they've had for many years.

I just, as an aside, ran into a woman yesterday, just yesterday afternoon. The AACI group had a reception yesterday and I was just talking to a woman. I mentioned this hearing and she mentioned how it was her sister, I believe, was a researcher at the National Institute of Environmental Health Sciences in North Carolina, had been there for a long time, is leaving because through the years she said the most income she and her husband ever had was \$125,000 a year. Lately, because she's worked all these years, she

bought some stock early on, that's her retirement, that's for her kids going to college, and according to her—I don't know, I'm just telling you what she told me—she has zero input to any kind of drugs or drug companies or anything. Yet she's told she's got to divest that stock. You know what? She's leaving. That's wrong. That's wrong. We've got to change this, Dr. Zerhouni. We've got to change this.

I look forward to working with you and I'll have some more questions about that.

Jim Battey, who's leaving, has been a great researcher, great leader. I've worked with him on deafness and communication disorders. As I understand it—I don't mean to get into all this personal stuff—but I understand there's a family trust set up that he has to administer and stuff like that, and he has to leave because of this. This isn't right. We have to have a change and we have to have a change soon, immediately.

Now, let me just switch to something else, and that's the whole issue of stem cell research. The administration's outdated policy on stem cells is making NIH increasingly irrelevant in one of the most exciting areas of research today. We know about California putting in \$300 million a year. NIH is spending less than one-tenth of that amount, NIH one-tenth the amount of one State. Inevitably, researchers are going to look to individual States for direction on stem cell research instead of the NIH.

What's happening to NIH? Is it just a shell of its former self? It's supposed to be the greatest biomedical research institution in the world. I'm beginning to wonder.

Our federally funded scientists are on the front lines in the war against cancer and heart disease, diabetes, on down the line. To me there is no higher priority in this appropriations bill than funding NIH at an adequate level.

So that's my opening statement and I just want to return to the conflict of interest rules. Now, you know I have the greatest personal admiration for you and friendship. I think you're doing a great job in leading the institution. But I must chastise you. These are too onerous. They've got to be redone, and they've got to be redone soon before you start losing more people out of there. I mean, you know, sometimes we tend to see a conflict of interest and we go overboard, and I think we've gone overboard here.

So I'm just asking, are you prepared to recommend to HHS that the Department issue new revised regulations that won't hurt NIH's ability to retain and attract top scientists?

#### PENDING CONFLICT OF INTEREST RULES

Dr. ZERHOUNI. Well, I'm glad you asked the question, because as you know, this has been a painful episode for NIH where we've looked at several hundred issues that came up through the activities of scientists for private pay with biotech and pharmaceutical companies, as you were concerned about. From my standpoint it was very important to take care of that issue, and we did.

We proposed the moratorium because I think there were two reasons there that prompted me to do that. One was the fact that there were activities there that truly did not advance research. They were more into the marketing and product endorsement ac-

tivities. I thought that we needed new guidelines. Second, I believed that our management system of ethics was not functional, and to establish a new one, to re-centralize it, takes a while.

Now, you should know that these rules and regulations are not under my direct authority.

Senator HARKIN. I understand.

Dr. ZERHOUNI. They are those of—

Senator HARKIN. I misspoke. It's HHS.

Dr. ZERHOUNI [continuing]. HHS and the Office of Government Ethics. We've consulted with them and indicated to them that some of the applications may need to be tested on the ground. That's why we insisted that these be called interim final regulations and they be subject to comments and evaluation and adjustments. I have to say that I'm as concerned as you are.

Remember that at this point the most impact I have seen, because the rules have not been implemented in terms of stock divestiture, is the impact on families and the impact on all of the employees that would be required to divest of stock. That part of the rule frankly is the one that I think we need to reevaluate very quickly, as you said. I have requested a delay in the application of this rule from Secretary Leavitt, who's been extremely responsive and extremely concerned about any impact.

In the preamble to the rule, as you may know, we have stated very clearly that the Department and NIH will carefully look at the impact on retention and recruitment and the impact on the activities of our scientists in terms of outside activities.

So we are totally prepared to look at that, I am totally prepared to look at that, and request from those who have the authority—the Office of Government Ethics and the Department—to consider changes. So far I would say that, number one, we've had a responsive interaction. Number one, we've had a 90-day delay, and no one has been asked to divest at this point.

But nonetheless, the uncertainty itself can be damaging to morale and damaging to recruitment and retention. You've mentioned the example of Dr. Battey, who's a very good colleague of mine, an outstanding scientist, and I understand very much his predicament and I've made that known to the Secretary and to the Department.

There's another case, as you know. I've taken a lot of time and effort in recruiting outstanding directors. When I became director there were six vacancies and two others. I was very proud of the fact that we've been able to recruit outstanding directors from outside of the NIH and inside of the NIH. The latest one was Dr. David Schwartz from Duke University, who last week sent me a letter saying that he was delaying his coming until this issue of stock divestiture is clarified.

So I feel the same way you do in the sense that the philosophy of the interim regulation as promulgated by those who promulgated that with our consultation is in my view one that would be more appropriate for a regulatory agency rather than a scientific agency, and does require in my view more selective approaches rather than these approaches.

I think the Department has been responsive. As you may know, the Department has excluded trainees from these rules. That's over 5,000 scientists who are not subject to these rules. However, we've

also encouraged our scientists at NIH to come forward. I've had multiple meetings with scientists who are very concerned about this, and gotten their comments, and based on those comments we'll adjust accordingly.

So I share your concern and I do believe that, as you will see, we will be adjusting accordingly to correct for that issue, which I think is the one that is at the core of the complaints that you've heard. But also I am concerned about any impediments that free academic exchange might incur because—with trade associations—because of this over-regulatory interpretation of what NIH does. I don't think NIH has the influence of a regulatory agency, and I think as we go through the evaluation comment period, you will see improvements in that, Senator.

Senator HARKIN. I appreciate that and I apologize for misstating. Sometimes I look out there I just see HHS, and I said—I meant not you but the whole Department—

Dr. ZERHOUNI. It's okay. I'm used to it.

Senator HARKIN. The whole Department for what they did. But we—

Dr. ZERHOUNI. I'll take responsibility for—

Senator HARKIN. We've got to settle this. I'm sorry. I've got to go vote, and I assume Senator Specter will be right back, and so the committee will stand in recess until the chair gets back.

Dr. ZERHOUNI. Thank you.

Senator SPECTER [presiding]. The hearing of the Appropriations Subcommittee on Labor, Health, Human Services, and Education will now proceed.

Dr. Zerhouni, at the outset I thanked you for the assistance which NIH has provided on an arrangement with the Institute of Medicine to fund an examination of certain areas of asbestos-related injuries. We are trying to put through an asbestos bill and there is a question as to whether there is a causal connection between asbestos and certain ailments, and the Institute of Medicine has agreed to expedite a study in the course of 1 year. I worked with Dr. Raynard Kington in your absence and we were able to work that out expeditiously, and I thank you for that.

Dr. Zerhouni, let's turn to the issue of the guidelines on ethics and the concerns which have been expressed by some. And I'm going to want to hear from—we're going to want to hear from Dr. James Battey in a few moments as to the range of the restrictions which have been imposed and the reaction and whether you think there might be some justification for a review of the standards and practices.

#### GUIDELINES ON ETHICS

Dr. ZERHOUNI. Senator, first and foremost, the rules as we have—as they have been promulgated by the Department of Health and Human Services and the Office of Government Ethics are interim final regulations. In that process we made it very clear that those rules will be subject to an impact analysis and a comment period, especially when it comes to recruitment and retention areas and the maintaining of the excellence of the science at NIH.

Now, as you know, when we developed the rules there was a component of the rules that was related to consulting with indus-

try. I believe that the rules that we have put in place do establish and re-establish public trust and maintain public trust in that we will ban those until we are completely certain that we have an oversight system that is more functional than the one we had before.

Senator SPECTER. Do they go too far?

Dr. ZERHOUNI. In that context—in the consulting area, I think this is something that we need to do because we do not have, I believe, at this point an ethics oversight management system that can assure you and assure myself that those interactions are—

Senator SPECTER. How about in areas other than consulting?

Dr. ZERHOUNI. In areas such as stock divestiture, as you know, the rules require that all employees and their spouses divest of stock in either directly or indirectly related industries of NIH. As I looked at that rule over the past 2 months, I've had extensive consultation with our scientists, with outside entities, directors of the Institutes, and it is clear to me that in the short 2 months, where these rules have not been implemented by the way, no one has been asked to divest, that this would have a deleterious impact. Best example, as you mentioned, is Dr. Battey, who really cannot disentangle himself from his family obligations; Dr. Schwartz, who's the new director that I just appointed and recruited from Duke University, who was to take his job on April 11, who has delayed his coming until we can understand these rules a little bit better.

Senator SPECTER. How about the issue raised that someone couldn't accept train fare to travel to a distant city to give a lecture?

Dr. ZERHOUNI. That is not correct. I've heard that. That, Senator, that is not correct. People can accept train fares, hotel reimbursement when they go to do an academic lecture at some other points.

Senator SPECTER. Is there any other area besides consulting and divestment on a broad category?

Dr. ZERHOUNI. I think the interaction between our scientists and trade associations, scientific associations, should not be hampered to the extent that we have seen them being hampered over the past two months. We need to work on that.

I have to tell you, Senator, that Secretary Leavitt has been very responsive and receptive. We've requested a delay in the implementation of the stock divestiture rule of 90 days so we can understand it better. We have also asked that all of our scientist trainees, 5,000 of them, be exempted from these rules.

So, again, I think we do believe that through this process of comments and evaluation that we have put in place in the interim final regulations, that we will be able to adjust accordingly.

Senator SPECTER. How about on the trade association issue?

Dr. ZERHOUNI. Right.

Senator SPECTER. How about on the trade association issue?

Dr. ZERHOUNI. Again, I think, Senator, from my standpoint, if you look at the framing of these interim final regulations, they make an assumption that NIH has the same influence as a regulatory agency. In that context obviously these interactions have to be scrutinized, but I don't at this point have a final opinion, but

it seems to me that they may restrict areas of academic interchange—

Senator SPECTER. So you do not have a final opinion, so you're still looking at that?

Dr. ZERHOUNI. We're still looking at that, but I do believe that we should not as a policy goal restrict interactions that are purely scientific or academic in any way, shape or form.

#### STOCK DIVESTITURE

Senator SPECTER. Let us hear from Dr. James Battey, if we may. Dr. Battey, thank you for joining us. We know that there has been an issue as to divestment which has been problematic for you with retention at NIH. Would you tell the subcommittee your situation?

Dr. BATTEY. Absolutely. But let me preface my remarks by wishing you Godspeed in recovering from your illness, Senator Specter.

Senator SPECTER. Well, thank you. Thank you.

Dr. BATTEY. I have the greatest job in the world as far as I'm concerned right now. I've been the Director of the National Institute on Deafness and Other Communication Disorders for 8 years, and I have enjoyed every single minute of it for 8 years. But I manage a family trust on behalf of my mother and father, it's their sole source of income, as well as my two sisters, as well as educating my father's seven grandchildren. That is a responsibility that I must put before even the greatest job in the world. I cannot divest the stocks in that trust. The cost to my family would be very, very substantial, and that is not something that I am willing to entertain on behalf of my sisters, my father's seven grandchildren, and my mother and my father.

Dr. ZERHOUNI. I should point out, Senator, that Dr. Battey at no time had any consulting activity with industry during his entire career. He's been one of the outstanding citizens of NIH.

Senator SPECTER. Well, Dr. Zerhouni, did Dr. Battey's situation run afoul of the ethical guidelines which have recently been established?

Dr. ZERHOUNI. Not all of them obviously. It really relates specifically to the obligation to divest, forced divestiture of all holdings related to the industries that relate to NIH.

Senator SPECTER. Well, is that rule—

Dr. ZERHOUNI. That's really what the issue is.

Senator SPECTER [continuing]. In effect at NIH?

Dr. ZERHOUNI. This rule is not in effect. It is proposed to be implemented by July 3. We have asked the Secretary and received a delay of 90 days. It was supposed to be activated 2 months after the beginning of the rule on February 3. It was clearly obvious to us at NIH that this would have a deleterious impact. We've been requesting and informing the Department, I believe that the Secretary by delaying the implementation of this part of the rule, the forced divestiture, by 90 days, is giving us the opportunity to adjust accordingly.

Senator SPECTER. If, Dr. Battey, if this rule is not promulgated and become final, can we save you from California?

Dr. BATTEY. There are a set of circumstances under which I would entertain remaining with the National Institutes of Health.



As I said before, I love this job, I think it's the greatest job in the world.

Senator SPECTER. Well, we will leave to Dr. Zerhouni the exploration of those set of circumstances. But my telephone number is in the book.

Dr. BATTEY. Senator, I very much appreciate your support.

Senator SPECTER. Because as I had said earlier, very much concerned about the impact and I'm not faulting anyone. This is a tough area to move in, and there are bound to be unintended consequences. But with your record and your reputation, it would be very unwise, not helpful, to have the NIH lose you on this issue. I'm glad to see that Dr. Zerhouni and the others who are promulgating the rules are having a delay and will take these issues into account.

Dr. BATTEY. Thank you. Let me just add that I agree 100 percent with Dr. Zerhouni that it is absolutely essential that the Agency maintain the public trust and be a neutral broker in the eyes of all those who consult with us and ask us to give opinions in the area of biomedical research.

Senator SPECTER. Well, I'm pleased to hear you say that, and let's see if we can't get it to work out to retain Dr. Battey and move ahead with the ethical guidelines in ways which are really meaningful and necessary.

#### STEM CELL RESEARCH

Before Senator Harkin returns, Dr. Zerhouni, just a question or two about stem cells. Where are we heading? Are we going to be losing all of our stem cell geniuses to Europe, to California, to Massachusetts?

Dr. ZERHOUNI. California right now is probably the State that has the most wide-ranging policy allowing research in the field of regenerative medicine. Clearly, when you look at the scientific evolution of this field, and as I've said before, from the purely scientific standpoint, there's no doubt that access to more cells is seen by scientists as very important to their progress.

Much can be done with the cells available through NIH and they're federally funded through the current policy. However, it is clear that when you look forward, NIH is funding about \$30 million worth of human embryonic stem cells and over \$390 million total in regenerative medicine. The California investment is about \$300 million total, not just in embryonic stem cells. So it's not fair to say that the Federal investment is one-tenth of the California investment. That relates to the human embryonic stem cells. The California investment is not specific to just human embryonic stem cells.

Senator SPECTER. Dr. Zerhouni, why shouldn't we utilize the stem cells which are frozen, several hundred thousand created for in vitro fertilization? They have the potential to save lives. Why shouldn't we use them for scientific research?

Dr. ZERHOUNI. From the purely scientific standpoint, scientists will tell you, I will tell you that there are areas of research that could be advanced, especially when you look at the 22 cell lines that we have. There is mounting evidence that we have contamina-

tion issues that may prevent their use for clinical applications, other issues of genetic stability are also emerging.

Clearly from the purely scientific standpoint, more cell lines may well be very helpful. The issue is not a scientific issue, as you well know. The issue is the policy is predicated on a moral and ethical line that says that we could not use Federal funds to remove the potential for life of these embryos.

Senator SPECTER. Well, what is the moral and ethical line if they're going to be destroyed? If they could create life—Senator Harkin and I took the lead in appropriating funds for embryo adoption. People would take the embryos and utilize them to produce children, people. But if they're going to be destroyed, where is the moral issue?

Dr. ZERHOUNI. I think you'll have to ask that from those who hold that view. I mean, obviously there are—there is a polarization of views on this issue. Some believe very strongly that an embryo is the beginning of life, and therefore, any use of that is inappropriate. Others obviously see the good on the other side. Every ethical issue is a balance between a social good and something that is seen by some as destructive.

I think that debate needs to go on, needs to occur. It is occurring, I think, amongst yourselves as legislators. From a purely scientific standpoint we believe, and we've said so, that more lines may well be helpful to this research.

Senator SPECTER. The legislation which Senator Harkin and Senator Feinstein, Senator Hatch, Senator Kennedy, and I have introduced bans cloning. We have the issue of nuclear transplantation, which does not come near the question of cloning. There are reportedly remarkable opportunities on nuclear transplantation to provide cures for the individual himself, herself, whose bodily substance is satisfied. Why not, Dr. Zerhouni?

Dr. ZERHOUNI. Well, again, the issue here is Federal funding being used on the one hand to use discarded embryos, as you mentioned. Then the other is somatic cell nuclear transfer where you create an embryo. The issue here is fundamentally the use of Federal funds for this kind of research. It's not a scientific issue.

Senator SPECTER. Well, I know the issue. The President's policy permits the use of some lines developed up to August 9, 2001. But there is growing evidence that the stem cell lines available on the NIH registry are showing epigenetic and genetic changes in small regions of the chromosomes. This is a prepared statement, Dr. Zerhouni, so I'm reading. Deputy Senator Taylor just made this available to me and I want to ask you the question.

I've been instructed to ask you this, Dr. Battey. When I get an instruction from Bettilou Taylor, I take it.

Dr. BATTEY. I think that's very well-advised, Senator.

#### FEDERAL FUNDING FOR STEM CELL RESEARCH

Senator SPECTER. Well, this is a joint question from Ellen and Bettilou and Tom and Arlen. All of those lines are being used to study basic biology of stem cells. Their use in clinical applications is questionable. There is confusion among scientists and administrators at universities where scientists have both Federal and non-federal funding for stem cell research about exactly what research

infrastructure or core facilities developed with NIH funds in the past can be used in studies involving stem cells not eligible for Federal funding.

Dr. Battey, in addition to the position which you identified, and until last week you were chair of the NIH Stem Cell Task Force, what is your view of the current limitations of Federal funding?

Dr. BATTEY. Senator, the state of the science is moving very, very rapidly here, and we have learned many things since the last time I had an opportunity to testify before this subcommittee. For example, scientists at the University—or in the city of Chicago have now made stem cell lines from embryos that were identified in pre-implantation genetic diagnosis to harbor mutations that cause disease.

These stem cell lines could potentially be used to create cellular model systems that would allow the development of drugs to treat these diseases. I'm talking about diseases like muscular dystrophy and Huntington's disease. These cell lines, however, were all created after August 9, 2001, and are therefore ineligible for Federal funding.

The issue you mentioned about funding streams, it's a real issue. Let me give you an example. Imagine for the sake of argument an investigator who has a cell line he got from Doug Melton, it's not eligible for funding, and a cell line from Wisconsin that is. That investigator extracts messenger RNA from those two cells and then wants to go to his core facility for doing a study of what's been expressed in terms of gene expression that was funded initially by support from the National Institutes of Health. Can that investigator analyze that sample in that facility?

These are the sorts of complex issues that are now arising on a daily basis in places where there are substantial amounts of funding for stem cell research that is outside the confines of that which can be funded using Federal dollars.

Senator SPECTER. Well, thank you very much, Dr. Battey. Senator Harkin has this on his agenda, and I'm going to excuse myself at this point and turn the hearing over to my distinguished colleague, Senator Harkin. We often say that when the gavel changes hands, it's seamless. Show them, Tom. We have had a unique partnership in this contentious Senate and Congress to put aside party differences in the interests of moving ahead on a factual basis. I think the American people are really sick and tired of the bickering, and Senator Harkin and I have, I think, established the kind of a relationship which is in the public interest. It's all yours, Tom.

Senator HARKIN [presiding]. The only follow-up I had with Senator Specter's question for you, Dr. Battey, was on the scientific basis of this. Now, I don't know what all these words mean, but your statement says: "there's growing evidence that the HESC lines available on the NIH human embryonic stem cell registry are showing epigenetic and genetic changes in small regions of the chromosomes." Please explain what that means.

#### EXPLANATION OF EPIGENETIC AND GENETIC CHANGES

Dr. BATTEY. I'll try to explain as best as I can. A genetic change, Senator, is an actual change in the order of bases in the DNA sequence itself. An epigenetic change is a change that involves mark-

ing on those DNA bases that have implications for which genes get expressed and under what circumstances. What is becoming increasingly apparent is that as the cells are cultured for prolonged periods of time, we are observing both small genetic changes as well as epigenetic changes. This does not come as any great surprise to a cell biologist, and in fact is observed almost any time you culture cells for prolonged periods of time.

The reason for that is, although all the words are complicated, the reason is very simple and easy to grasp, and that's that when you grow cells in culture, you are continually selecting for a more rapidly growing cell. That is intrinsic to the process of passaging and growing cells.

So it is inconceivable to me that you would not evolve changes that would confer a growth advantage as you culture cells over prolonged periods of time. In fact, what is remarkable is how stable these embryonic stem cell lines are over time. The fact—but nevertheless, these changes will evolve if you culture the cells for maybe 50, 75, or 100 passages.

Senator HARKIN. To my layman's mind, it seems what you're saying is that somehow this would affect their use in any kind of further down-the-road treatment in humans?

Dr. BATTEY. That we don't know. That is not clear yet. If the changes, however, move the cell towards a more rapidly growing state, it is possible that you would have a cell that would evolve a genetic change that would take it one step closer to becoming a tumor of the stem cells, which is a teratoma. I think that's the major concern.

Dr. ZERHOUNI. Senator, the best analogy—sorry.

Senator HARKIN. No, go ahead. Yes, please.

Dr. ZERHOUNI. The best analogy to this is the one I had to come up with to explain this in layman's terms. That is that if, suppose you have an original document and you want to make Xerox copies of that document, and you make billions of copies each generation from the previous document. What may happen is that after the 150th generation, after making billions of copies of the DNA, you'll have errors, and you'll have a poorer copy and a poorer copy and a poorer copy as you go forward.

At the onset of this field, 5 or 6 years ago, everyone thought that stem cells were renewable in a perfect state, as if you had a perfect copy each time. Well, as the science has advanced and our methods of measurements have become more accurate, we are finding that in fact there are errors that occur over the transmission of information through that copying process. That may, in fact, have profound implications as to the viability of an experiment and the viability of the use of these over a long period of time.

Senator HARKIN. Again, in my layman's mind, it sounds like that argues for getting as many stem cell lines as possible.

Dr. ZERHOUNI. From a scientific standpoint, I think there are lots to be learned. In addition to the new science that has occurred recently, in terms of disease-specific cell lines that could be used such as the lines that Dr. Battey mentioned that have specific diseases in them, so that you could use that to study that disease process in a laboratory. From the scientific standpoint, this might be helpful.

Senator HARKIN. I just had a couple of other questions that I really wanted to go over here. Dr. Zerhouni, one of them had to do with, again, the success rate down to 21 percent overall. I noticed that at NCI, National Cancer Institute, it's 19 percent. At NCCAM it's 8 percent. I'm concerned about, again, what message this sends to young investigators who have a particularly hard time winning grants when money gets tight.

If a young med school student with huge loans to pay knows he faces only a 1-in-5 or a 1-in-10 chance of getting a grant, he or she may want to think twice about whether they want to enter this career. Would you just speak if you can for a little bit on the impact that you might see that a 21 percent success rate would have on your ability to attract young scientists to medical research?

#### NATURE OF SUCCESS RATES

Dr. ZERHOUNI. Again, the 21 percent success rate reflects two facts. One is the doubling has been very successful in attracting a larger number of excellent scientists to NIH. So the number of applications has in fact increased over time. I wanted to show you again the graphic there. The black line shows the number of applications rising all the way to 44,000. So we have more—go ahead.

Senator HARKIN. Now, are those applications or are those peer-reviewed applications that are—

Dr. ZERHOUNI. Peer-reviewed applications.

Senator HARKIN. Peer-reviewed.

Dr. ZERHOUNI. Right. The applications—

Senator HARKIN. Not the total. These are just the—

Dr. ZERHOUNI. These are the ones that are peer-reviewed by NIH that are—

Senator HARKIN. Made it through.

Dr. ZERHOUNI. Made it to review. Of those, we funded 32 percent in 2001, 25 percent in 2004, and 22 and 21. Obviously if the number of applications had stayed level, our success rate would have been higher. But the fact is we have more areas of research that we are into today than we were 5 or 10 years ago.

Now, your concern about young scientists is my concern as well. As you may know, I have requested a study from the Institute of Medicine. Two years ago we engaged our advisory councils about the issue of the lengthening of the time it takes for a young scientist today to be independent and to have their own research ideas worked on. Thirty years ago, 27 percent of our NIH grantees were 35 years or younger. Today, less than 4 percent of our NIH grantees are 35 years or younger.

That reflects two things—I'm sorry.

Senator HARKIN. What was that year cut-off?

Dr. ZERHOUNI. 30 years ago.

Senator HARKIN. 30.

Dr. ZERHOUNI. 27 percent of our scientists 30 years ago were younger than 35 years of age. Today it's 4 percent. On average when you look at the first grant, median is about 39, 40 years of age. This to me is a little too long. I really believe that there is a lot of creativity that occurs early in a scientific career.

The effect is twofold. One is the lengthening of the training period, but also the competitiveness of our grant process. That's why

a 21 percent success rate, if not balanced by new grants, as I've done, and if not carefully managed, can lead to a loss of talent.

Think about it this way, Senator. If you're a 25-year-old scientist and you look at your career and you have to wait until age 39 to have a chance to get a grant from NIH, you might consider other career tracks. That to me is the one thing that I worry the most about. We're going to consider very carefully the IOM recommendations and try to do the best we can within the fiscal constraints that we have.

But I think it is a trend, Senator, that all of us have to be aware of, and that is the plight of the young scientist, not just in biomedical sciences, by the way, Senator. It affects science and technology in general.

Senator HARKIN. It seems to me in my memory bank someplace, that this has been a discussion point in the past. Do you have a fund in the Director's office or something like that where—who was it termed it the “ah-ha” fund? Some young scientist says ah-ha, I got this idea, and you can kind of pick some of these young people and say, oh, they're on to something maybe, maybe, we don't know. But don't you have some fund like that? Is there something at NIH that allows that to happen under your direction?

#### VARIOUS SOURCES OF FUNDING

Dr. ZERHOUNI. I do not have a fund for that. But through the Roadmap, we've established a Pioneer Award to try to in fact encourage that, to try to find out if there are scientists out there that we're not funding through the process.

Institutes themselves, by the way, through loan repayment programs, career award developments, K-22 awards, all kinds of mechanisms are responsive to a different degree to this issue of the young scientists. We have Shannon awards, which provide a young scientist with transitional dollars.

I think, as the IOM recommends, it's time for us to look at all of our policies across NIH and find out, especially in tougher times, what we need to do proactively to in my view protect the pipeline of talent that 20 years from now will be the discoverers of the new cures and new treatments and new knowledge that we need.

We have a retreat with the NIH directors planned later this year to talk just about this as well. We have discussed this issue amongst ourselves quite a bit, as we are concerned about it.

#### AVIAN INFLUENZA

Senator HARKIN. I'll look at that some more myself, see if there's some way we can set something up like that. There were a couple of other areas I wanted to cover, one for Dr. Fauci and one for Dr. von Eschenbach. I'll start with Tony.

A lot of stuff being written about avian flu. Why is the spread of this avian influenza so alarming? What steps is the Institute taking to address this issue?

Dr. FAUCI. Well, thank you for that question, Senator Harkin. It's a very important public health issue. The concern surrounding the avian flu threat that we are currently undergoing now relates to the fact that the situation in countries in Southeast Asia, particularly Thailand, Vietnam, and to a lesser degree Cambodia, is

that there a virus called H5N1 circulating among chicken flocks. That is the way we designate influenzas by an H and an N, which are two of the proteins that are the important identification markers.

The regular flu that's circulating around this winter was an H3N2, a totally human influenza virus. The H5N1 is a bird flu. It has been infecting and killing large numbers of chickens in Asia. But what has happened over a period starting from the first identification in 1997 in Hong Kong of H5N1, which infected 18 people by jumping from the chicken to the human, and killing six of those, over the past year-and-a-half, in 2003 and now in a very accelerated way in 2004 and 2005, we've now had larger numbers of chickens infected and larger numbers of people. As of last night's count, there were 79 official cases confirmed and 49 official deaths confirmed.

Now, that may seem like a small number, but first of all, the mortality is very high, and second, there's a transition of the viruses getting a greater efficiency of spreading from the chicken to the human. Then what we're very concerned about is human-to-human spread. That has not occurred efficiently up to this point. There is at least one documented case in Thailand of a mother who got it from her 11-year-old child who, the child got it from the chicken, but the mother actually got it from the child.

If there is increased efficiency of spread from person to person, we have the possibility of what we call a pandemic. Now, that means that the society in general, our civilization, doesn't have any baseline immunity to H5N1, because unlike H3N2, where each year we get exposed to one variety or another of that strain, we get vaccinated or we get infected, so that our society has some degree of background immunity to an H3N2. We have zero background immunity to H5N1.

So the possibility of there being rampant spread, particularly with the high mortality that we're seeing right now, is a very sobering prospect that we're looking at. What are we doing about it?

Senator HARKIN. So the flu shot I got does not protect me from—

Dr. FAUCI. Not even a little bit. Not even a little bit. So—but don't worry because there's not H5N1 right here now. But we're concerned about it.

So what are we doing about it? The NIH component of the broader Department of Health and Human Services pandemic flu preparedness plan is the research limb. You know, the CDC does the surveillance, the identification, the public health measures. The FDA does the regulation of the vaccines and the drugs that we're screening for, and that's all done under the Office of Public Health Emergency Preparedness.

What we're doing is fundamental basic research on the virus, understanding its virulence and pathogenesis, getting sequence data on all of the various strains so that we can make them available to investigators to do things like screening for drugs, targeting for drugs, and the development of vaccines.

Probably the thing that's of most practical concern to you and the committee and the general public is that we have moved very rapidly in identifying the H5N1 using a particular molecular technique

developed by one of our grantees to develop a seed virus. Two weeks ago, we started the screening for a trial. Last week we gave the first injections, and as of yesterday, we have over 150 people enrolled in a phase 1 trial of H5N1 in three centers in our network of vaccine centers in Rochester, New York, UCLA, and Baylor, I believe.

We have now data that we're going to be collecting on the safety, what is the proper dose of the vaccine, and what is the difference in the immunogenicity in normal adults. That will be finished within a period of a couple of months, people from 18 to 64. Then we're going to move on to people greater than 65, and then we're going to do it in children.

In addition, finally, as part of the departmental program, we've purchased 2 million doses for the strategic national stockpile of H5N1 in anticipation of being able to scale this up in commercialized lots, not just thousands or millions, but tens of millions if we need it.

Finally, the Department's plan is to stockpile Tamiflu, which is the antiviral to which this particular virus is susceptible.

Senator HARKIN. What did you say?

Dr. FAUCI. Tamiflu. The regular name for it is Oseltamivir. It's an anti-influenza drug.

Senator HARKIN. I'm glad you've cleared that up for me.

#### TRAVEL RISKS ASSOCIATED WITH AVIAN INFLUENZA

Well, now, the only follow-up question I have is—okay, so we're not exposed to avian influenza, but they are in Southeast Asia. How concerned should we be of people traveling back and forth, picking up the virus, bringing it back here, and transmitting it?

Dr. FAUCI. At this point not. But the CDC, together with WHO, is heightening in a very accelerated way their surveillance mechanism in Southeast Asia. Since the virus does not transmit efficiently at all from human to human, it is extraordinarily unlikely that you would have a situation where someone would be infected, that most likely would be a chicken farmer, who would then get on a plane and come to Washington.

So the chance of that is extremely unlikely. For that reason, there are no public prohibitions on travel with regard to this.

I just want to mention one thing, I just thought of it. I gave you—just because I want the record to be correct—the other center that's doing the trial is not Baylor. It's the University of Maryland in Baltimore.

Senator HARKIN. Thanks very much, Dr. Fauci.

Dr. FAUCI. You're welcome.

#### HUMAN CANCER GENOME PROJECT

Senator HARKIN. Dr. von Eschenbach, I want to ask something Dr. Jim Watson brought up to me a couple of times, and that has to do with the human cancer genome project.

Dr. VON ESCHENBACH. Yes, sir.

Senator HARKIN. About the need for that kind of effort. I understand that NCI and the Human Genome Research Institute, Dr. Collins, have teamed up on an effort called the human cancer ge-



nome project. Just what is this? What are you doing? Tell me about this.

Dr. VON ESCHENBACH. Well, thank you, Senator, for the question, and also thank you very much for your passion and concern for patients, especially cancer patients. This effort is intended to address much of our opportunity in understanding cancer. We know, though it is a series of complex diseases, it is also a disease process. There is a portion of that process that defines our susceptibility to cancer and then the development and progression of that cancer to the point where it causes the suffering and death that we see all around us.

So we're trying to understand that cancer process. We're trying to understand it at the very fundamental genetic and molecular and cellular level as to why and how we're susceptible to different cancers, how and why they develop and then progress in some patients to the point that they actually take our life.

We have a series of investigations to understand that process. We're trying to understand it at the genetic level and also understand it at the molecular and proteomic level. We've even launched recently an effort in nanotechnology to begin to utilize that field to understand the process.

The specific project that you are referring to is one of those initiatives where we are teaming up with another NIH Agency, the National Human Genome Research Institute, to co-partner in an effort to understand and to determine all the genetic changes and mutations that determine our susceptibility to cancer and define the development of cancer.

We believe that if we understand those genes and those genetic changes, we'll be able to use that knowledge and that information to be able to select and screen patients to determine susceptibility, to be able to define the risk that one has for a particular type of cancer, so that we then have that knowledge and can use that to intervene earlier in a way to try to prevent that process from occurring. Also to be able to use the knowledge of those genetic changes so that we can find better methods to detect the development of cancer, because if we can pick up the development of those genetic changes and know that cancer is now starting in someone's body, we could then eliminate that cancer when it's still very early and do that much more safely and much more easily.

If we can detect and eliminate cancer early, we could eliminate the outcome of cancer, the suffering and death that we see. So this is one initiative that we believe holds great promise for achieving the goal of 2015, the elimination of suffering and death due to cancer.

Senator HARKIN. So you've embarked on this and—

Dr. VON ESCHENBACH. It's in process of development, sir. And we have a pilot project that we are in the midst of planning and developing so that we can create the infrastructure for a broader application of this.

Senator HARKIN. So when we meet again here later on, you'll be able to keep us updated as to what the progress of this is?

Dr. VON ESCHENBACH. Absolutely, sir.

Senator HARKIN. I appreciate that very much. I really don't have any more time. Did anybody else have any—Dr. Zerhouni, did you have anything else you wanted to add for the record?

Dr. ZERHOUNI. No. I really appreciate the questions you've posed today.

Senator HARKIN. Thank you. Again, I apologize for jumping on you on the conflict of interest, but I hope there's some people here from HHS, because that's really who I was directing it at.

But I'll say, we need you in forefront of this too. This is your NIH.

Dr. ZERHOUNI. I certainly am.

Senator HARKIN. I just don't think we can afford to continue to put this off. We've got to address it right away.

Dr. ZERHOUNI. I think you've heard me, sir.

Senator HARKIN. I know, and I appreciate that. Thank you all very much for the great job you do. Hopefully we can get that .5 up, but I don't know. We'll try our best.

Dr. ZERHOUNI. Thank you very much.

#### ADDITIONAL SUBMITTED STATEMENT

Senator HARKIN. Thank you all very much.

The subcommittee has received a statement from The National Alliance for eye and Vision Research which will be placed in the record.

[The statement follows:]

#### PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

The National Alliance for Eye and Vision Research (NAEVR) is pleased to submit this written testimony to the file of the April 6, 2005, hearings of the Labor, Health and Human Services, Education and Related Agencies Subcommittee of the Senate Appropriations Committee.

#### ABOUT NAEVR

Founded in 1997, NAEVR is a non-profit advocacy organization comprised of 50 professional, consumer and industry organizations involved in eye and vision research. NAEVR's goal is to achieve the best vision for all Americans through advocacy and public education about the value and cost-effectiveness of eye and vision research sponsored by the National Institutes of Health (NIH), the National Eye Institute (NEI) and other federal research entities.

#### NAEVR REQUESTS FISCAL YEAR 2006 NIH FUNDING AT \$30 BILLION TO MAINTAIN THE MOMENTUM OF DISCOVERY

Although NAEVR realizes that Congress faces an expanding set of challenges at home and abroad, we join the community of support for medical research in requesting Congress to fund the NIH at \$30 billion in fiscal year 2006, or a 6 percent increase over the fiscal year 2005 level, to maintain the momentum of discovery. NAEVR believes that the NIH has made tremendous contributions that have served to improve the quality of lives for millions of Americans and contain healthcare costs.

NAEVR commends Chairman Specter's leadership in introducing Senate Amendment 173 to the fiscal year 2006 Senate Budget Resolution that would add \$1.5 billion to the NIH beyond that proposed in the administration's budget, to a level of approximately \$30 billion. NAEVR also recognizes the leadership demonstrated by the full Senate in successfully passing the amendment and Senate Budget Resolution, and we strongly urge the Senate and House conferees to maintain this number in the conference bill.

Congress' past bipartisan leadership in doubling the NIH budget from fiscal year 1998 to fiscal year 2003 has had a profound impact on the health care of all Americans, in terms of earlier, more accurate diagnosis of disease; more targeted, effective treatment options; more comprehensive, cost-effective prevention strategies; and the

transformation of acute diseases to chronic, manageable diseases. With this basis, NIH has plans to further transform how basic and clinical research is conducted through initiatives such as the *NIH Roadmap for Medical Research* (the NEI is a lead Institute on the Nanomedicine project) and *NIH Neuroscience Blueprint*, in which 15 Institutes are engaged, including the NEI.

NAEVR commends NIH Director Dr. Zerhouni for his leadership in eliminating roadblocks that prevent collaborative research and using NIH-directed dollars in a cost-effective manner. However, his efforts to maximize the return on medical research dollars can only go so far. For example, in the fiscal year 2006 funding process, NIH would need an increase of at least 3.5 percent just to keep pace with the Biomedical Research and Development Price Index (BRDPI). Since the fiscal year 2006 funding level in the administration's budget proposal would represent the third year in which the NIH would not keep pace with inflation, the gains realized from the past investment in the NIH will be jeopardized.

In summary, to ensure that NIH's momentum is not eroded further, and to continue the fight against diseases and disabilities that affect millions of Americans, NAEVR requests that Congress seek an NIH budget of at least \$30 billion in fiscal year 2006.

NAEVR REQUESTS FISCAL YEAR 2006 NEI FUNDING AT \$711 MILLION AS VISION HEALTH IS A "TOP PRIORITY" AMONG MANY PRIORITIES

NAEVR requests that Congress fund the NEI at \$711 million in fiscal year 2006, or a 6 percent increase over fiscal year 2005. This "Citizens Budget" for the NEI represents the eye and vision research community's judgment as the level necessary to advance the breakthroughs resulting from NEI's basic and clinical research that will result in treatments and therapies to prevent eye disease and restore vision.

In presenting this request, NAEVR asks Congress to make this nation's vision health a "top priority" among the many priorities it faces in the fiscal year 2006 funding cycle for the following reasons:

- Eye and vision research responds to the nation's top public health challenges and touches the lives of all Americans.
- The eye is a unique biological system offering exceptional experimental advantages in which to conduct genetic, neuroscience and cellular mechanism research.
- Vision impairment and eye disease is a major public health problem that is growing and which disproportionately affects the aging and minority populations.
- The economic and societal costs of vision impairment and eye disease are significant and growing; adequately funding the NEI is a cost-effective investment in our nation's health.
- Past NEI-funded basic and translational research is resulting in treatments and therapies to slow the progression of vision loss and restore vision.

EYE AND VISION RESEARCH RESPONDS TO THE NATION'S TOP PUBLIC HEALTH CHALLENGES AND TOUCHES THE LIVES OF ALL AMERICANS

Dr. Zerhouni has identified the NIH's top public health challenges as an aging population; chronic diseases; health disparities; emerging diseases (primarily comorbidities); and biodefense. NEI is responding to all of these challenges as they relate to eye and vision research:

- Not only has the NEI sponsored studies to characterize the incidence of age-related eye diseases such as age-related macular degeneration (AMD), glaucoma, diabetic retinopathy and cataracts, it sponsors extensive research into the cause and potential prevention of and treatments for these chronic diseases.
- Working with the National Center on Minority Health and Health Disparities (NCMHD), the NEI has sponsored studies to characterize vision impairment and eye disease disparities to direct further research—whether into the underlying physiological cause and potential concomitant therapy, or to the socio-economic or access issues that may enable it to focus its public health education programs.
- NEI has taken its basic research on diabetic retinopathy, a co-morbidity of diabetes, and tested treatments through a Clinical Trials Network. This optimal example of translating basic research "from bench to bedside" has resulted in treatments that are more than 95 percent effective and save the United States \$1.6 billion annually.
- Going beyond the traditional focus on battlefield visual acuity, NEI's biodefense research has resulted in new therapies to treat infectious eye diseases and promote corneal healing.

While addressing the nation's top public health challenges, NEI research also touches all Americans, whether directly or through loved ones. NEI research has the potential to ensure the best vision health of individuals at all stages of life—from newborns to the most elderly—thereby ensuring their independence, productivity and quality of life.

THE EYE IS A UNIQUE BIOLOGICAL SYSTEM OFFERING EXCEPTIONAL EXPERIMENTAL ADVANTAGES IN WHICH TO CONDUCT GENETIC, NEUROSCIENCE AND CELLULAR MECHANISM RESEARCH

As the entire medical research community gains a better understanding of the genetic basis of disease, the eye emerges as a unique biological system in which to study cellular mechanisms and pathways. The eye and vision community is at the forefront of genetic research, as the eye offers accessibility and a system in which one can measure the potential effect from a treatment. For example, NEI-sponsored researchers have recently announced the discovery of a gene strongly associated with a person's risk of developing AMD, which is the leading cause of vision loss in older Americans. This may enable researchers to develop tests for the disease before symptoms begin to appear and when drug therapies might help slow its progress.

Since the retina is a direct outgrowth of the brain and nerve cells underlie the ability to process vision, the eye also serves as an important system in which to study neurodegenerative diseases. For example, NEI-funded researchers have recently announced the regeneration of the optic nerve in mice, which could potentially result in treatments for Americans blinded by glaucoma or other injuries that destroy the optic nerve, as well as for other Central Nervous System disorders.

VISION IMPAIRMENT AND EYE DISEASE IS A MAJOR PUBLIC HEALTH PROBLEM THAT DISPROPORTIONATELY AFFECTS THE AGING AND MINORITY POPULATIONS

Over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer in public opinion polls. In recent NEI-sponsored research, patients with advanced AMD equated that condition to the gravest chronic diseases. These societal implications of vision impairment and eye disease are important since, as of the year 2000 census, there were more than 119 million Americans age 40+ who are most at risk from age-related eye disease such as AMD, glaucoma, diabetic retinopathy and cataracts.

In 2004, an NEI-sponsored study reported that vision loss from eye diseases will increase as Americans age. Also in 2004, the NEI reported on an African American subset analysis in its Ocular Hypertension Treatment Study (OHTS) and initial findings from its Los Angeles Latino Eye Study (LALES), both of which were co-sponsored by the NCMHD. Combined, these three studies reported that:

- Blindness or low vision currently affects 3.3 million Americans age 40+, or 1 in 28, and is projected to reach 5.5 million by year 2020.
- Age-related eye diseases currently affect more than 35 million Americans age 40+, and include intermediate-to-advanced AMD, glaucoma, diabetic retinopathy and cataracts. This number is projected to increase to about 50 million by the year 2020.
- More than 1.8 million Americans currently have advanced AMD, and this number is expected to grow to 3 million by the year 2020. Another 7.3 million Americans currently have intermediate-stage AMD. Currently, 200,000 Americans each year develop advanced AMD, and this number is expected to double by 2020. Because AMD affects the part of the eye called the macula, which is necessary for central vision, it affects a person's ability to read and drive. This has an enormous impact on quality of life and independence for older Americans.
- Glaucoma, a chronic potentially blinding disease that requires life-long treatment to control it, currently affects 2.2 million Americans, with 3.3 million expected to develop it by the year 2020. Glaucoma is now the leading cause of blindness in the fast-growing Hispanic population age 65+. Glaucoma is almost three times as common in African Americans as in White Americans and is the leading cause of blindness in the African American population.
- Diabetic retinopathy is the leading cause of blindness in the industrialized world in people between ages 25 and 74. It currently affects 4.1 million Americans age 40+, or one out of 12 Americans with diabetes in that age group, and is expected to increase to 7.2 million by the year 2020. Although successfully treatable in more than 95 percent of cases, many people do not know they are diabetic until symptoms, such as vision loss, occur. And with estimates of 50 million Americans having diabetes by the year 2020 at a yearly cost of \$1 trillion, and one-third of all American children born in year 2000 developing it in

their lifetimes, there will be increasing demand for research into new treatments and prevention therapies.

—Cataracts, which are the leading cause of low vision, currently affect nearly 20.5 million Americans age 65+, which is projected to increase to 30.1 million Americans by the year 2020. In the United States, a cataract is widely treatable by removing the natural lens and implanting an intraocular lens (IOL). However, in the rest of the world, cataracts are the leading cause of blindness due to lack of access to adequate care.

The past investment in the NEI's basic research has yielded breakthrough discoveries in the potential cellular mechanisms that result in these diseases, and its clinical research has resulted in an array of treatments for these conditions. However, the expanding population at risk for eye and vision disease will demand new and more effective therapies that restore vision or ultimately prevent the onset of these diseases. Adequately funding the NEI now ensures that its basic and clinical research "in the pipeline" comes to fruition and can be responsive to this growing public health problem.

THE ECONOMIC AND SOCIETAL COSTS OF VISION IMPAIRMENT AND EYE DISEASE ARE SIGNIFICANT; FUNDING NEI IS A COST-EFFECTIVE INVESTMENT

Although the NEI estimates that the current annual cost of vision impairment and eye disease to the United States is \$68 billion, this number does not fully quantify the impact of lost productivity and diminished quality of life. And as noted above, this financial burden to both the public and private sector is expected to increase dramatically, primarily due to an aging population and the growing prevalence of eye diseases that result in vision loss.

Adequately funding the NEI can delay, save and prevent expenditures, especially those associated with the Medicare and Medicaid programs, and is, therefore, a cost-effective investment. For example:

—As previously cited, the NEI-sponsored Early Treatment Diabetic Retinopathy and Diabetic Retinopathy studies have saved as much as \$1.6 billion per year in costs of blindness and vision impairment and resulted in treatments that are more than 95 percent effective.

—NEI-funded researchers have developed treatments for Retinopathy of Prematurity (ROP), a blinding complication in premature babies. As a result, more than 1,500 infants born this year with the most serious form of this condition can experience sighted lives, which would have cost the government \$1 million in benefits and lost taxes over the lifetime of each child.

—Economists estimate that cataract surgery provided Americans over \$300 billion in benefits in 2003 alone.

Funding the NEI at \$711 million in fiscal year 2006 is a cost-effective investment, as it will directly save healthcare expenses and return individuals to productive roles in society.

PAST NEI-FUNDED RESEARCH IS RESULTING IN TREATMENTS AND THERAPIES TO SLOW THE PROGRESSION OF VISION LOSS AND RESTORE VISION

The NEI has an impressive record of accomplishment over the past 5 years, as documented in its *National Plan for Eye and Vision Research*. Some of the most exciting developments that have widespread implications for Americans of all ages and races include:

—NEI is conducting additional clinical trials on nutritional supplements that may slow the progression of AMD, following previous research demonstrating that zinc and three antioxidant vitamins are effective in reducing vision loss in people at high risk for developing advanced AMD.

—An NEI-sponsored study has found that eye injections of bone-marrow derived stem cells prevented vision loss in two rodent models of Retinitis Pigmentosa (RP), a family of eye diseases that cause vision loss. This study raises the possibility that patients could receive an injection of their own bone marrow stem cells to preserve central vision.

—NEI-supported investigators are moving closer to human clinical trials of a gene therapy to treat neurodegenerative eye diseases, including Leber Congenital Amaurosis (LCA), which is a rapid retinal degeneration that blinds infants in the first year of life. Previous research has restored vision in dogs with LCA. This gene therapy not only has direct implications for the 9 million Americans affected by AMD, RP, Usher Syndrome and the entire spectrum of retinal degenerative diseases, but can potentially lead to therapies for glaucoma, diabetic retinopathy and cataracts.

## CONCLUSION

NAEVR supports fiscal year 2006 NIH funding at \$30 billion to ensure that our nation's medical research infrastructure can maintain its momentum of discovery. NAEVR also requests that Congress make our nation's vision health a "top priority" among many priorities by funding the NEI at \$711 million in fiscal year 2006. NEI-funded research results in therapies that reduce health expenses and return individuals to productive lives. It is a cost-effective investment in maintaining the momentum of discovery and vision health for all Americans.

## ADDITIONAL COMMITTEE QUESTIONS

Senator HARKIN. 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

## OBESITY RESEARCH

*Questions.* Last year, NIH announced release of a comprehensive Strategic Plan for Obesity Research. What initiatives have you undertaken, particularly to address the critical problem of childhood obesity, since release of this plan?

*Answer.* The NIH is pursuing a broad spectrum of research avenues consistent with the recommendations in the Strategic Plan for NIH Obesity Research. An important area of focus of these efforts is childhood obesity, to address the serious impact obesity has on children—potentially leading to a lifetime of serious health problems. Highlights of such efforts include fostering new research on prevention and treatment of pediatric obesity in primary care settings and other site-specific settings, which may include the home, day-care, school, or other community venues. In another effort, the NIH is beginning a project to develop a rating system for youth obesity-related policies. The current effort involves developing, for use as a research resource, a system to rate factors associated with physical activity and nutrition that are addressed by such policies. Such factors may include, for example, aspects of physical education or recess in schools. Once developed, this research resource would then be made available to investigators as a tool to facilitate analysis of the relative impacts of these factors on behaviors relevant to obesity. This effort would encompass policies at both the state and local levels. In developing this research resource, the NIH is coordinating with the CDC and other organizations which are supporting related efforts.

Other recently-launched NIH research would impact obesity in both adults and children. For example, the NIH is encouraging new studies to address the influence on obesity of factors in the "built environment," such as aspects of community design that may hinder physical activity. An upcoming conference will focus on environmental factors and obesity in youth. Improved technologies would facilitate a wide range of investigations. Such improved technologies would encompass, for example, the areas of more accurately measuring calorie consumption (energy intake) and physical activity (energy expenditure), and monitoring whether a person's energy intake and expenditure match (a state of energy balance) or whether one is greater. Thus, the NIH released research solicitations to bring innovative bio-engineering technology to address issues in energy balance, intake, and expenditure. Capitalizing on major ongoing NIH research investments, the NIH is continuing to solicit proposals for ancillary studies to several existing obesity-related clinical trials and networks; the NIH is also encouraging other productive partnerships between basic and clinical researchers. Interdisciplinary research focused on obesity is also being enhanced as a result of a recent NIH Roadmap initiative to support new Exploratory Centers for Interdisciplinary Research; several of these centers will focus on obesity. The NIH is also continuing to pursue genetic studies of obesity. Efforts are underway to develop an Intramural Obesity Clinical Research Center, on the NIH campus, to generate new knowledge regarding the prevention, treatment, and underlying molecular mechanisms of obesity and its associated diseases. Intramural-extramural collaboration will be a focus of these efforts.

Examples of efforts currently being developed include a new initiative to study how factors such as maternal weight during pregnancy can lead to obesity in offspring. Another effort is being planned to support collaborative research on the neurobiological basis of human eating behavior, bridging the gap between under-

standing at the genetic and molecular level of neural pathways involved in food intake and the understanding of behavioral influences on human obesity.

#### INFLUENZA

*Question.* Dr. Fauci, why is the spread of avian influenza so alarming?

*Answer.* The spread of avian influenza is of great concern because in the past, highly virulent pandemic influenza strains have originated as avian influenza. Influenza pandemics are global outbreaks that emerge infrequently and unpredictably and involve strains of virus to which humans have little or no immunity. Three deadly influenza pandemics have occurred in the 20th century: in 1918, 1957, and 1968. The 1918–1919 pandemic was by far the most severe, killing approximately 500,000 people in the United States and 20–40 million people worldwide—almost two percent of the global population at that time. Worldwide, the pandemics that began in 1957 and 1968 killed approximately 2 million and 700,000 people, respectively.

H9N2 and H5N1 influenza are two avian viruses that have jumped directly from birds to humans and have significant pandemic potential. In 1999 and 2003, H9N2 influenza caused illness in three people in Hong Kong and in five individuals elsewhere in China; fortunately, the virus did not acquire the ability to spread from human to human. Between January 28, 2004 and April 14, 2005, there were 88 confirmed cases of and 51 deaths from H5N1 avian influenza infection in humans in Cambodia, Thailand, and Vietnam, according to the World Health Organization. To date, there have been a small number of cases where human-to-human transmission of the virus may have occurred. However, public health experts fear that the longer and more widely the H5N1 virus circulates in poultry, the greater the likelihood that the virus may evolve into one that is more easily transmitted between people. If this were to happen, a worldwide pandemic could follow.

*Question.* What steps is your Institute taking to address this issue?

*Answer.* The National Institute of Allergy and Infectious Diseases (NIAID) is using a multi-faceted approach to address the threat of avian influenza, including surveillance of animals, vaccine and antiviral development, basic research, and genome sequencing. Through a contract to St. Jude Children's Research Hospital, NIAID is supporting disease surveillance in wild birds, live bird markets, and pigs in Hong Kong, allowing scientists to track potential emergent influenza strains. In January 2005, the contract was expanded to include animal surveillance in Vietnam, Thailand, and Indonesia.

The Institute has taken a number of steps to develop and clinically test vaccines against the two influenza viruses with the greatest pandemic potential. For example, under contract to NIAID, Chiron produced 40,000 doses of an H9N2 inactivated vaccine; a Phase I clinical trial of this vaccine in healthy adults began March 31, 2005. NIAID intramural scientists have also developed an attenuated H9N2 vaccine candidate that will soon be evaluated in humans.

NIAID has also initiated clinical testing of an H5N1 influenza candidate vaccine developed by NIAID-supported researchers at St. Jude Children's Research Hospital. In January 2004, these researchers obtained a clinical isolate of the highly virulent H5N1 virus that was fatal to humans in Vietnam in late 2003 and early 2004. They used a new technique called reverse genetics to create an H5N1 candidate vaccine from this strain. In May 2004, NIAID awarded contracts to Sanofi (formerly Aventis) Pasteur and Chiron for the manufacturing and production of inactivated vaccine against H5N1 influenza using this strain. Sanofi Pasteur delivered vaccine to NIAID in early March 2005; delivery of the Chiron vaccine is estimated to be in fall 2005. NIAID's Vaccine and Treatment Evaluation Units (VTEUs) currently are conducting a clinical trial of the Sanofi Pasteur vaccine in healthy adults. Following the review of the safety and immunogenicity data from the adult trial, NIAID plans to initiate trials of the H5N1 vaccine in healthy elderly and other populations. In addition, NIAID intramural researchers have developed three attenuated H5N1 vaccine candidates, which have been shown to be protective in mice; initial clinical trials of one of these vaccine candidates may begin as early as this year.

Efforts also are underway to test and improve antiviral drugs to prevent or treat avian influenza. NIAID is supporting an animal study to determine if combination therapy with two classes of antiviral drugs—neuraminidase inhibitors and adamantanes—is more effective than a single antiviral in reducing viral replication and emergence of drug resistant strains. The Institute is also supporting the development and testing of a long-acting next generation neuraminidase inhibitor that can be administered once per week.

NIAID supports a number of basic research projects that could lead to significant advances in pandemic influenza preparedness, including research that could lead to

vaccine strategies that would provide broader protection against a wide range of influenza strains and strategies to allow rapid production of a vaccine against a newly emergent strain. In addition, the Influenza Genome Sequencing Project, launched in the fall of 2004, is a collaboration between NIAID, the Centers for Disease Control and Prevention (CDC) and other organizations. The complete genetic sequences of thousands of influenza virus isolates will be determined and made available to the scientific community; to date, approximately 120 viruses have been sequenced. This program will enable scientists to better understand the emergence of influenza epidemics and pandemics by observing how influenza viruses evolve as they spread through the population. Moreover, scientists will be able to match viral genetic characteristics with virulence, ease of transmissibility, and other properties; this knowledge could lead to improved methods of treatment and prevention, as well as guide the public health emergency response should an influenza pandemic emerge.

#### BIOTERROR THREATS

*Question.* Dr. Fauci, please update us on the progress in the development of countermeasures against bioterror threats?

*Answer.* Since the attacks of September 11, 2001, and the anthrax attacks the following month, the United States has made significant progress in developing countermeasures against bioterror threats. The National Institute of Allergy and Infectious Diseases (NIAID) supports a comprehensive biodefense research and development program, which includes the development of biodefense countermeasures to combat Categories A, B, and C biological agents, as well as the expansion of the national research infrastructure and resources available to biodefense researchers. Basic research on microbes and host immune defenses serves as the foundation for applied research to develop the vaccines, therapeutics and diagnostics that the United States will need in the event of a bioterror attack.

The NIAID biodefense program has benefited from the passage of the Project BioShield Act of 2004, which granted the National Institutes of Health and NIAID authorities to expedite and simplify the solicitation, review, and award of grants and contracts for the development of critical medical countermeasures. NIAID used its new BioShield authorities to make recent grant awards for research aimed at the development of therapeutics for botulinum toxin, Ebola virus, anthrax, pneumonic plague, tularemia, and smallpox. Using BioShield authorities, the standard eighteen-month timeline from the conception of an initiative to grant award was reduced to approximately nine months. In fiscal year 2005, the Institute anticipates making additional awards using these BioShield authorities for research related to the protection of the immune system against damage by radiological or nuclear attacks.

The following are a few specific examples of NIAID's progress in the research and development of biomedical countermeasures against Category A bioterror agents:

##### *Anthrax*

In 2002 and 2003, NIAID initiated early and advanced product development and testing of the next-generation anthrax vaccine (rPA) by awarding contracts to two companies, Avecia and VaxGen. In November 2004, DHHS used its own Project BioShield authorities to award a contract to VaxGen to supply 75 million doses of rPA anthrax vaccine to the SNS. In addition, NIAID-supported scientists are conducting research to identify new targets for therapeutics. Scientists supported by NIAID determined the structure of the anthrax toxin, providing a better understanding of how the toxin causes disease and giving scientists the opportunity to design drugs that will specifically inhibit the anthrax toxin.

##### *Smallpox*

In 2003, NIAID initiated the advanced development of Modified Vaccinia Ankara (MVA) smallpox vaccine through contracts to Acambis and Bavarian Nordic. Contracts awarded in October 2004 are supporting larger scale manufacturing of the MVA vaccine as well as additional studies of safety and effectiveness in animals and humans. Though a vaccine is the only proven way to prevent smallpox infection, therapeutics to fight an infection are also an important component of the biodefense arsenal. NIAID-supported scientists have discovered a new way to block the ability of smallpox to spread from cell to cell, which may lead to the development of next-generation antiviral drugs to combat smallpox and other viral infections.

##### *Plague*

NIAID is supporting the manufacture of a plague vaccine through a contract awarded to Avecia in October 2004; this award will also support preclinical testing in animals and initial human clinical trials.



*Tularemia*

In collaboration with the Department of Defense (DOD), NIAID is conducting a Phase I clinical trial using the DOD's Live Vaccine Strain (LVS) tularemia vaccine. In October 2004, NIAID modified an existing contract with DynPort Vaccine Company to support the manufacture of additional LVS vaccine in anticipation of possible future clinical trials as well as for use in evaluation of the stability of the vaccine.

*Botulinum toxin*

In March 2005, NIAID made its first contract award using Project BioShield authorities to XOMA LLC, for the production of botulinum toxin monoclonal antibodies (serotype A) for clinical evaluation. In fiscal year 2005, NIAID expects to use Project BioShield authorities to make an additional contract award for the production of a recombinant botulinum toxin vaccine (serotype E) for clinical evaluation.

*Viral hemorrhagic fevers*

NIAID's Vaccine Research Center (VRC) is currently conducting the first human trial of a vaccine to prevent Ebola infection. In addition, NIAID grantees and scientists recently made a critical discovery related to how Ebola virus infects cells. These findings raise the possibility that a broad-spectrum antiviral therapeutic could be effective against multiple hemorrhagic fever viruses such as Ebola and Marburg.

## BIODEFENSE FUNDING

*Question.* Dr. Fauci, we have heard that members of the scientific community have criticized that increased biodefense funding at NIH has come at the expense of other important public health research. Can you comment on this?

*Answer.* The terrorist attacks of September 11, 2001, and the dissemination of anthrax spores through the U.S. mail later that fall prompted the Administration, with bipartisan support from Congress, to dramatically increase spending on biodefense research, with the specific goal of developing medical countermeasures to protect the public against agents of bioterror. More than \$1.5 billion was added to the National Institutes of Health (NIH) budget in fiscal year 2003 for biodefense research. These funds are additive to funds for other infectious diseases research; the biodefense funds did not and will not divert resources from other important infectious diseases research.

The non-biodefense resources of the National Institute of Allergy and Infectious Diseases (NIAID) increased by more than 50 percent from fiscal year 2000 to fiscal year 2005, keeping pace with or exceeding the average annual increases received by NIH during this same period.

## DEVELOPING ADVANCED TECHNOLOGIES

*Question.* From everything being written in the media, there is reason to be optimistic that we are close to unraveling the mysteries of cancer. Much of the progress being made is a direct result of new technology that wasn't available even only a few years ago. If there are still gaps in available technology that are preventing researchers from having a complete understanding of the complexities of cancer, has NCI considered ways in which the necessary tools could be developed?

*Answer.* Research over the past three decades has led to unimagined progress in our understanding of the cancer process at the genetic, molecular, and cellular levels. The combination of scientific talent, infrastructure, partnerships, and expertise coupled with an extraordinary array of advanced technologies is allowing us to understand cancer as a process—a process that begins with a single genetic alteration and proceeds through several stages to a lethal disease. Even now, as we stand an inflection point for progress in eliminating the suffering and death due to cancer, emerging technologies hold the key to accelerating our understanding of the complexities of cancer and how to prevent, diagnose, and treat cancer in its many forms. As we search for the most effective ways to harness the power of scientific discovery and to enhance our understanding of cancer's complexities, we know that the most direct path will be through the optimal integration of science and technology, specifically advanced technologies such as bioinformatics, cancer imaging, proteomics (the study of proteins), and nanotechnology (man-made devices minuscule enough to enter living cells).

The National Cancer Institute (NCI) has already taken steps to achieve paradigm shifting technology advances through the launch of the cancer Bioinformatics Grid (caBIG), an unprecedented platform to be available to the entire cancer research community. NCI has also established the Alliance for Nanotechnology in Cancer to

unite a broad array of programs to maximize the technology outputs. Initiatives in proteomics and cancer imaging are underway as well. As these technologies mature, we must also create the technology development resources and the seamless system needed to capitalize on their discoveries.

#### PERSONALIZED MEDICINE

*Question.* Over the past year, there has been a great deal of discussion surrounding research areas such as genomics, proteomics, and metabolomics. Articles suggest that research in these areas will provide research breakthroughs that will translate into new forms of targeted therapies and a way to personalize the treatment that cancer patients will receive in the future. Is this a realistic expectation or just science fiction?

*Answer.* Personalized medicine is not only a real possibility; it is critical to achieving NCI's goal to eliminate the suffering and death due to cancer by 2015. The Nation's investment in cancer research has led us to a point today where we're beginning to understand cancers at the molecular and genetic and cellular levels, and this understanding is influencing our selection of therapy and moving us to personalize medicine and personalize oncology. As our understanding of the cancer process increases, so does our ability to seek out and target key points in that process to disrupt and reverse the development of cancer. Part of our challenge is to understand how those targets differ from cancer type to cancer type and how each patient might react differently to potential therapies. Technologies such as molecular and genetic profiling and proteomics are opening the door to understanding these diseases and how they behave on an individual basis.

Using molecular profiling, NCI scientists have been able to identify and predict mantle cell lymphoma patients' survival following diagnosis based on the each cancer's distinct signature. Knowing whose disease is slow-moving and whose is progressing rapidly should help determine who would do well with a watchful waiting approach and who may benefit from early and aggressive treatment, possibly with new therapeutic regimens. For chronic lymphocytic leukemia, scientists have known for several years that there were two types of this leukemia, but the means for telling the two apart and affecting treatment choices was complex and not available to most patients. The same NCI group recently showed that expression of a single gene, ZAP-70, is a surrogate for this distinction, paving the way for better treatment choices for more patients.

Recent breakthroughs are also enabling scientists to identify patterns of protein markers associated with cancer initiation and progression and with particular cancers. Biomarkers (tumor indicators found in body fluids or tissues) hold promise for making personalized medicine a reality. They have many potential applications including early diagnostic testing, monitoring response to treatment, detecting metastatic disease, and building "designer" therapies. Already, information-rich blood sample proteins are being used to detect patients with ovarian cancer, effectively differentiating early-stage cancer patients from unaffected individuals. Similar methods potentially may be used to monitor a patient's response to molecularly targeted drugs, which could prove useful in designing patient-tailored therapies.

#### CANCER BIOMEDICAL INFORMATICS GRID

*Question.* NCI has built an impressive network of cancer centers around the country. Have you developed any resources that would enable the cancer centers and the broader cancer research community to share data and information?

*Answer.* By using the power of modern information technology, NCI is leading the way in developing a bioinformatics platform that promises to revolutionize the biomedical research enterprise. Scientists in various disciplines will have access to a common infrastructure for collaboration and integration of findings, and new "plug and play" tools developed by the researcher community will make it possible for investigators to greatly accelerate their research. For example, researchers at Cancer Centers across the country will be able to access data on the molecular characteristics of patients with a particular type of cancer who are being treated with a specific drug. Diverse data mounted on common platforms will permit researchers to use innovative analytic tools to mine the information in ways inconceivable a few years ago.

Up to the present, bioinformatics resources have been developed in organizational isolation, with tremendous variability in rules, processes, vocabularies, data content, and analytical tools. NCI will address these concerns and strengthen the potential for bioinformatics integration with the cancer Biomedical Informatics Grid (caBIG). The caBIG will provide a unifying architecture to transparently connect information and tools much like a home entertainment system in which components are made

by different manufacturers but built to common standards that allow users to combine them in various ways. Our long-term goal for bioinformatics is to improve the sophistication of information technology use and surmount the barriers that limit interaction across research institutions. NCI is currently piloting a core infrastructure with the participation of 50 Cancer Centers.

We are also fostering the development and use of new informatics technology to accelerate, better coordinate, and facilitate participation in NCI-supported clinical research. Currently, volumes of valuable raw data are not tapped, effective best practices are not widely distributed, and resources are wasted because of duplication of effort. With new bioinformatics tools and infrastructure, trials will be completed more quickly in multi-institutional settings with uniform electronic case report forms and data reporting systems. Databases and analytical tools will make information from all clinical trials available to NCI-supported researchers for efficient patient accrual, information retrieval, and data analysis. Informatics systems will assist the cancer community with priority setting and allow for fuller participation and a more transparent decision making process. Advocacy groups and individual patients will be empowered to participate in clinical research and to authorize use of materials for basic science investigations. Confidential clinical and proprietary information will be protected by controlled, secure access. Just as e-business models have transformed the American market place, the caBIG platform will overcome traditional institutional limitations. Community practitioners, clinical research organizations, and academic centers will be linked through this new model of clinical research. Healthcare providers will become full partners in the research enterprise and educated consumers of research findings.

#### CANCER SURVIVORSHIP

*Question.* Recent statistics show that there are now nearly 10 million cancer survivors in the United States. This is a dramatic change from the outcome that the majority of people diagnosed with cancer faced in the not too distant past. What have been the key advances in medicine that have provided so many more people with a healthy outcome after being diagnosed with cancer?

*Answer.* Healthy outcomes for cancer can be primarily attributed to two key areas—early detection and prevention, and better treatment regimens. Newly aligned goals focused on preventing cancer from occurring and detecting it early when it is most curable are the keys to reducing the incidence of cancer. Dramatic developments in technology and a more complete understanding of the causes and mechanisms of cancer have given us more effective ways to prevent the disease. New evidence-based interventions encourage lifestyle improvements in diet and physical activity, discourage smoking, and promote the use of safe and fully tested chemoprevention approaches for people at risk. Pioneering proteomic and biomarker advances and the promise of nanotechnology give hope for the early detection and diagnosis of cancer and prediction of patient response to treatment. Advanced information systems and methods of evaluation maximize the impact of existing technologies. NCI is ramping up specimen repositories and widely accessible bioinformatics resources to support the development of these breakthroughs.

Newer and better drugs are being developed every day, and combinations of many of these drugs are leading to longer survival times for many cancer patients. For example, the long-term outlook for breast cancer survivors improved significantly with news of a study that revealed the benefits of a drug that inhibits the synthesis of the hormone estrogen. The large, international study of the drug letrozole was specific to postmenopausal women who had been treated for early stage breast cancer that was estrogen-receptor positive and had just completed a five-year course of tamoxifen. Women who took letrozole (Femara®) were 43 percent less likely to experience a recurrence compared to women who took a placebo. The study, begun in 1998, was stopped ahead of schedule in 2003 when the positive effects became clear so that the women taking a placebo could be offered the drug.

Another example is the promising agent, iodine-131 tositumomab (Bexxar®), which is easier to take and less toxic than standard chemotherapy and has significant impact in extending the lives of patients who took it. In a phase II trial that included 76 patients with advanced-stage follicular lymphoma, nearly all of the patients (95 percent) responded to treatment, and three out of four were free of the disease after a single course of treatment. Five years later, most of the patients were in remission.

## CANCER PREVENTION

*Question.* The development of new ways to treat cancer seems to be highlighted in the press quite often. It makes more sense to find ways to prevent cancer—can you tell us about any progress NCI has made in cancer prevention?

*Answer.* The prevention of cancer focuses on studying and modifying behaviors that increase risk, mitigating the influence of genetic and environmental risk factors, and interrupting the carcinogenesis process through early medical intervention. We can save many lives, for example, by continuing to advance understanding of the biological and behavioral basis of nicotine addiction and energy balance. Evidence from recent NCI-sponsored studies suggest specific gene variations can affect smokers' cravings and that bupropion, an antidepressant used to help smokers quit, may ease these cravings, especially in women. Other medications to help smokers quit are under development and current evidence suggests that information and referrals from quit lines, as well as behavioral counseling from healthcare providers, significantly increase abstinence rates.

NCI is also supporting the development of prevention vaccines and chemopreventive agents for suppressing the carcinogenic process either at its inception or in pre-invasive stages. A new vaccine that targets the infectious agent human papilloma virus (HPV), implicated in cervical cancer, is being tested in clinical trials and is anticipated to be available to women at risk in the near term. Preclinical studies are beginning to identify prevention agents that impact cellular level targets to intervene in the cancer process, and clinical trials will test the value of these agents in preventing disease. NCI has established a new consortium of research centers to conduct early phase cancer prevention clinical trials. In 2004, NCI completed recruitment of 19,747 postmenopausal women at increased risk of breast cancer to participate in a clinical trial of the chemopreventive agent Raloxifene. Another prevention trial, the Prostate Cancer Prevention Trial, ended early after showing that men who took finasteride reduced their chances of getting prostate cancer by nearly 25 percent compared to men taking a placebo. A new proteomics technique has been used to successfully distinguish people who responded well to a drug that reduces colon polyps from those who did not. This technique increases our ability to target preventive agents to those who will most benefit. The impact preventative medicine and behavioral research have on reducing the cancer burden will continue to grow as similar techniques are developed and refined.

As we make such breakthroughs, we must actively translate prevention research into improved outcomes and facilitate the role of public policy to see that all people have knowledge of and access to preventive medicine and approaches. NCI understands that the media are a critical component of health communication as it relates to cancer prevention and we are working to optimize dissemination to patients, caregivers, and at-risk populations. For example, inadequate nutrition and physical activity appear to contribute to a sizable proportion of cancers. Through NCI's 5 A Day for Better Health Program, we seek to increase public awareness of the importance of eating 5 to 9 servings of fruits and vegetables every day for better health and provide consumers with specific information about how to include more servings of fruits and vegetables into their daily routines. NCI has also established Centers of Excellence in Cancer Communication Research, two of which are examining how the media communicate about cancer prevention. Through efforts like these, NCI is seeking ways to better work within media constructs to raise the level of dissemination and understanding of evidence-based cancer prevention messages.

## CLINICAL RESEARCH AND ACADEMIC HEALTH CENTERS

*Question.* Dr Zerhouni, as a result of the recent doubling of NIH by Congress we've seen a remarkable increase in fundamental knowledge about diseases like Alzheimer's, Parkinson's and diabetes. But I'm sure you understand that knowledge, in and of itself, is not enough unless it's put to use. Many of us are concerned that the next step in the process—the clinical research that translates into cures and improved treatments—isn't getting enough attention. Please tell us specifically what's being done to get science from the bench to the bedside, and whether you have enough legislative authority to put more emphasis on that side of the equation?

*Answer.* In order to improve human health, scientific discoveries must be translated into practical applications. Such discoveries typically begin with a clinical observation in a single patient or group of patients, or at "the bench" with basic research—in which scientists study disease at a molecular or cellular level. However, the discovery must then be translated to the clinical level, or the patient's "bedside." Translation is complicated, with input needed from a multidisciplinary team of scientists and other professionals.

In recent years, NIH-supported studies have addressed important translational issues, which have had direct implications for patient care on the front lines of medicine. The Women's Health Initiative assessed whether hormone replacement therapy (HRT) in post-menopausal women reduced heart attack rates; results demonstrated that it did not, and in fact, increased health risks; the Antihypertensive and Lipid-Lowering Treatment to Prevent Heart Attack Trial (ALLHAT) compared the occurrence of heart attack and stroke in high-risk hypertensive patients treated with either newer classes of drugs or with long established, inexpensive diuretics, and found that the diuretics were at least as effective as the new, more expensive medications; the Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT) tested whether an implantable cardiac defibrillator (ICD) or an antiarrhythmic drug would help prevent sudden death in heart failure patients, and reported that the ICD significantly reduced deaths (while the drug was no better than placebo); the National Emphysema Treatment Trial (NETT) tested the effectiveness of bilateral lung volume reduction surgery (LVRS) in the treatment of emphysema, and established that that LVRS benefits some but is harmful to others. Results were used as the basis for CMS coverage decisions regarding LVRS.

Despite these and other important findings, NIH recognizes that concerns have been raised about the status of clinical and translational research. The agency is accelerating and strengthening this focus through the "Re-engineering the Clinical Research Enterprise" initiative, which is part of the NIH Roadmap. By integrating clinical and translational resources—such as informatics, biostatistics, career development, regulatory support—into a unified program, the NIH aims to greatly enhance the efficiency and scope of clinical research. This will allow more rapid translation of basic research into studies that can be performed in human subjects and provide tools for the rapid and broad dissemination of the results of clinical trials.

As a result of Roadmap initiatives, academic institutions are beginning to undergo transformative changes to break down organizational roadblocks and disciplinary silos and bring individuals with different types of expertise into newly collaborative, integrative structures focused on solving complex health problems. There are also experiments underway that will allow for the creation of enhanced training and career pathways for individuals in the translational and clinical sciences. Because there is broad heterogeneity among the individual cultures of the AHCs, NIH is encouraging flexibility in experimenting with different and innovative approaches to address the need for training the clinical and translational investigators of the 21st century.

Moreover, the NIH Clinical Roadmap is working to develop a cadre of community-based physicians trained to carry out clinical studies in the context of their own health care settings, and to be leaders in translating cutting edge research findings directly into clinical care. An ongoing study is evaluating the feasibility and mechanisms necessary to succeed in implementing such a program.

Also under the aegis of the Roadmap, the NIH has established a new Clinical Research Policy Analysis and Coordination Program to stimulate the development of coordinated policies, practices, and tools to harmonize Federal regulatory policy and to ensure efficient oversight of clinical and translational research and of human subject protections.

In addition, NIH is fostering intergovernmental relationships with the Centers for Medicare and Medicaid Services (CMS), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC) and other agencies and health care plans to help ensure that clinical research results are used to develop evidence-based, cost-effective healthcare.

In its efforts to address the bottlenecks in translating results from clinical research into improved treatments and other interventions, the NIH aims to create a coordinated and supportive new infrastructure that will facilitate the more rapid translation of discoveries from the laboratory to the healthcare setting.

*Question.* On a related note, the academic health centers where clinical research is carried out—like Case Western Reserve, for example—are being squeezed. Part of the problem is the result of unfunded federal mandates like HIPAA. How does this affect NIH's ability to support clinical research, and ultimately help patients?

*Answer.* NIH recognizes the many requirements to which institutions must respond as they conduct and oversee clinical research. While these requirements pertain to important matters like human subject protections and safety oversight, NIH believes that much can be done to streamline them, thereby enhancing their effectiveness and diminishing unnecessary burden. To promote specific initiatives in this regard, the NIH established as a key element of its Roadmap effort a new Clinical Research Policy Analysis and Coordination (CRpac) Program.

CRpac's goal is to create a trans-government forum for stimulating the harmonization, streamlining, and optimization of policies and requirements pertaining to the

conduct and oversight of clinical research. CRpac staff thus work closely with other Federal agencies and offices that have responsibilities related to the funding and oversight of clinical research, including the Office for Human Research Protections, the Food and Drug Administration, the Department of the Veterans Administration, the Department of Defense, and other Federal agencies that have adopted the “Common Rule” for human subjects protections. Ensuring the more effective protection of research participants, as well as promoting the more efficient translation of research findings into clinically useful products, are two major aims of this program.

Some specific foci of the CRpac program include harmonizing diverse adverse event reporting requirements; clarifying policy where variability in the interpretation of the human subjects regulations exists; providing guidance on the use of IRBs and DSMBs; and stimulating a dialogue and consensus on clinical trial design issues to advance the science, safety, and ethics of translational research.

*Question.* Again, what do you need in the way of legislative authority to meet the demands placed on these academic health centers?

*Answer.* NIH has sufficient legislative authority and flexibility to meet the demands placed on academic health centers.

#### ALZHEIMER’S DISEASE

*Question.* For the past several years this Subcommittee has consistently encouraged NIH to assign a high priority to research on Alzheimer’s disease. In fiscal year 2002, the Subcommittee went so far as to encourage NIH to boost its investment in Alzheimer’s disease research to \$1 billion. But despite the steady increase in appropriations for the Aging Institute, I understand that your investment in Alzheimer research actually declined by nearly \$20 million between fiscal year 2003 and fiscal year 2004. Would you explain how that could possibly happen?

*Answer.* It is true that NIH funding for Alzheimer’s disease (AD) research—for which the National Institute on Aging (NIA) is the lead NIH institute, although several NIH Institutes support AD research—decreased from fiscal year 2003 to fiscal year 2004. Since its inception in 1974, the NIA has placed a very high priority on Alzheimer’s disease and AD-related research, such that AD has received by far more funding by NIA than any other aging-related disease research. In fiscal year 2004, despite the Institute’s best efforts, which included the funding of a major new multi-million dollar initiative, the Alzheimer’s Disease Neuroimaging Initiative, the NIA—and to a lesser degree, the NIH as a whole—experienced its first-ever decrease in AD funding.

In fiscal year 2004, the number of Research Project Grant (RPG) applications submitted across all NIA programs was unusually high, up 40 percent from fiscal year 2003. This made fiscal year 2004 a very competitive year overall for RPG funding at NIA. Of the applications the Institute received that were judged highly meritorious in peer review, considerable more dealt with other diseases and conditions included in the NIA mandate, while far fewer were AD-related, than in the preceding year. This was highly unusual, and there is every expectation that it will not re-occur and that funding for AD-related research will increase in fiscal year 2005.

*Question.* Can you give the Subcommittee some assurances that this will not occur again?

*Answer.* An immediate assurance can be offered to the Subcommittee that Alzheimer’s disease research continues to be a high priority for the NIA, and that the situation is being continually monitored and proactive steps have been taken that should prevent the re-occurrence of this unanticipated situation. So far during fiscal year 2005, AD research applications have been more competitive in peer review than this time last year, so that AD-related awards are outpacing non-Alzheimer’s disease awards. In addition, \$8 million of approximately \$10.2 million available for new NIA initiatives in fiscal year 2005 has been allocated for AD initiatives. Finally, the fiscal year 2005 Centers allocation will provide an increase in the AD Centers program funding of at least 1.5 percent above fiscal year 2004.

We are continuing to monitor the situation closely, but currently fiscal year 2005 AD funding is on track and consistent with application success rates seen in previous years. If this rate continues through the rest of the fiscal year, fiscal year 2005 AD funding will most assuredly be higher than fiscal year 2004.

[In millions of dollars]

	Fiscal year			
	2003	2004	2005	2006
Alzheimer's Total NIH .....	658	633	647	649
Aging Institute share .....	(502)	(483)	(496)	(498)

## POLYCYSTIC KIDNEY DISEASE

*Question.* The National Institutes of Health in general—and the National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], in particular, has—under your NIH Roadmap to the Future initiative—focused anew on translating basic research discoveries into therapeutic interventions to treat/cure some of the world's most prevalent life-threatening diseases, including polycystic kidney disease or PKD . . . the most common life-threatening genetic disease affecting 600,000 Americans. I would appreciate your comments about whether the discovery of the PKD genes in 1994/1995 culminating in the current clinical drug trial for PKD in humans—enabled by research partnerships between the Federal government (via NIDDK), private funding sources, and industry, combined with innovative technological advances such as provided from the CRISP study—is an example of what was envisioned in the development of the NIH Roadmap initiative, and—if so, in what respects?

*Answer.* The intent in developing the NIH Roadmap for Medical Research was to tackle very broad scientific challenges and thereby to generally move translational research forward for the benefit of all. Thus, NIH Roadmap initiatives are not specific to any particular diseases, but are expected to yield benefits for a wide range of diseases. While not directly funded under the Roadmap, the PKD research you cited—such as the Consortium for Radiologic Imaging Studies of Polycystic Kidney Disease (CRISP) study—is indeed consistent with the vision of the broader NIH Roadmap for Medical Research. The CRISP study has been a successful collaborative effort of imaging specialists and clinicians focused on PKD. The focus of the CRISP study is investment in the groundwork that will facilitate the development and eventual testing of clinically practical intervention strategies for PKD. The CRISP investigators have used state-of-the-art imaging techniques to develop new non-invasive methods that can reliably assess PKD progression. Such methods are important as they will facilitate design of future clinical trials of new therapies for PKD, which will likely require shorter follow-up periods and fewer patients than current trials of kidney disease. Similarly, it is hoped that NIH Roadmap initiatives will, among other things, provide technologies and other resources to facilitate discovery and characterization of disease genes; integrate expertise from multiple disciplines to more effectively attack problems in health and disease; enable more rapid testing of promising therapies in animal models of disease and in humans; and promote partnerships between the public and private sectors. By optimizing scientific tools and removing barriers to progress for researchers across all research fields, the NIH Roadmap should help pave the way to an accelerated pace of discovery from the bench-to-the-bedside for specific diseases such as PKD.

*Question.* In testimony before Congress on April 22, 2004, Dr. Allen Spiegel, the Director of NIDDK, said that “PKD represents an intersection of public health need, scientific opportunity and input from stakeholders regarding research directions, and that the NIDDK—working in conjunction with patient groups, such as the PKD Foundation, and investigator groups, such as the American Society of Nephrology—resulted in a strategic plan to exploit research opportunities, engage in expanded molecular research, develop new animal models and establish four PKD Research Centers.” In sum, he said NIDDK is committed to moving the research agenda forward toward the goal of developing more effective diagnosis, treatment and prevention of disease. Therefore, considering these developments and the fact that the prime cause of death for PKD patients is chronic cardiovascular disease, that PKD patients suffer greatly from psychosocial problems like depression, anxiety and suicide due to PKD's chronic nature, and the recessive form of PKD has such a high rate of morbidity and mortality in neonates and infants, to what extent is NIH considering “inter-institutional” research involving NIDDK, NHLBI (the National Heart, Lung and Blood Institute), NICHD (National Institute of Child Health & Human Development) and the NIMH (the National Institute for Mental Health) as a means to uncover potential interventional methods which could address these significant co-morbidities?

*Answer.* There are two major avenues through which the NIH is able to pursue collaborative research opportunities and initiatives on the co-morbidities of PKD

and other chronic kidney diseases. First, the statutory Kidney, Urologic, and Hematologic Diseases Interagency Coordinating Committee (KUHICC)—chaired by the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK)—encourages cooperation, communication, and collaboration among all relevant Federal agencies. Meetings of the Kidney Diseases Subcommittee provide an important opportunity for the NIH Institutes and Centers to initiate collaborations on shared interests in kidney disease.

Second, as the lead Institute for research on chronic kidney diseases, including PKD, the NIDDK has spearheaded collaborative efforts to address many of the comorbidities experienced by PKD and other chronic kidney disease patients. Let me provide a few examples. A major new collaborative study being led by NIDDK, with participation of the NICHD, the NHLBI and the NINDS, is the Pediatric Chronic Renal Insufficiency Cohort Study (“CKIDS”). This important new undertaking will address the impact of chronic kidney disease on cardiovascular morbidity as well as neurocognitive development and emotional health; it will include children with both the recessive and dominant forms of PKD. In a related area, an initiative on chronic illness self-management in children is currently being supported by the NIDDK, NHLBI, NICHD, and the National Institute on Nursing Research. The NHLBI convened a working group, “Cardio-Renal Connections in Heart Failure and Cardiovascular Disease,” on August 20, 2004 to further understanding of the interaction of the heart and the kidney in cardiovascular disease. The NHLBI is also a cosponsor of a planned NIDDK program announcement “Pilot and Feasibility Program Related to the Kidney” to foster the development of high-risk pilot and feasibility research; it is anticipated that this PA will be issued in 2005. In 2001, the NIDDK collaborated with the NIMH and the NIH Office of Behavioral and Social Sciences Research (OBSSR) in holding a major conference to determine the state of knowledge with regard to the co-morbid condition of depression in patients with diabetes, kidney disease, and obesity/eating disorders, and to propose a research agenda for the future. Finally, NHLBI and NIDDK have created a working group to address the relationship between hypertension and kidney disease, and are working collaboratively to design new initiatives in this area. All of these collaborative activities complement NIDDK’s continuing efforts to address comorbidities of chronic kidney disease, such as the Chronic Renal Insufficiency Cohort (CRIC) study, which is examining the relationship between cardiovascular disease and chronic kidney disease in adults, in order to try to find opportunities to prevent and better treat both. Another example is the Folic Acid for Vascular Outcome Reduction in Transplantation (FAVORIT) trial, which is testing whether treatment to lower total homocysteine levels using a high-dose combination of folic acid, vitamin B12, and vitamin B6 will reduce cardiovascular damage in kidney transplant recipients. Both of these large studies include substantial numbers of patients with PKD.

#### BASIC BEHAVIORAL RESEARCH

*Question.* As a matter of some concern I would like to bring to your attention an item relating to the National Institute of General Medical Sciences. I would also like to include Dr. Berg, as Director of NIGMS, on this item.

Dr. Zerhouni, for the past seven years, starting in fiscal year 1999, the Committee has included report language urging NIGMS to fund basic behavioral research and training. Two years ago, Senator Inouye, Senator Harkin, and I had a colloquy on the senate floor expressing the Committee’s strong support for basic behavioral research and training. Following the colloquy, I know the NIH commissioned a Task Force to study the matter and report back to the Director’s Advisory Committee. I understand that report was made available to you and your Advisory Committee last December and it, too, very strongly urged that NIH initiate such a program and create an Institutional presence for it in an Institute like NIGMS.

Dr. Zerhouni, what are your plans to implement a basic behavioral research and training program at NIGMS?

*Answer.* In keeping with the preferred approach of performing portfolio analysis across NIH rather than on an institute-by-institute basis, a working group of the Advisory Committee to the Director, NIH, was formed to examine basic behavioral research across NIH. The working group reported to the Advisory Committee on December 2, 2004. Their analysis revealed that the institutes and centers (including NIGMS) supported approximately \$2.68 billion in behavioral research, including approximately \$936 million in basic behavioral research, in fiscal year 2003. In addition to this base, several components of the NIH Roadmap for Medical Research are directed toward basic behavioral research. In particular, several mechanisms are being used to stimulate interdisciplinary research at the interface of the behavioral/social and biological sciences, provide the interdisciplinary training necessary for



postdoctoral investigators to work in these areas, and support development of innovative methods and technology that will facilitate research at the intersection of the behavioral, social and biomedical sciences.

Following the submission of the working group report, NIGMS has taken several steps to more clearly articulate the basic behavioral research it supports, encourage the submission of more research applications in these areas, and increase the number of investigators who can work at the interface of the behavioral and biological sciences:

*Research Training at the Interface of the Behavioral and Biological Sciences.*—Basic behavioral research is of critical importance to the mission of the NIH and can play a crucial role in understanding the etiology of disease and enhancing preventive and therapeutic inventions. Greater understanding of the molecular, genetic, and neural processes governing behavior, and the reciprocal effects of behaviors on physiological processes, is crucial for a complete understanding of human health and those diseases in which behavior is a risk factor, diagnostic indicator, or symptom. To advance our knowledge in these areas, researchers will need to integrate multiple disciplinary perspectives, methodologies, and levels of analysis. NIGMS has a strong background in developing and supporting such interdisciplinary research training. While some existing NIGMS training programs such as the Medical Scientist Training Program and the Systems and Integrative Biology program include elements of the behavioral sciences, there has not been a program dedicated to training at the basic behavioral science-biological science interface. NIGMS has developed a proposal for such a predoctoral program and is coordinating its further development with other NIH Institutes having an interest in this area.

*Collaborative Research on Basic Mechanisms of Behavior.*—To encourage the multidisciplinary research that is needed for a fuller understanding of the basic mechanisms of behavior, NIGMS has proposed an initiative to facilitate collaborations between basic behavioral scientists and investigators with expertise in state-of-the-art genetics, molecular biology, and genomics. It is anticipated that this collaborative research, performed with model organisms, will either enhance existing models or lead to the development of new models of normal or abnormal human behavior. The concept for this solicitation is to be presented for approval at the May 2005 meeting of the National Advisory General Medical Sciences Council.

*Assessing Interactions Among Social, Behavioral, and Genetic Factors in Health.*—NIGMS is a major contributor to an Institute of Medicine committee examining the state of the science on gene-environment interactions that affect human health. The study will identify approaches and strategies to strengthen the integration of social, behavioral, and genetic research in this field as well as consider relevant training and infrastructure needs. The results of this study will be used by the NIH to guide its programs in these areas.

#### WORK WITH PUBLISHERS

*Question.* I know that you are putting together an Advisory Working Group to provide advice on implementation of the NIH Public Access policy. I understand that the Working Group will not be able to convene prior to the May 2nd implementation date of the new policy.

Publishers are eager to work with you as they formulate their own policies for accommodating the NIH policy. They are important to the success of the NIH plan and I urge you to consult with them before May 2nd, as you finalize the details of the implementation policy.

Do you plan to consult with stakeholders before finalizing the details for implementing the access policy?

*Answer.* Throughout the implementation phase, we have had inquiries from and communicated with a number of publishers and members of the library community concerning the operation of the submission system. The initial submission system has been designed to enable individual investigators to submit their manuscripts in keeping with the basic goals of the Policy. We plan to seek feedback from users, and we will make system enhancements based on substantial input from all stakeholders, including publishers, to facilitate submissions in the future by others designated to do so for the authors.

*Question.* Given that your policy is to take effect May 2, can you outline the process NIH is following to assure such representation, and whether you expect to have scientific publishers identified and cleared for membership by May 2?

*Answer.* Invitations to Working Group members have been made. The following publishers have accepted and will be participating in the Working Group: Jeffrey M. Drazen, M.D., Editor-in-Chief, New England Journal of Medicine; Brian Nairn, Chief Executive Officer, Health Sciences; Elsevier Mark E. Sobel, M.D., Ph.D., Exec-

utive Officer, American Society for Investigative Pathology; and Annette Thomas, Ph.D., Managing Director, Nature Publishing Group

#### SPINAL MUSCULAR ATROPHY

*Question.* It is my understanding that the new Spinal Muscular Atrophy “model” for preclinical research and development for candidate therapeutics is in place. Please outline the applicability of this model to Muscular Dystrophy.

*Answer.* The SMA Project, which is now underway, represents a new and as yet untested approach for developing therapies for diseases that meet certain criteria essential to a highly targeted therapy development strategy. SMA is a consequence of inherited mutations in the SMN1 gene. The SMN2 gene product has a very similar function to that of SMN1; thus, increasing the expression of the intact SMN2 gene was both a rational and plausible mechanism for therapeutic development. Moreover, since research had already identified several chemical structures with the biologic activity of increasing SMN2 protein expression, there was a consensus that development of drugs targeting SMN2 expression represented the best pathway for SMA treatment development. In sum, the key traits in the design of the SMA project were: (a) a consensus pathway to SMA treatment development, such that resources were not diverted away from other, potentially successful, strategies and (b) the availability of lead chemical compounds on which to base drug development. It remains to be seen whether the unique drug development strategy that was selected for the SMA pilot program will be sufficiently effective to warrant its consideration for other neurological disorders.

The important question with respect to MD is not whether the SMA model could be applied to MD in some way, but whether it is the best possible approach to apply the resources available for MD therapy development. There were critical criteria used in the NINDS’s design of the SMA project (consensus on strategy and availability of lead compounds) that do not currently apply to MD. In the area of MD, there are at least five or six potential strategies under active study, any of which may prove to be effective in the treatment of MD. These strategies range from those that have a relative high probability of success in delaying the loss of muscle mass and thereby augmenting quality of life, to those that have a higher risk of short-term failure but in the long run may more dramatically increase both quality and length of life. At this point in time, there is no consensus on any one strategy for emphasis, since the potentially most successful strategy is not nearly as clear as it was for SMA. Instead of choosing to divert resources to any one of a number of plausible strategies in MD therapy development, the NIH is making parallel investments in all of the strategies. As research progresses along these multiple, parallel pathways, their relative potential for therapeutic development and availability of candidate lead compounds likely will change and the NIH would adjust its aggressive pursuit of an MD therapy accordingly. Unless an arbitrary choice was made to exclude potentially successful treatment strategies in order to provide the necessary focus, an SMA-type program is not applicable to MD.

*Question.* The committee understands that the SMA Model statement of work is based upon an NIH Strategic plan developed by a steering committee. How does this separate steering committee reconcile research priorities with the NIH Director’s strategic vision?

*Answer.* The formal statement of work for the Spinal Muscular Atrophy (SMA) Project was developed by the NINDS scientific and contract staff to specify what services the contractor for the SMA Project would provide. The NINDS recruited the scientists and physicians on the SMA Project steering committee from industry, academia, the FDA, and the NIH based on their expertise in drug development and areas relevant to SMA. NINDS scientists serve on this committee in an ex officio capacity. This committee is advisory to NINDS, and the recommendations of the committee are implemented by NINDS in the context of the Director’s strategic vision for NIH, which emphasizes applying innovative approaches to translate basic science progress into the development of therapies.

*Question.* Please outline NIH assessment of the technical and contractual risk associated with the SMA model.

*Answer.* There are two major aspects of risk associated with the SMA Project, neither of which can be meaningfully quantified. First and foremost, the scientific challenges of developing a therapy for a neurogenetic disorder are enormous. Medical science, despite extensive efforts, has had few successes so far in this endeavor for many reasons, not the least of which is the complexity of the nervous system and its diseases. Thus, the goal of developing a therapy within four years to the point that it is ready for human testing is extremely ambitious. This is one of the reasons that the selection criteria for the first disease of focus were necessarily stringent,

and explains why the project must focus on one basic therapeutic strategy in order to move quickly toward the goal. The second aspect of risk concerns the structure of the program itself. The program is intended to expedite therapy development, but several aspects of the project are novel and untested, so whether it will indeed be an efficient and effective use of resources remains to be seen. In effect, the SMA Project must develop de novo a virtual drug company and develop a drug. It has proven challenging to identify contractors who are willing and able to perform services in disease areas that are outside the normal scope of their operations, particularly with such a rapid and restricted time line. Once the contracts are in place, the coordination of the various efforts and the marshalling of the whole toward accomplishment of the goal present considerable organizational, as well as scientific challenges, as evidenced by the high failure rate among even established biotechnology and pharmaceutical companies in this type of endeavor. It is difficult to anticipate what hurdles might arise in such a novel undertaking.

*Question.* The committee understands that the SMA model was chosen because of the state of scientific understanding of this disease. What are the specific metrics and measures of merit for this determination?

*Answer.* The NINDS chose SMA as the focus of the SMA Project because this disease best met the criteria that are critical for success of a narrowly focused approach to therapy development. These criteria include: (1) severity of disease (2) scientific readiness—which includes a defined genetic cause (loss of the SMN1 gene), a consensus strategy for treatment (increasing the SMN2 gene product), and the availability of “lead” chemical compounds. The focus of the SMA Project is a type of translational research that is normally conducted only in industry settings, which is the chemical conversion of an active chemical compound into a drug that is safe enough for human testing. Applying this strategy relies on the availability of “lead” chemical compounds that have a desirable biological activity and have the potential to be chemically improved for human use. Most importantly, previous academic and privately funded efforts had applied this strategy and identified small drug-like molecules with the desired activity, and the SMA Project is optimizing the activity and pharmacology of these molecules to make them suitable for clinical testing.

*Question.* What would be the comparable level of understanding in MD research that would justify an MD model for translational research?

*Answer.* Like SMA, MD is a severe, debilitating disease, and for some of the forms of MD, there are defined causes. However, unlike SMA, there is no consensus strategy for treatment, there is no single biological activity to target for treatment, and there are no “lead” compounds identified as potential therapeutics.

In the case of Duchenne MD, there are several quite different and equally promising approaches to develop therapies. These include strategies to replace the defective gene, to repair that gene, to alter gene splicing, to override premature gene stop codons, to upregulate potentially compensatory genes, to increase the regenerative capacity of muscle by providing various trophic substances or by blocking the effects of growth inhibiting substances, to reduce the rate of muscle degradation by blocking various components of that process, and to replace cells via stem cells or progenitor cells. Unfortunately, none of these approaches have yet yielded the drug-like molecules that could form the basis of a drug development program for MD to the same degree that these are available for SMA, and the goal of identifying promising leads in these approaches to therapy development for MD is better served by a more diverse and competitive approach. The narrow focus of optimization efforts applied in the SMA Project will only be relevant to MD once these leads have been identified.

The NIH is aggressively investing resources in translational research for MD through other mechanisms. These include the Wellstone Muscular Dystrophy Centers, the NINDS Cooperative Program in Translational Research, and investigator initiated research grants. Given finite resources, undertaking an SMA Project for MD at this time would require the NIH to divert funds from these other programs. The broad-based approach that the NIH is currently pursuing is the more appropriate way to advance MD translational research at this time.

#### MUSCULAR DYSTROPHY CENTERS

*Question.* Please outline for the committee how MD centers are promoting translational research from advancements in basic MD research.

*Answer.* Several of the Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers are supporting projects on translational research, which is research designed to take basic research to the stage of clinical testing. For example, investigators at the University of Washington are doing translational research in dystrophic mice that is designed to lead to a phase I clinical trial of gene therapy

for Duchenne MD (DMD). Researchers at the University of Pittsburgh are also exploring methods for improved gene delivery using an adeno-associated virus (AAV) in a canine model of MD. AAV is a viral vector (the “delivery vehicle” for a gene) that has been designed to carry a mini-dystrophin gene to a specific muscle location. If successful, this technique could allow the muscle to become more resistant to injury and restore function. A second translational study at the University of Pittsburgh center is using a dystrophic mouse model to explore the delivery of normal muscle derived stem cells to diseased heart tissue. The newest center at the University of Iowa will study the use of stem cell and novel gene therapy strategies for MD. One project in particular will study the development of mouse embryonic stem cells as therapeutic tools for muscular dystrophy. This center will also emphasize study of muscle membrane repair mechanisms that could lead to an alternative strategy for treatment of MD.

An essential component of the Wellstone Centers program are the research cores at each center, which are developing improved research resources for use by the entire MD research community to accelerate translational research. For example, the core modules at the University of Washington are developing research and clinical grade gene transfer vectors and these vectors will be studied for their utility in gene therapy for the muscular dystrophies. The Wellstone Center at the University of Rochester uses one of its core modules to serve as a repository of resources, including cell lines, animal models, small molecules, and autopsy tissue. Core modules at the University of Pittsburgh support translational and clinical studies in clinical vector production for gene therapy. One of the cores within the new University of Iowa center will develop new in vitro models by inactivating genes that cause the various types of MD in an existing human embryonic stem cell line.

Collaboration and coordination among the Wellstone Centers is another important component of the Centers program, and the Centers are awarded funds to support these collaborative efforts. Currently, the Wellstone Centers are using these funds to support two dog colonies—one at University of Missouri and one at the Fred Hutchinson Cancer Research Center—as a national resource for research in MD, and working to ensure that these colonies are maintained and available for translational research. The dog MD models appear to have a phenotype that is very similar to that of Duchenne MD patients. The dog model is also important for assessing immune problems that may be associated with vectors used for gene therapy; thus, testing in the dog is an important stage after initial work in mouse muscular dystrophy models. These dogs are currently being used by researchers at a number of the Wellstone centers, as well as other researchers in the MD field.

#### MUSCULAR DYSTROPHY

*Question.* Muscular Dystrophy researchers are exploring various avenues for therapeutic solutions, which include small molecule compounds, gene therapy and stem cell research. Please outline for the committee efforts in integrating these research efforts and prioritizing research investment strategies.

*Answer.* NIH-funded researchers are pursuing a number of strategies to develop treatments for the MDs. These encompass drug-based (such as small molecule compounds), gene-based (such as gene therapy) and cell-based (such as stem cells) approaches. For example, several studies are aimed at developing drug-based therapies to protect muscle mass and slow muscle degeneration by blocking various components of the degenerative process. Compounds such as protease inhibitors and glycosylating enzymes are potentially promising in this area. Other studies are pursuing strategies to enhance muscle repair and regeneration mechanisms to slow, and possibly stabilize muscle degeneration by either providing various trophic substances or by blocking the effects of growth inhibiting substances. In addition, NIH-funded researchers are optimizing cell-based muscle replacement strategies, particularly strategies using stem cells or progenitor cells to populate skeletal and cardiac muscles with muscle fibers that express the absent proteins. Scientists are also developing and testing strategies for gene replacement therapy, including both gene or drug therapy strategies to replace the defective gene or increase expression of functionally homologous or compensatory genes. Finally, genetic modification therapies are being studied to bypass inherited mutations, using, for example, drug and antisense oligonucleotide exon skipping strategies.

NIH is taking steps to ensure integration and coordination of these research efforts. For example, coordination of research efforts at the Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers is facilitated by a Steering Committee made up of representatives from the Centers and from the NIH institutes that fund them (NIAMS, NINDS, and NICHD). The steering committee’s goal is to maximize collaborative utilization of the unique resources in infrastructure, exper-

tise, and clinical recruitment created by the Wellstone Centers. This integration is particularly important in the areas of gene therapy and stem-cell based treatment strategies as a number of the Centers have projects and support cores focused on these two areas.

Integration of research efforts and prioritization of strategies is also an important function of the Muscular Dystrophy Coordinating Committee (MDCC). This summer, a scientific working group will meet to develop and prioritize specific research aims based on broad research goals in the Muscular Dystrophy Research and Education Plan developed by the MDCC. Treatment strategies is one of the programmatic areas addressed in Plan and includes approaches such as developing effective gene therapy techniques, optimizing potential cell-based therapies, and pursuing pharmacological treatment approaches. The working group will not only prioritize research strategies, but will also identify additional obstacles and barriers to the progress of MD research and treatment, noting those that are likely to be addressed through ongoing research and programs, and those that might benefit from additional emphasis. At the next meeting of the MDCC (November 2005), the MD Scientific Working Group recommendations will be presented for discussion by MDCC member agencies.

The MDCC also serves as a venue to coordinate research efforts among member agencies and organizations. The November 2005 MDCC meeting will have a specific focus on translational research, examining the relationship of current translational efforts by the NIH, the Department of Defense, the Muscular Dystrophy Association, and Parent Project Muscular Dystrophy. This meeting will identify the translational research strategies that are currently supported by federal agencies and advocacy groups and will reinforce efforts to minimize overlap and maximize utilization of resources available for MD.

*Question.* Please outline for the committee the specific translational research efforts for MD; indicating their relative maturity. What percentage of research is investigator-initiated versus Institute generated?

*Answer.* Translating scientific advances into therapies that can help people with muscular dystrophies is a very high priority for the NIH, and multiple strategies for therapeutic development are currently being pursued. The relative maturity for the most promising of these translational research approaches and some of the NIH-funded research and research initiatives in these areas are described below. These approaches are presented in ascending order of risk and projected development time, starting with the lowest risk and shortest time frame. The risk/development time assessments should be recognized as estimates, and those that are most easily achieved may dramatically improve quality of life for muscular dystrophy patients but are not the cures that may be possible from higher risk/longer time frame approaches.

*Blocking the loss of muscle mass.*—Muscle fiber degeneration and the profound loss of muscle mass is the most visible consequence of MD and is directly responsible for progressive deterioration of muscle function in several types of MD. Strategies to block muscle fiber degeneration have shown promise. For example, several studies have shown that systemic treatment with a protease inhibitor reduces muscle membrane damage and ameliorates muscle degeneration in the mdx mouse model of DMD. Investigators in the NINDS intramural research program are currently pursuing the use of a protease inhibitor as a therapeutic strategy in MD patients.

A project has also been approved for funding through the NINDS's "Cooperative Program in Translational Research" for development of protease inhibitors that may be capable of delaying muscle degeneration in a variety of types of MD.

*Enhancing muscle regeneration mechanisms.*—Muscle has an inherent repair capacity that allows it to overcome damage but this mechanism appears to be overwhelmed in MD. NIH-funded researchers have identified genes that regulate muscle regeneration; these represent potentially important therapeutic targets for MD. One of these genes, GDF8 or myostatin, inhibits muscle development and regeneration. Myostatin inhibition studies using molecular genetics or a specific blocking antibody suggest that the strategy can increase muscle mass in several types of MD. The very recent development of a strategy using an endogenous myostatin inhibitor may hold promise. Alternatively, growth factors that promote muscle growth and regeneration also have shown promise as a therapeutic strategy.

*Replacing degenerating muscle with new muscle derived from stem cells.*—Muscle and other tissues contain stem cells that can be directed to form muscle fibers. There has been considerable progress in isolating and expanding stem cells, directing their fate, targeting them to dystrophic muscle, and using imaging technology to monitor the efficacy of stem cell transplantation. Overcoming the host immune

response is one of the significant obstacles to the success of cell-based therapy in MD.

A project at the Wellstone Center at the University of Pittsburgh is focused on delivery of stem cells to diseased muscle, while the Center at the University of Iowa will use one of its cores as a stem cell resource for the MD community. In addition, a project funded as a result of an NIH program announcement entitled, "Muscular Dystrophy: Pathogenesis and Therapies," as well as other NIH-supported studies, are exploring how to coax stem cells to become skeletal muscle cells with the ultimate goal of transplanting these differentiated cells.

*Gene therapy.*—Gene targeting to replace a defective gene must overcome the problems of accessing the muscle tissues and avoiding an immune response to the delivery system. In addition, the large size of the dystrophin gene—in the case of Duchenne MD—has necessitated the development of novel vectors and mini-dystrophin and micro-dystrophin constructs. NIH-supported research has made considerable progress in these areas. Dystrophin constructs that are capable both of restoring muscle function and of being contained in the AAV vectors have been generated and tested in animal models. An additional obstacle in gene therapy is delivering the gene construct to sufficient numbers of muscle fibers such that muscle function is improved. Delivery systems are currently being tested for achieving the goal of treating MD patients.

A number of projects at the Wellstone Centers are pursuing gene therapy strategies, and the research cores at two of the Centers are developing tools for use in gene therapy studies, as outlined earlier. The NINDS Cooperative Program in Translational Research also recently funded a major project that brings together a team of basic and clinical scientists to carry out the steps necessary to bring gene therapy for Duchenne MD to readiness for clinical trials. In addition, the program announcement, "Muscular Dystrophy: Pathogenesis and Therapies," has resulted in a number of funded projects focused on developing novel or modified vectors, using mini-dystrophin constructs, and studying ways to effectively deliver the genes to muscle.

*Genetic strategies to bypass the mutations that cause MD.*—Other approaches to correct a defective gene besides gene replacement are also being pursued. For example, antisense oligonucleotide (AO) technology may be used to skip, or splice out, those portions of the gene containing mutations and then produce a shortened, but still functional protein. Through research in cell culture and in animal models, AO administration has been shown to enhance expression of normal dystrophin protein. Studies supported by the NIH have made critical breakthroughs in AO technology and in demonstrating proof of principle in cell culture. While this technology is very promising, the delivery of AOs is subject to the many of the same obstacles as in the gene therapy studies described above. Other approaches include the use of drugs to produce "read-through" past the gene defect. An NINDS-supported clinical trial for gentamicin-mediated read-through in DMD patients is underway.

Both of these approaches—AO therapy and identification of compounds to promote read through—are being pursued in studies funded as a result of the program announcement, "Muscular Dystrophy: Pathogenesis and Therapies."

It is difficult to estimate the percentage of MD translational research that is investigator-initiated versus institute generated, although the NIH MD portfolio contains a significant amount of both types. Investigators may submit a grant to the NIH as part of the regular submission process, or in response to a particular Institute-generated initiative. The NIH Institutes, with considerable input from the research community, have been working to develop initiatives and programs to stimulate translational research in the MDs. For example, in April 2005, NIAMS announced a request for applications for Centers of Research Translation. Furthermore, NIH is currently developing a translational research initiative specific to MD, which will stress the milestone-driven approach to research and will include substantial project development and grant management interactions with NIH program staff.

*Question.* Accelerated review of research proposals remains a concern for patient advocacy groups and the committee. Please outline for the committee all efforts NIH has undertaken with the Center for Scientific Review to expedite review decisions. Please provide supporting data regarding the length of time from RFP to award on MD related research.

*Answer.* NIH's peer review process is widely recognized as the cornerstone of the remarkable success of the NIH extramural program. The NIH Center for Scientific Review (CSR) receives all grant applications submitted to NIH (approximately 75,000 per year), logs them in, refers these applications to a peer review panel to be evaluated on technical and scientific merit, and identifies a potential funding source at NIH. The majority of applications that come to NIH are reviewed by CSR,

while the remaining ones are reviewed by specific institutes, in particular those that are received in response to a specific solicitation.

Currently, the interval between NIH receiving an application and the application being considered for funding is typically 6–7 months. For example, in the case of the Senator Paul D. Wellstone MD Cooperative Research Centers, applications in response to the first Request for Applications (RFA) were received in February 2003, and awards were made in September 2003. NIH and CSR are considering ways to reduce this interval. However, it is essential that efforts to speed the process do not compromise the core values of NIH peer review system—a thorough and fair review of the application by a review panel with the appropriate scientific and technical expertise. One approach to accelerate the review cycle is the electronic receipt of applications. NIH is now accepting several types of grant applications electronically and will continue to introduce electronic receipt of other application types. When electronic receipt of grant applications is fully implemented at NIH, the system should offer considerable time savings because data, which in the past have been manually entered, will be automatically captured as soon as applications are submitted. In addition, it may be possible to automatically analyze some of the data initially captured during electronic receipt and streamline the referral process, thereby offering additional time savings.

Expediting review of grant applications while maintaining review quality is a high priority for NIH. To underscore this, Dr. Zerhouni has recently created a new NIH Peer Review Advisory Committee to provide guidance on developing ways to advance NIH peer review and ensure its vitality. In addition, in March 2005, Dr. Zerhouni named a new CSR Director, Dr. Antonio Scarpa. When Dr. Scarpa begins work on July 1, 2005, he is expected to place a high priority on the goal of compressing the peer review cycle.

#### PEER REVIEW ON MUSCULAR DYSTROPHY

*Question.* Continuity in Peer Review for Muscular Dystrophy research remains a concern. Please outline for the committee all efforts to ensure peer reviewers' areas of expertise encompass the full body of muscular research.

*Answer.* The peer review of the majority of applications received by NIH is conducted at the Center for Scientific Review (CSR). In response to concerns expressed by the MD community, a working group of the Center for Scientific Review (CSR) Advisory Committee met in March 2001 to evaluate the review of skeletal muscle biology research applications. The Skeletal Muscle Biology Working Group was composed of 17 leading scientists in the field and several NIH staff. A particular concern of the working group was the locus of review for muscular dystrophy applications. Ultimately, the working group recommended the formation of a Skeletal Muscle Biology Special Emphasis Panel (SMB SEP). Nearly all muscular dystrophy related research applications reviewed by CSR were to be reviewed in this committee. The SMB SEP met for the first time in October 2001.

The Skeletal Muscle Biology Working Group offered this recommendation as an interim solution pending recommendations to be made by the larger Musculoskeletal, Oral and Skin Sciences (MOSS) Study Section Boundaries Team (also a working group of the CSR Advisory Committee) that was scheduled to meet in July 2001 as part of a CSR-wide reorganization process. The MOSS Team meeting in July 2001 drew heavily on and expanded the recommendations of the Skeletal Muscle Biology Working Group. The MOSS Team recommended elevating the status of the review group from a special emphasis panel to a permanent regular study section. This recommendation was accepted by the CSR Advisory Committee, and a new regular study section named Skeletal Muscle Biology and Exercise Physiology (SMEP) was implemented. The last meeting of the SMB SEP was in June 2003 and the first meeting of the SMEP study section, its successor, was in October 2003. The SMEP study section is now the primary locus of review for muscular dystrophy related research applications at CSR.

The range of science in the applications reviewed by SMEP is extremely broad, spanning fundamental molecular biology to therapeutic interventions. To match this breadth, the committee is composed of a number of individuals with the expertise necessary to cover these varied topics. Eleven of the regular members assigned to review these applications are noted investigators who themselves conduct muscular dystrophy related research. As members rotate off the committee they are replaced by individuals with a similar background—five new members have been nominated for the coming year. In addition, to supplement this broad expertise, the committee has used twelve temporary members who also are involved in conducting muscular dystrophy related research.

As stated above, the majority of applications received by NIH are reviewed by CSR. In contrast, applications that respond to specific initiatives are reviewed by individual NIH Institutes. Like CSR, the Institutes are also committed to ensuring that individuals with the appropriate expertise review applications, and continuously work to identify and invite scientists with specific knowledge and appropriate background to participate in the review of applications.

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QUESTIONS SUBMITTED BY SENATOR JUDD GREGG

UMBILICAL CORD BLOOD STEM CELLS

*Question.* Given that Umbilical Cord Blood Stem Cells are already being used to treat over 70 life threatening diseases, should the National Institutes of Health take steps to educate the public, and if so, how should education take place?

*Answer.* The NIH scientists address questions from representatives of the news media and the public who directly contact the NIH. In addition, NIH scientists speak at conferences that are convened by professional and public interest organizations and they provide advice to the Health Resources and Services Administration in the development of a national cord blood bank program. Future directions for public education would involve convening a strategy development workshop of researchers and relevant stakeholder groups to determine what is currently being done to address education issues, identify major education gaps, and recommend and prioritize specific education outreach activities and areas requiring further research.

In addition to these efforts, the NIH maintains a stem cell information website at <http://stemcells.nih.gov>. The NIH Stem Cell website is frequently visited by individuals seeking information on stem cell research, including cord blood stem cells. For example, the website has an NIH report entitled "Stem Cells: Scientific Progress and Future Research Directions." This report has a chapter (<http://stemcells.nih.gov/info/scireport/chapter5.asp>) on hematopoietic (blood-forming) stem cells, including stem cells from the umbilical cord. Several stem cell literature databases that include cord blood stem cell research studies can also be found on the NIH website at <http://stemcells.nih.gov/research/literature.asp>. There are also links to several organizations, including the National Marrow Donor Program® and the International Cord Blood Society, that have informational sites on cord blood stem cells. The website also contains a "Frequently Asked Questions" section (<http://stemcells.nih.gov/info/faqs.asp#umbilical>) with information on "Where can I donate umbilical cord stem cells?" Overall, the NIH Stem Cell website provides useful scientific information to the public about stem cell science.

*Question.* What research is currently being done regarding the use of Umbilical Cord Blood Stem Cells to treat disease?

*Answer.* The NIH currently funds clinical research to evaluate the safety and effectiveness of matched sibling cord blood transplantation in children with sickle cell anemia and thalassemia (Cooley's anemia). The first multi-center, unrelated-donor cord blood banking and transplantation study (COBLT), which was funded by the NIH, was recently completed. The COBLT study evaluated the safety and effectiveness of cord blood transplantation in adult and pediatric patients with hematologic malignancies as well as pediatric patients with inborn errors of metabolism and immune deficiencies. Its results were shared with the Institute of Medicine for a recent report on Cord Blood: Establishing a National Hematopoietic Stem Cell Bank Program. Publication of the COBLT study results is in progress.

A major obstacle to cord blood transplantation in adult recipients is the limited hematopoietic stem cell dose available in a single cord blood unit. The NIH currently funds research exploring alternative approaches to optimize transplant outcome. These approaches include the transplantation of two partially matched cord blood units from different cord blood donors, use of a less toxic (non-myeloablative) conditioning regimen prior to cord blood transplantation, and expansion of cord blood stem cells in culture and their use in conjunction with non-expanded cord blood for transplantation in patients with hematologic malignant diseases. These studies are in the early phase of clinical investigation. In addition, the NIH funds the Center for International Blood and Marrow Transplant Research, which conducts registry studies to evaluate the clinical outcomes of cord blood transplantation.

The NIH also funds a variety of basic and pre-clinical research projects to examine the properties of cord blood stem cells, including the immune responses of cord blood cells during and after transplantation, the growth properties of cord blood stem cells, and conditions to improve the outcome of cord blood transplantation.



## QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

## POLYCYSTIC KIDNEY DISEASE (PKD)

*Question.* In testimony before Congress last year, Dr. Allen Spiegel said the NIDDK is committed to moving the PKD research agenda forward toward the goal of developing more effective diagnosis, treatment and prevention of the disease. Considering that the prime cause of death for PKD patients is chronic cardiovascular disease, PKD patients suffer greatly from psychosocial problems like depression, anxiety and suicide due to PKD's chronic nature, and the recessive form of PKD has such a high rate of morbidity and mortality in neonates and infants, to what extent is NIH considering "inter-institutional" research involving the NIDDK, NHLBI, NICHD, and the NIMH as a means to uncover potential interventional methods which could address these significant co-morbidities?

*Answer.* The NIH has two major avenues for pursuing collaborative research opportunities and initiatives on the co-morbidities of PKD and other chronic kidney diseases. The first avenue is the statutory Kidney, Urologic, and Hematologic Diseases Interagency Coordinating Committee (KUHICC). This Committee, which is chaired by the National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK), encourages cooperation, communication, and collaboration among all relevant Federal agencies. Meetings of the Kidney Diseases Subcommittee provide an important opportunity for the NIH Institutes and Centers to initiate collaborations on shared interests in kidney disease.

The second avenue is through the activities of the NIDDK, the lead NIH Institute for research on chronic kidney diseases, including PKD. In this capacity, the NIDDK has spearheaded collaborative efforts to address many of the comorbidities experienced by PKD and other chronic kidney disease patients. Let me provide a few examples. In 2001, the NIDDK collaborated with the National Institute of Mental Health (NIMH) and the NIH Office of Behavioral and Social Sciences Research (OBSSR) in holding a major conference to determine the state of knowledge with regard to the co-morbid condition of depression in patients with diabetes, kidney disease, and obesity/eating disorders, and to propose a research agenda for the future. A major new collaborative study being led by NIDDK, with participation of the National Institute for Child Health and Human Development (NICHD), the National Heart, Lung, and Blood Institute (NHLBI) and the National Institute of Neurological Disorders and Stroke (NINDS), is the Pediatric Chronic Renal Insufficiency Cohort Study ("CKIDS"). This important new undertaking will address the impact of chronic kidney disease on cardiovascular morbidity as well as neurocognitive development and emotional health; it will include children with both the recessive and dominant forms of PKD. The NHLBI convened a working group, "Cardio-Renal Connections in Heart Failure and Cardiovascular Disease," on August 20, 2004 to further understanding of the interaction of the heart and the kidney in cardiovascular disease. The NHLBI is also a cosponsor of a planned NIDDK program announcement (PA), "Pilot and Feasibility Program Related to the Kidney," to foster the development of high-risk pilot and feasibility research; it is anticipated that this PA will be issued in 2005. An initiative on chronic illness self-management in children is currently supported by NIDDK, NHLBI, NICHD, and the National Institute on Nursing Research. Finally, through a working group they created to address the relationship between hypertension and kidney disease, the NIDDK and NHLBI are working collaboratively to design new initiatives in this area. All of these collaborative activities complement the NIDDK's continuing efforts to address comorbidities of chronic kidney disease. Examples of these efforts include the Chronic Renal Insufficiency Cohort (CRIC) study, which is examining the relationship between cardiovascular disease and chronic kidney disease in adults, in order to try to find opportunities to prevent and better treat both, and the Folic Acid for Vascular Outcome Reduction in Transplantation (FAVORIT) trial, which is testing whether treatment to lower total homocysteine levels using a high-dose combination of folic acid, vitamin B12, and vitamin B6 will reduce cardiovascular damage in kidney transplant recipients. Both of these large studies include substantial numbers of patients with PKD.

## PUBLIC ACCESS

Dr. Zerhouni, I commend you for instituting a new policy that will increase public access to NIH-funded research. I'm hopeful that this policy will help speed the pace of scientific progress and give patients and taxpayers better access to research that they are, after all, paying for.

*Question.* There's still some question, though, about how many researchers will voluntarily submit their papers to PubMed Central, and how much of an embargo

time they'll require between the publication of a paper in a scientific journal and when the paper will be posted for public access. Have you considered, as a way of leading by example, requiring your own intramural researchers to deposit their final papers in PubMed Central and make those papers accessible immediately at the time of publication?

*Answer.* We have provided NIH staff training about the Policy and intramural research managers are now actively encouraging authors to submit manuscripts and designate public release as soon as possible. The Policy-related submissions will directly benefit NIH-supported investigators because recent studies have shown that freely available articles get cited more in other research publications. An increase in the number of citations helps improve the professional standing of investigators. Due to these benefits we anticipate that intramural authors will choose the earliest release dates.

I also believe that the voluntary nature of the final policy permits sufficient flexibility to accommodate the needs of different stakeholders and leaves the ultimate decision in the hands of scientific investigators who are in the best position to judge the circumstances and the time frame under which their work may be made accessible to the public at large. This flexibility allows authors to delay posting of manuscripts if there are concerns about the policy's adverse impact on their area of research. Therefore, we believe that by having a Policy that provides maximum flexibility, authors will respond with maximum participation.

*Question.* I'm also concerned that the policy could place researchers in a difficult position. It's up to researchers to negotiate with publishers to get permission to post the articles in the NIH database. Since participation is voluntary, publishers might pressure researchers not to release their work at all, or to wait a full 12 months. Do you share this concern? How will you know if this pressure is taking place?

*Answer.* We will be gathering statistics on grantee participation rates and their specified embargo periods. An NIH Public Access Working Group of the NLM Board of Regents has been established and includes representatives of various stakeholder groups that will advise the NLM Board of Regents on implementation and assess progress in meeting the goals of the NIH Public Access Policy. The above statistics will be presented to this Working Group and, if it appears necessary, the Working Group may suggest modifications of the policy to ensure that the public archive is sufficiently timely and comprehensive.

*Question.* Finally, could you provide this subcommittee with a report, as soon as possible after December 1, 2005, on how many eligible articles were deposited in PubMed Central during the first six months of the policy and what the average embargo period was. Additionally, we would like to know how many articles are in the pipeline awaiting posting. Lastly, do you have any way of tracking through PubMed the number of articles supported with NIH funds but not submitted to PubMed Central? In other words, will you be able to provide both the numerator and the denominator of the equation that will demonstrate success of your policy?

*Answer.* We estimated that the results of NIH-supported research were published in approximately 60,000 to 65,000 articles based on the number of articles published in the last several years that contained an NIH grant number within the text. We will estimate participation by comparing the actual number of papers deposited in the NIH Manuscript Submission (NIHMS) system for a given interval with the historical average. For example, 5,000 deposited articles per month would indicate approximately 100 percent participation. By the close of the calendar year sufficient data should be available to make an assessment of the degree of participation. Statistics for the distribution of the embargo periods requested by authors will be readily available from the submission system.

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QUESTIONS SUBMITTED BY SENATOR DANIEL K. INOUE

CANCER COUNCIL OF THE PACIFIC ISLANDS

*Question.* The Cancer Center in Hawaii continues to provide vital research that will benefit Native Hawaiians, Pacific Islanders, and the world community. Last year, the Senate requested that a task force review the continuing and unique needs of Native Hawaiians and Pacific Islanders, specifically as those findings relate to the higher incidence of some types of cancers in these populations. Please provide an update from the Director's task force on your findings.

*Answer.* As recommended by the work of National Cancer Institute's (NCI) task force in the Pacific Rim, NCI has created the Cancer Council of the Pacific Islands (CCPI), a community-and region-based council comprised of representatives of the professional native physicians and other health professionals representing the six

U.S.-associated jurisdictions of the Pacific to address the cancer health needs within each of these jurisdictions. NCI has supported the development of this task force and conducted needs assessments in all jurisdictions, and continues to support capacity building and to address high priority cancer needs in these communities. The CCPI provides a community-based forum through which all federal agencies conducting programs in these jurisdictions coordinate efforts.

The accomplishments of the Cancer Council of the Pacific Islands are substantial. These accomplishments are also significant in that, for the first time, Island leaders are provided a controlling voice in the design, development, and implementation of their own survey instrument and subsequent activities. With the assistance of selected professors and students from the University of Hawaii, a comprehensive cancer assessment was administered in Kosarae, Chuuk, Pohnpei, Yap, Belau, Marshall Islands (Ebeye, Majuro), Northern Mariannas, American Samoa, and Guam. We are now implementing the prioritized listings of health needs identified as a result of those assessments.

NCI recently awarded a 5-year Community Networks Cooperative Agreement to the Lyndon Baines Johnson Tropical Medical Center in American Samoa to directly address cancer disparities, train minority investigators, reduce access barriers, and provide research infrastructure to link American Samoa to NCI research—Cancer Information Service (NCI's cancer information helpline), innovated screening, and diagnostic technologies and clinical trials, in particular.

Recently, the CCPI met with NCI, the Health Resources and Services Administration, the Centers for Disease Control and Prevention (CDC), and other federal partners, as well as C-Change (a coalition of the nation's key cancer researchers and policymakers), to work on developing Comprehensive Cancer Plans for each jurisdiction, and a regional plan for the Pacific Rim. NCI is providing technical assistance and administrative support to augment CDC's efforts in developing these plans. Once these plans are developed, each jurisdiction and the CCPI will be able to apply for CDC implementation funds. NCI is committed to this community-based effort in the Pacific Rim and continues to develop collaborative programs for the CCPI with federal agencies who can improve the health and well-being of the Pacific Island communities.

#### CANCER AND ETHNICITY

*Question.* Additionally, I chaired hearings in Honolulu during which data was presented showing striking differences in the incidents of cancer among various ethnic groups. I am told the FDA now encourages clinical testing for new drugs in a variety of ethnic groups because the drugs themselves have a different effect on each group. Has NIH or NCI been pursuing additional research on the genetic or cultural causes of cancer and the efficacy of treatment by different ethnic groups?

*Answer.* Two years ago, the National Cancer Institute (NCI) launched the Breast and Prostate Cancer and Hormone-related Gene Variants Cohort Consortium (BPC3 Study) to pool data and biospecimens from 6 large cohorts to conduct research on gene-environment interactions in cancer etiology. One of these cohorts, the Multi-ethnic Cohort (MEC) Study, is evaluating the genetic and biochemical determinants of cancer risk in traditionally understudied minority populations and consists of 215,251 men and women (ages 45–75 years at baseline) from Hawaii (Asians, Whites, and Native Hawaiians) and California (African-Americans and Latinos). NCI has begun a Minority Accrual Initiative, whose goals include increasing the number of minority investigators and minority patients in cancer research. The University of Hawaii received funding to foster minority accrual to clinical trials through this initiative. Historically, the University of Hawaii and its affiliated hospitals have accrued large numbers of minority patients, both Asian-Americans and Native Hawaiians, to prevention and treatment trials.

NCI has also encouraged collaborations between sites with relatively non-diverse populations (e.g., Rochester, Minnesota) and sites with large minority populations (e.g., Wayne State, Howard University) to increase minority accrual to early clinical trials where substantial data regarding variations in drug disposition can be acquired. Drug disposition data from all NCI's Cancer Therapy Evaluation Program trials is evaluated to determine whether any differences are evident for these sub-categories of patients. In addition, Phase 3 clinical trials are analyzed for differences in outcome according to race and age among other factors and have resulted in publications in these areas and new research approaches to eliminate disparities. The bioinformatics infrastructure that supports these clinical trials will facilitate even greater data sharing across trials and more robust comparisons and data analysis in the future.

In a public-private partnership, NCI has funded seven sites to explore approaches to improve accrual of minority and older patients to early clinical trials. In addition, for large clinical trials groups that accrue approximately 25,000 patients per year to NCI sponsored clinical trials, there are a number of specially funded programs that focus on increasing the accrual and evaluation of under-represented racial, ethnic, and demographic groups (elderly and rural) to clinical trials. These include supplements to specific programs in the NCI Clinical Cooperative Groups and the long-standing Minority-Based Cancer and Community Oncology Program. There is also a large program funded in collaboration with the National Institute of General Medical Sciences that supports a Pharmacogenetics Network. This Network evaluates pharmacogenomics in drug development which includes the study of the impact of race/ethnicity on drug efficacy.

*Question.* How satisfied are you with the amount and quality of research done in this area?

*Answer.* Preliminary findings from the Hawaii Tumor Registry show that foreign-born Asians, when compared to U.S.-born Asians and Caucasians, have a lower percentage of cancer diagnosed at an early stage, a higher percentage of cancer diagnosed at a late stage, and lower rates of cancer survival. In an effort to overcome these disparities, we have strengthened NCI community-based programs in Hawaii including the Community Network Program, Imi Hale Native Hawaiian Cancer Network, the American Samoa Community Cancer Network at the Lyndon B. Johnson Tropical Medical Center in American Samoa, and strengthening support for the Cancer Research Center of Hawaii, a NCI-designated cancer research center whose mission is to bring together researchers who focus on understanding the etiology of cancer and on reducing its impact on the people of Hawaii.

NCI expects to continue to expand research in cancer health disparities to increase our understanding of why some populations experience greater incidence, mortality, and lower survival from cancer than the majority of Americans. In the NCI report, Making Cancer Health Disparities History, published in March 2004, a Trans-HHS Cancer Health Disparities Progress Review Group (PRG) comprised of leading cancer experts, researchers, patients, cancer survivors, and advocates in cancer and health disparities reviewed the status of cancer health disparities in the United States and forged a set of 14 priority recommendations for Department of Health and Human Services (HHS) to lead the Nation in eliminating cancer health disparities. On March 28, 2005, the HHS Health Disparities Council established a Subcommittee on Cancer with NCI as its chair. The subcommittee will focus on six of the PRG's 14 recommendations that will address needs ranging from the planning and coordination of program efforts to discovery, development, and delivery of research advances to all Americans.

Communities, caregivers, and researchers must form strong alliances and explore creative solutions for developing culturally competent venues for service delivery. Community-based participation must be an integral part of the planning, development, and implementation of solutions to bring research advances to all populations. This cross fertilization will build synergism and ensure stronger, more dynamic alliances for overcoming cancer health disparities.

#### BEHAVIORAL RESEARCH

*Question.* Since 1999, the Committee's report has urged the National Institute of General Medical Sciences (NIGMS) to fund basic behavioral research. The legislative mandate for NIGMS specifically includes behavioral science research, yet I am not satisfied basic behavioral research has been adequately or even minimally addressed. I understand a working group was established as part of the NIH Advisory Committee to the Director on Research Opportunities in the Basic Behavioral and Social Sciences. I feel we have been extremely patient and sufficient time has elapsed to review this issue. Please provide a report to the Committee outlining the recommendations of the working group and your timeline for implementation.

*Answer.* In keeping with the preferred approach of performing portfolio analysis across NIH rather than on an institute-by-institute basis, a working group of the Advisory Committee to the Director, NIH, was formed to examine basic behavioral research across NIH. The working group reported to the Advisory Committee on December 2, 2004. Their analysis revealed that the institutes and centers (including NIGMS) supported approximately \$2.68 billion in behavioral research, including approximately \$936 million in basic behavioral research, in fiscal year 2003. In addition to this base, several components of the NIH Roadmap for Medical Research are directed toward basic behavioral research. In particular, several mechanisms are being used to stimulate interdisciplinary research at the interface of the behavioral/social and biological sciences, provide the interdisciplinary training necessary for

postdoctoral investigators to work in these areas, and support development of innovative methods and technology that will facilitate research at the intersection of the behavioral, social and biomedical sciences.

Following the submission of the working group report, NIGMS has taken several steps to more clearly articulate the basic behavioral research it supports, encourage the submission of more research applications in these areas, and increase the number of investigators who can work at the interface of the behavioral and biological sciences:

*Research Training at the Interface of the Behavioral and Biological Sciences.*—Basic behavioral research is of critical importance to the mission of the NIH and can play a crucial role in understanding the etiology of disease and enhancing preventive and therapeutic inventions. Greater understanding of the molecular, genetic, and neural processes governing behavior, and the reciprocal effects of behaviors on physiological processes, is crucial for a complete understanding of human health and those diseases in which behavior is a risk factor, diagnostic indicator, or symptom. To advance our knowledge in these areas, researchers will need to integrate multiple disciplinary perspectives, methodologies, and levels of analysis. NIGMS has a strong background in developing and supporting such interdisciplinary research training. While some existing NIGMS training programs such as the Medical Scientist Training Program and the Systems and Integrative Biology program include elements of the behavioral sciences, there has not been a program dedicated to training at the basic behavioral science-biological science interface. NIGMS has developed a proposal for such a predoctoral program and is coordinating its further development with other NIH Institutes having an interest in this area.

*Collaborative Research on Basic Mechanisms of Behavior.*—To encourage the multidisciplinary research that is needed for a fuller understanding of the basic mechanisms of behavior, NIGMS has proposed an initiative to facilitate collaborations between basic behavioral scientists and investigators with expertise in state-of-the-art genetics, molecular biology, and genomics. It is anticipated that this collaborative research, performed with model organisms, will either enhance existing models or lead to the development of new models of normal or abnormal human behavior. The concept for this solicitation is to be presented for approval at the May 2005 meeting of the National Advisory General Medical Sciences Council.

*Assessing Interactions Among Social, Behavioral, and Genetic Factors in Health.*—NIGMS is a major contributor to an Institute of Medicine committee examining the state of the science on gene-environment interactions that affect human health. The study will identify approaches and strategies to strengthen the integration of social, behavioral, and genetic research in this field as well as consider relevant training and infrastructure needs. The results of this study will be used by the NIH to guide its programs in these areas.

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#### QUESTIONS SUBMITTED BY SENATOR HARRY REID

##### CHRONIC FATIGUE SYNDROME

*Question.* Funding for research on chronic fatigue syndrome (CFS) has fallen to less than \$5 million per year, at the same time national prevalence estimates for this serious condition have risen to nearly one million American adults and adolescents. In June 2003, Dr. Vivian Pinn announced plans to issue a Request for Applications (RFA) for research on CFS following an NIH workshop on neuro-immune mechanisms in CFS. Almost two years later this RFA has not been issued. What are NIH's immediate plans to stimulate research into CFS, a condition that CDC reports costs the U.S. economy \$9.1 billion a year in lost productivity?

*Answer.* Funding levels for CFS have remained at approximately \$5–\$6 million a year without a significant decline in dollars in years. NIH continues to encourage an increase in the number of CFS research proposals that are submitted for review and funding each year. Applications to PA-02-034, The Pathophysiology and Treatment of Chronic Fatigue Syndrome, based on recommendations from an October 2000 symposium, tripled from its release in December 2001 through fiscal year 2004. This PA was revised and reissued under the same title as PA-05-030 in December 2004 to include research ideas from the June 2003 scientific workshop, Neuroimmune Mechanisms and Chronic Fatigue Syndrome: Will Understanding Central Mechanisms Enhance the Search for the Causes, Consequences, and Treatment of CFS? This program announcement specifically invites the submission of investigator-initiated grant applications to support research on the epidemiology, diagnosis, pathophysiology, and treatment of CFS in diverse groups and across the life span. Applications that address gaps in the understanding of the environmental and

biological risk factors, the determinants of heterogeneity among patient populations, and the common mediators influencing multiple body systems that are affected in CFS are encouraged.

The proceedings of this June 2003 workshop were recently published (NIH Publication No. 04-5497) and posted on the ORWH/CFS website (<http://www4.od.nih.gov/orwh/cfs-newhome.html>). Seven new projects related to CFS were funded in fiscal year 2004 and address topics raised at this workshop. One of these is an intramural project which reflects the impact of a new Trans-NIH Intramural Interest Group on Scientific Integrative Medicine that resulted from the June 2003 CFS Workshop. Also based on this workshop, the ORWH and the Trans-NIH Working Group for Research on Chronic Fatigue Syndrome will be issuing a new interdisciplinary Request for Applications (RFA) later in fiscal year 2005. This new RFA on CFS has progressed through the usual steps following the workshop when the intent was announced. In addition, NIH continues to plan relevant scientific activities and efforts on which to base future CFS research initiatives.

*Question.* Last fall, an analysis of NIH funding for chronic fatigue syndrome (CFS) was presented to the DHHS CFS Advisory Committee by the CFIDS Association of America. This report documented that NIH had overstated its funding of CFS research for fiscal year 1999-fiscal year 2003 by 19.6 percent through the inclusion of studies unrelated to CFS. Total funding of CFS research for this five-year period is just \$26 million—a very small amount given magnitude of the condition and the generous increases Congress provided to NIH during these same years. What efforts are being taken to ensure that spending figures issued by NIH are accurate and reliable and what is NIH doing to expand support of research on CFS?

*Answer.* The funding figures provided by the NIH on expenditures related to CFS are based upon the best scientific and budgetary deliberations and are consistent and accurate. As with all scientific and budgetary data collections, these funding figures reflect projects designated as CFS research by Institute and Center (IC) staff, each utilizing his/her best scientific judgment. These figures include funding for basic and laboratory studies that are pivotal in the development of clinical and translational research; although such studies may not seem specific for CFS, they deal with the basic biologic processes that are fundamental to developing a better understanding of CFS and are thus integral to CFS research. The NIH continues to implement efforts to increase CFS research through an increase in funded proposals.

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#### QUESTIONS SUBMITTED BY SENATOR HERB KOHL

##### EPILEPSY RESEARCH

*Question.* As you know, epilepsy is a major public health problem, affecting 2.5 million Americans throughout their life spans. The impact of epilepsy—ranging from debilitating side-effects of treatment to brain damage and even death—has long been under-recognized. Epilepsy is a public health problem of major proportions.

Because epilepsy may occur at any age and as a result of many different, poorly understood and complicated causes, Congress has encouraged the NIH to focus on this problem with a multi-disciplinary approach involving efforts by the NIMH, NIA, NICHD and NHGRI in coordination with the lead institute, NINDS.

Epilepsy is the perfect model for a disease that will succumb to a coordinated, multi-disciplinary research effort such as you outlined in “The NIH Neuroscience Blueprint”. A few of the above-mentioned Institutes have begun to address epilepsy, but coordination and communication between them is a necessity if this multi-disciplinary approach is to prove fruitful.

It seems critically important to establish a working group to coordinate research efforts, clinical trials and learn from the co-morbidities which are so common in patients with epilepsy. Dr. Zerhouni, how do you intend to facilitate the coordination which needs to exist between these research efforts in order to reduce the burden of this all-too-common neurological disorder?

*Answer.* The National Institute of Neurological Disorders and Stroke (NINDS) is the lead NIH Institute for epilepsy research and the primary funding source for studies of seizure disorders. Several other NIH Institutes and Centers also fund epilepsy related projects, including the National Institute of Child Health and Human Development (NICHD), the National Human Genome Research Institute (NHGRI), the National Institute of Mental Health (NIMH), and the National Institute on Aging (NIA). In order to better facilitate coordination of research efforts in this area, these Institutes formed an Interagency Epilepsy Working Group. Since its establishment in January 2003, several other NIH Institutes with an interest in epilepsy re-

search have joined, including the National Institute of Biomedical Imaging and Bioengineering (NIBIB), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the NIH John E. Fogarty International Center (FIC), as well as a representative from the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention (CDC).

The members of the Interagency Epilepsy Working Group are primarily extramural program staff who administer epilepsy research grants and develop program activities to facilitate research efforts. The purpose of this group is to increase communication among institutes and agencies supporting epilepsy related research and to explore opportunities for increased coordination. An example of these cooperative activities is a recent workshop sponsored by the NINDS and the NIMH on the treatment of non-epileptic seizures, held on May 1–3, 2005. The goals of the workshop were to better define diagnostic criteria for non-epileptic seizures, develop outcome measures for clinical trials, and to discuss a research strategy for this condition.

The Interagency Epilepsy Working Group meets on a regular basis, most recently in October 2004 and April 2005. The April Working Group meeting focused on the development of biomarkers for epilepsy related research. Working Group members presented examples of relevant Institute activities which could be adapted to epilepsy and discussed possible approaches to planning a workshop in this important area of research. In addition, members of the Working Group participated in the most recent meeting of the Epilepsy Benchmark Stewards in February 2005. The Epilepsy Benchmarks are milestones developed by the epilepsy community in 2001 to measure progress in epilepsy research, and Stewards have been designated to monitor progress toward meeting each Benchmark goal. The purpose of the February meeting was to review Benchmark progress and to begin planning a large epilepsy conference for 2007 to assess and update the Epilepsy Benchmarks. Working Group members will continue to be involved as conference planning progresses.

#### K30 GRANT AWARDS

*Question.* As you know, the K30 grant program supports the training of clinical researchers—health professionals who translate laboratory discoveries to improvements in the care of patients. It is my understanding that this year, funding was insufficient to accommodate a decision to increase the size of awards from \$200,000 to \$300,000, resulting in the University of Wisconsin losing their K30 award as of June. While I applaud your efforts to increase the award amount, I am concerned that programs like the one at Madison, who depend on K30 grants, will be forced to close their doors.

The shortage of clinical researchers trained to advance medical science and improve the care of patients has been well-documented in reports from the National Academy of Sciences and the NIH. The University of Wisconsin's program has trained 144 clinical researchers to date. What will you do to ensure the K30 grant program is funded at a level sufficient to restore and expand the program at the \$300,000 level?

*Answer.* The NIH recognizes the need for clinical research training to ensure that the nation's needs for clinician researchers are met. As such we have a number of programs designed to create well-trained patient-oriented researchers. A major part of this effort is the Clinical Research Curriculum Award (K30). To help address the needs of this specific trans-NIH program, a decision was made to increase the total funds available from \$10,958,000 in fiscal year 2004 to \$14,700,000 in fiscal year 2005. Additionally, all Institutes and Centers funding clinical research will contribute to these awards and the size has been increased to \$300,000. While we realize that we cannot fund all meritorious applications, we do expect to award 49 grants out of the 81 applications received which is a 61 percent success rate.

#### IRRITABLE BOWEL SYNDROME

*Question.* Dr. Zerhouni, for the last several years, my colleagues and I on the Appropriations Committee have asked NIDDK to develop a strategic plan for research into Irritable Bowel Syndrome (IBS), a chronic complex of disorders that malign the digestive system. Can you update this Committee on the timetable for development and implementation of a strategic plan for IBS at NIDDK?

*Answer.* The NIH concurs that a strategic plan for IBS will identify areas of scientific opportunity and serve as a stimulus in the prevention, diagnosis, and management of this functional disorder. Due to recent Congressional interest, the NIH is in the early stages of creating a new Commission on digestive diseases, which will develop a long-range research plan for the entire spectrum of these diseases, including IBS.

The congressional directive to establish the Commission is in the Senate report language accompanying the Labor/HHS appropriations bill (Senate Report 108-345, page 165). In documentation accompanying the President's Budget request for fiscal year 2006, the NIH has informed the Labor/HHS appropriations committees that it considers the establishment of the commission at this time to be both appropriate and useful (HHS fiscal year 2006 Justification of Estimates for Appropriations Committees, pp. OD 64-65).

This Commission will perform an assessment of the state-of-the-science in digestive diseases and develop a Long-Range Research Plan for Digestive Diseases—with broad stakeholder input from scientific and lay experts. A parallel effort, under the leadership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), will compile current data on the burden of digestive diseases, which would also feed into the Commission's planning process. As noted in the draft charter for the Commission, the Long-Range Research Plan would focus solely on research—consistent with the NIH mission.

The Commission is important because the Long-Range Research Plan it develops will serve as a beneficial scientific guidepost to both the NIH and the digestive diseases community, and would serve the public health. According to recent estimates, the total costs associated with major forms of digestive diseases approach \$43 billion annually. The Plan will focus on research in specific diseases, including IBS, and will also address the training and education of researchers in digestive diseases research; programs for the collection, dissemination, and exchange of information and resources in health and disease relevant to digestive diseases research; and identification of cross cutting, innovative research disciplines and technologies and opportunities for synergy in both basic and clinical research within the Institutes and Centers of the NIH. The inclusion of IBS as a part of a larger strategic planning effort, instead of conducting a stand-alone IBS planning effort, will provide greater opportunity to identify cross-cutting themes common to multiple digestive diseases and common hurdles shared by many.

#### AGE-RELATED MACULAR DEGENERATION

*Question.* I understand that the rate of occurrence of age-related macular degeneration (AMD) will double over the next 15 years, robbing our seniors of their sight. Can you tell us about the research into this disease, and specifically, what therapies may be emerging to stop or reverse this trend?

*Answer.* The National Institutes of Health strongly supports research for age-related macular degeneration (AMD) and has contributed greatly to the understanding of the disease and to the development of new therapies for the disease. Four recently published studies supported by the National Eye Institute report on the identification of inherited variations in a gene that greatly increase the risk of developing AMD. The gene, known as complement factor H, is involved in the body's immune defense system. These findings suggest a possible role for inflammation in the cascade of biological events that leads to AMD. This important discovery may lead to development of new approaches to preventing, diagnosing, and treating this disease.

The National Eye Institute conducted Age-Related Eye Disease Study (AREDS) found that a daily high-dose specific formulation of antioxidants and zinc can slow the progression of AMD from intermediate to advanced stages of the disease. Based on an analysis of prevalence data and the AREDS study findings, it is estimated that more than 300,000 Americans could avoid developing advanced AMD and its associated vision loss over the next five years by taking this formulation.

An advanced form of AMD called "wet" AMD develops as a result of new, abnormal blood vessels that grow beneath the retina, leak blood and fluid, and produce scar tissue. Left untreated, catastrophic loss of central vision may occur. The FDA has approved two new treatments, verteporfin and pegaptanib, for controlling "wet" AMD. These newly approved treatments were developed by industry, but benefited from early support for basic research that provided a better understanding of the underlying biology. A number of even newer treatments, also aimed at preventing or reducing this abnormal blood vessel growth in AMD, are being evaluated in ongoing clinical trials.

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#### QUESTIONS SUBMITTED BY SENATOR RICHARD J. DURBIN

##### DRUG RESEARCH AND DEVELOPMENT

*Question.* NIH has made tremendous contributions to the public good through investments in medical research and therapeutic clinical trials. I'm troubled, though,



that U.S. citizens are paying twice for pharmaceuticals, once through taxpayer support for NIH-funded research and then again at the pharmacy when they purchase the drugs that NIH funding helped to develop.

For example, I have a hard time believing that prices charged for drugs like Taxol, AZT, Gleevec, and others that are substantially funded by taxpayer money are fair.

Is there anything NIH can do to retain or recoup some of the market value of these therapies that are developed based on NIH-funded research?

Answer. Since 2003, NIH has executed 610 new licenses and has collected \$112 million in royalty income from its intramural research program. This represents about two-thirds of the royalty income collected by all federal agencies. Most of NIH's licenses are executed for early-stage technologies with small companies that do not yet have product sales. NIH, however, carefully crafts its licensing terms so that it captures a reasonable share of the profits for those products that achieve commercialization. In addition, NIH has established a Monitoring and Enforcement Branch in the Office of Technology Transfer dedicated to monitoring the expeditious development of our licensed technologies and to ensuring that we receive the full return on our investment.

In May 2000, the U.S. Congressional Joint Economic Committee issued *The Benefits of Medical Research and the Role of NIH*, which examined the role of federal funding for medical research and the benefits that derive from that research. The Committee report concluded that the benefit of increased life expectancy to the United States as a result of advances in health care from NIH-funded medical research results in a payoff of about 15 times the taxpayers' investment in NIH. Clearly, there are financial and public health related benefits of remarkable value that flow from NIH-funded biomedical research.

The NIH contributes to affordability by conducting and funding research that leads to the development of a wider selection of drugs or new drugs, where no drugs were available. More alternatives can translate into more choices for the public, greater market competition, affordability and, ultimately, overall return to society by the improvement of the quality of life. Thus, as long as NIH continues to focus on its core mandate, namely conducting and funding broad-based research that could lead to the development of new drugs and therapies in the future, we believe that NIH is acting as a responsible partner in the national enterprise to improve the quality of life for the public and to make drugs more affordable.

#### PUBLIC ACCESS

*Question.* Your first steps toward more readily accessible research information for the public are commendable and appropriate. As I understand the process, the results of NIH-funded research should be available 12 months after it is published.

But why are you proposing that making research results accessible to the public is "recommended?" If this is such a good idea—and I think it is—why isn't it required?

Answer. The voluntary nature of the Policy was established to encourage investigators to deposit their manuscripts in NIH's public archive. We believe this approach will ultimately result in broader participation. The Policy-related submissions will directly benefit NIH-supported investigators because recent studies have shown that freely available articles get cited more in other research publications. An increase in the number of citations helps improve the professional standing of investigators. Due to these benefits we anticipate that authors will decide to participate and to choose the earliest release dates.

I also believe that the voluntary nature of the final policy permits sufficient flexibility to accommodate the needs of different stakeholders and leaves the ultimate decision in the hands of scientific investigators who are in the best position to judge the circumstances and the time frame under which their work may be made accessible to the public at large. Therefore, we believe that by having a Policy that provides maximum flexibility, authors will respond with maximum participation.

*Question.* A year's delay after publication in a journal strikes me as a very long time, given the pace of biomedical developments today. How much time do you expect most participating researchers to let go by between publication and release of the study publicly?

Answer. The Public Access Policy strongly encourages all NIH-funded researchers to make their peer-reviewed author's final manuscripts available to other researchers and to the public at the National Library of Medicine's (NLM) PubMed Central (PMC) immediately after the official date of final publication. At the time of submission, authors are also given the option to release their manuscripts at a later time,

up to 12 months after publication. NIH expects that only in limited cases will authors deem it necessary to select the longest delay period.

The Policy-related submissions will directly benefit NIH-supported investigators by offering an alternate means by which they can fulfill the existing requirement to provide publications as part of progress reports. It is anticipated that, in the future, investigators applying for new and competing renewal support from the NIH will also utilize this resource by providing links in their applications to their PubMed Central-archived information. Further, recent studies have shown that freely available articles get cited more in other research publications. Increased citations help improve the professional standing of investigators. Due to these benefits we anticipate authors will choose the earliest release dates.

*Question.* What rates of participation and time delays would you consider a success?

*Answer.* Our goal is to build a comprehensive archive of the results of research that NIH funds. Rather than specifying a particular target number, we will be looking for an increasing number of manuscripts to be submitted over time and a decreasing delay period. Issuance of this policy is the beginning of a process that will include refinements as experience develops, outcomes are evaluated, and public dialogue among all the stakeholders is continued. An NIH Public Access Working Group of the NLM Board of Regents has been established. The Working Group includes representatives of the various stakeholder groups and will advise the NLM Board of Regents on implementation and assess progress in meeting the goals of the NIH Public Access Policy. Once the system is operational, modifications and enhancements will be made as needed based on the recommendations of the Working Group, or a permanent subcommittee of the Board, providing ongoing advice on improvements.

We hope that secondary effects of the Policy might also be viewed in terms of "success." Since the Proposed Policy's release in September 2004, we have heard that an increasing number of publishers, within and outside of the United States, are considering changes to or adoption of Open Access publishing models. For example, in January the Nature Publishing Group altered its open access model to increase accessibility to its publications. We are optimistic that these changes will provide the public with free electronic access to Journal articles, through the publisher's web site, on a faster time scale or for the first time. This "change in the landscape" complements the benefits of the NIH Policy since the majority of articles in Journals (approximately 90 percent) do not result from NIH-funded research.

#### SUBCOMMITTEE RECESS

Senator HARKIN. Thank you very much.

The subcommittee will stand in recess to reconvene at 9:30 a.m., on Monday, July 11 in room SD-192. At that time we will hear testimony from the Honorable Patricia Harrison, President and CEO, Corporation for Public Broadcasting.

[Whereupon, at 11:18 a.m., Wednesday, April 6, the subcommittee was recessed, to reconvene at 9:30 a.m., Monday, July 11.]

**DEPARTMENTS OF LABOR, HEALTH AND  
HUMAN SERVICES, EDUCATION, AND RE-  
LATED AGENCIES APPROPRIATIONS FOR  
FISCAL YEAR 2006**

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**MONDAY, JULY 11, 2005**

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

The subcommittee met at 11 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.  
Present: Senators Specter, Stevens, Inouye, and Durbin.

**CORPORATION FOR PUBLIC BROADCASTING**

**STATEMENT OF KENNETH Y. TOMLINSON, CHAIRMAN, BOARD OF DIRECTORS**

**OPENING STATEMENT OF SENATOR ARLEN SPECTER**

Senator SPECTER. Good morning, ladies and gentlemen. The hour of 11 o'clock having arrived, the Appropriations Subcommittee on Labor, Health, Human Services, and Education will now proceed. This morning's hearing will focus on the funding for public broadcasting. The subcommittee is now in the final phases of preparing our submission to the full committee, which will be done later this week, and I thought it would be useful to consider the issue which has received public attention as to the appropriate level of funding for public broadcasting.

There has been some concern expressed as to whether there is sufficient balance on public broadcasting. The subcommittee thought it would be useful to have this hearing to explore these issues before we make our final recommendations before the subcommittee meeting tomorrow and the full committee on Thursday. Then of course, there is floor action. So we think this would be helpful as a prelude what committee action on the appropriate level of funding should be. Congress likes to keep its hands off of these matters to avoid any politicization at all, but we do have the oversight responsibility and we have the appropriations function, so we are going to proceed with this hearing.

I would like to call the witnesses at this time: Ms. Patricia Harrison, President and CEO of the Corporation for Public Broadcasting; Mr. Ken Tomlinson, Chairman of the Board of Directors; Mr. Pat Mitchell, President and CEO of Public Broadcasting Service; Mr. John Lawson, President and CEO of the Association of

Public Television Stations; Mr. David Boaz, Executive Vice President of the Cato Institute.

Well, welcome, ladies and gentlemen. Thank you for coming in on a Monday hearing. Monday morning activities in the Congress are somewhat limited by tradition, but it is a very, very busy week with a great many items on our Congressional agenda.

Our first witness is Mr. Ken Tomlinson, Chairman of the CPB Board of Directors. First elected to the board in 1993, he began his career as a journalist with the Richmond Times-Dispatch in 1965; was a correspondent in Vietnam and was Director of the Voice of America for 2 years. Mr. Tomlinson was Editor in Chief of the Reader's Digest until he retired in 1996.

Our practice, ladies and gentlemen, as I think you have already been advised, is to have 5-minute opening statements, leaving the maximum amount of time for questions and answers following the opening statements.

Mr. Tomlinson, thank you for joining us and we look forward to your testimony.

#### SUMMARY STATEMENT OF KENNETH Y. TOMLINSON

Mr. TOMLINSON. Thank you, Mr. Chairman. I did submit my testimony for the record so that we could preserve as much time as possible.

I am proud to be here in support of Federal funding for public broadcasting. I happen to believe that increasing the education basis of our children's programming alone merits a great deal of focus in terms of what we do in the coming weeks and months. As you well know, it is easier to show cartoons than to produce programming that has an education basis. We should be working so that our education-based programming helps young people learn how to read, but also helps people become interested in civic responsibility and, in the tradition of Tom Friedman, in math and science as well.

We have a rich history of cultural programs coming out of WNET in New York that I would like to see us be able to continue and expand. Obviously, across the river at WETA we have the great tradition of the "Jim Lehrer News Hour." This is journalism dating back to the original "McNeil-Lehrer Report," journalism that represents the highest standard. There has never been any question of balance on that program.

#### PREPARED STATEMENT

We look at the importance of the digital conversion. We look at the demands we face in terms of the need for a new interconnection system. I have brought the issue of the importance of political balance, common sense political balance, to the public debate. This should not overshadow the needs that public broadcasting has, and I am very pleased to be here to support those needs.

Thank you.

[The statement follows:]

#### PREPARED STATEMENT OF KENNETH Y. TOMLINSON

I come to you this morning as an individual who supports Federal funding for public broadcasting.

I believe that education-based children's programming represents one of the most critical responsibilities for public broadcasters. We need to produce programming that will inspire children from all walks of life to want to read—to want to acquire knowledge about our nation's history and our own civic responsibilities. Taking a cue from Tom Friedman, we also should be inspiring interest in math and science, because surely we must recognize we live in a world that is flat.

The cultural programs—the great performances that in recent years have been produced by WNET in New York—are an important part of the mandate of public broadcasting. The current affairs programs coming from WETA—I speak specifically for the tradition of journalistic excellence that is the history of the NewsHour with Jim Lehrer—merit our support. So, too, is the excellent programming that has come to us over the years from WGBH in Boston.

The clock is ticking on the deadline for funding a new interconnection system for public broadcasting. The opportunities presented by a transition to digital broadcasting will open exciting new doors for the public broadcasting system.

In recent months I have asserted over and over again that you cannot understand the case for federal support of public broadcasting until you see the fruits of these services in states like North Carolina, Kentucky, and South Dakota. If you want to get an idea of the digital future of public broadcasting, go to North Carolina and see, thanks to public support for a bond issue, four channels that make public broadcasting far more relevant and far more valuable to the people of that state.

I would be remiss this morning, however, if I failed to address issues surrounding my work to meet the legal mandate that Congress placed on CPB to require political balance. Listen to Section 19 of the law that governs what we do: CPB shall facilitate the development of programs “of high quality, diversity, creativity, excellence, and innovation, which are obtained from diverse sources, will be made available to public telecommunications entities, with strict adherence to objectivity and balance in all programs or series of programs of a controversial nature . . .”

I did not initiate the controversy over balance, and I am the first to recognize this controversy has not been good for the health of public broadcasting. So allow me to review the actions that I have taken to encourage political balance for the sake of encouraging a wide base of support for what we do.

In late 2003, I went to the leadership of PBS to make the point that NOW with Bill Moyers had become a symbol of our ignoring our legal mandate to require balance. It was not that Bill Moyers work does not represent outstanding political advocacy broadcasting. I did not ask for a moment of the show to be removed from public broadcasting schedules. My point was that law requires a diversity of opinions, and on Friday evenings, public broadcasting would do well to reflect conservative points of view as it did so eloquently liberal points of view.

When PBS leadership asserted NOW to be balanced, I asked that a consultant review six months of the program and assess the political direction of the program's content. Later, I would ask the consultant to review other programs on public broadcasting to illustrate that unlike NOW they reflected diverse political opinions. The contract for this consultant was processed under the supervision of CPB staff and our General Counsel according to CPB rules and regulations. I had never known CPB board members to be involved in approving contracts with consultants—and I had observed any of a number of consultants brought in by CPB executive leadership to do similar tasks—so I did not run this issue by the board. At no time did I make any effort to keep the contract secret from my fellow board members.

Much has been made in recent days over the classifications of viewpoints expressed by Senator Chuck Hagel and former Congressman Robert Barr. As the researcher's work illustrates, Bill Moyers did not invite Senator Hagel on his show to give him a platform for advocating his belief that free trade is critical to the success of U.S. foreign policy. That would have run counter to Bill Moyers' deeply held beliefs that, by the way, were frequently given time on his program. No, Senator Hagel was asked to come to the Moyers show to talk about aspects of the war in Iraq that differed from the positions of President Bush.

Bob Barr was not invited on NOW to discuss his political philosophy that largely is in conflict with Mr. Moyers' position. Bob Barr was on the Moyers program to attack the Patriot Act, which not coincidentally, Bill Moyers questioned.

Again, there is an important audience for the liberal advocacy journalism that is Bill Moyers. The law, however, requires CPB to encourage balance when such programming is presented.

Fortunately the board leadership of PBS recognized that Friday evening programming should reflect diverse points of view. When it was clear that PBS was following through on this commitment, I ended the study and did not make it public because to do so would have called attention to the fact that for nearly two years

public broadcasting ignored our legal responsibility for presenting diverse viewpoints on controversial issues.

All of this occurred more than a year ago. So why did the issue become a staple in certain press venues in recent months? The answer to that question lies in the politics of public broadcasting—as well as the politics of year 2005. But one thing is certain. The more this debate continues, the more we jeopardize future public support for public broadcasting.

Clearly, it is time for us to lay aside partisanship, seek popular consensus for what public broadcasting should be doing, and go forward to meet the challenges that lie ahead.

I look forward to responding to any questions that the Senators might have.

Senator SPECTER. Thank you very much, Mr. Tomlinson.

We now turn to—you had concluded your verbal presentation?

Mr. TOMLINSON. Yes, sir.

Senator SPECTER. Thank you.

We turn now to Ms. Patricia Harrison, President and CEO of the Corporation for Public Broadcasting. Prior to taking her current position, she served as Assistant Secretary of State for Education and Cultural Affairs. In 1997 she was elected Co-Chairman of the National Republican Committee, serving there until January of 2001, a graduate of American University.

Thank you for joining us, Ms. Harrison, and we look forward to your testimony.

**STATEMENT OF PATRICIA HARRISON, PRESIDENT AND CHIEF EXECUTIVE OFFICER, CORPORATION FOR PUBLIC BROADCASTING**

Ms. HARRISON. Thank you, Mr. Chairman. I too have submitted my written testimony—

Senator SPECTER. All written testimony will be made a part of the record in full.

Ms. HARRISON. I would like, with your permission, to use my time just to make a few brief remarks.

Senator SPECTER. That is fine.

Ms. HARRISON. Thank you. First let me express my strong commitment to and belief in the mission of public broadcasting. Although I have been in the position of President and CEO of CPB for only 5 working days, it is a belief I have long held. It began when I served as an intern at WAMU as a student at American University. It continued when my children were small and we all watched “Sesame Street” together, and then much later “Masterpiece Theater.” It grew as I listened to NPR in the morning before I began my day as Assistant Secretary at the State Department.

I believe that public broadcasting is in the public interest, that it furthers the general welfare of all our citizens, that it is a vital connection to community for millions of Americans, all races, all ages, urban and rural, and for new Americans and their children. Public broadcasting strengthens our civil society and it merits the investment of monies represented by our budget request for 2006 and 2008.

My second point: I am committed to protecting the nonpartisan nature of public broadcasting. As you said, I come to CPB after almost 4 years as Assistant Secretary of State, managing a bureau of hundreds of people, civil servants, Foreign Service officers, working with 1,500 public and private organizations and 80,000 volunteers to facilitate 30,000 nonpartisan educational, cultural, and professional exchanges annually.

I am ready to work with Congress, the CPB Board, staff, the public broadcasting stations, national organizations, public and private funders in an open and transparent way in order to serve the millions of Americans who turn to public broadcasting each week.

Now let me turn to the budget. CPB is requesting \$430 million in advance appropriations for fiscal year 2008, the vast majority of which will go directly to local television and radio stations for locally based, locally relevant operations. The corporation requests \$45 million in fiscal year 2006 for the ongoing conversion to digital technology. We are requesting \$40 million in 2006 to fund the replacement of the public television interconnection system.

Mr. Chairman, I recognize that we make these requests at a time of great pressure on the Federal budget. But when we appeal to Congress for funds, we should recognize that hundreds of thousands of Americans are already including public broadcasting support in their personal budgets by writing checks to support these programs, and the fact is that every dollar of Federal funding is matched six times over by voluntary contributions from viewers, foundations, universities, State and local governments, corporations, and small business owners, and of every dollar of Federal funding we receive 95 cents of that dollar goes to the local stations and services they provide. Public broadcasting really represents the best example of public-private partnerships.

We have all read the research on the importance of early learning and, though "Sesame Street" showed us the way 37 years ago, the need is even greater today. Public television is responding to that need and in fact it is public television's responsibility. Whether we are talking about ages 2 through 8 and early learning programs or middle school to high school with a focus on history and civics, the aim is to ensure our country's successor generation is prepared for the future.

For those who have questioned the relevance of public broadcasting in a multi-channel world, the answer is that public broadcasting is more relevant than ever. We address community needs, we provide entertainment, education, information programming, and none of this is matched anywhere else in the 500-channel universe. That is just one of the reasons more than 100 million Americans tune in every week for uninterrupted programs where they are treated as citizens, not just as consumers.

#### PREPARED STATEMENT

Mr. Chairman, members of the committee, on behalf of my new colleagues in public broadcasting let me say how much we appreciate the vital support Congress continues to provide. I look forward to working with the committee on behalf of public broadcasting in the public interest.

Thank you and I will be happy to address any questions you may have.

[The statement follows:]

#### PREPARED STATEMENT OF PATRICIA S. HARRISON

Mr. Chairman and members of the subcommittee, thank you for this opportunity to discuss with you the Corporation for Public Broadcasting's funding requests for fiscal year 2006 and fiscal year 2008. Although I became CPB's President only 1

week ago, I have long understood and appreciated the vital role that public broadcasting plays in the lives of so many Americans.

I accepted the challenge of leading CPB because I believe that public broadcasting serves as a vital connector to community for so many Americans rural and urban. Public broadcasters offer television and radio worth watching and listening to, and that is why so many of us spend our most precious resource—our time—on public broadcasting. I believe public broadcasting is a unique source of education, information, and entertainment that fully deserves strong, continuing congressional support.

There is another reason I wanted to lead CPB. It is based on my almost 4 years serving as Assistant Secretary of State for Educational and Cultural Affairs. In that capacity, I managed a bureau of hundreds of people, worked with 1,500 public/private partnerships and 80,000 volunteers to conduct 30,000 cultural, professional and educational exchange programs annually, including the prestigious Fulbright and International Visitor programs.

These vital programs were also connectors between the American people and citizens from other countries. In the early 1990's, the budget was cut for exchanges and just when we needed to have this critical outreach after September 11, 2001, the resources were not there. I am very proud that I was able to increase our budget with the help of Congress. My goal was to reach out beyond the elites to younger, more diverse audiences, and to affirm and connect with what we have in common as opposed to our differences. One example—with the strong support of Senators Kennedy and Lugar, we were able to create the first high school program for boys and girls from the Arab Muslim world.

I see a similar challenge facing public broadcasting today. This is an important time to affirm what we have and to work to make it better, to reinvigorate public broadcasting and underscore its unique relevance in the multi-channel world.

I have a proven track record of leadership, and I am ready, willing and eager to help lead this organization into a strengthened relationship with public broadcasting stations, national organizations, public and private funders, and the millions of Americans who turn to public broadcasting each week.

As I begin my tenure at CPB, I am particularly fortunate to be able to build on what the corporation's staff and their colleagues throughout the public broadcasting community have already done. Mr. Chairman, today I will mention just a few of these initiatives—work that is possible, Mr. Chairman, because of the commitment made by Congress and so many others in the public interest, and work that I believe will help us leverage an even greater return on the public's investment.

As the distinguished committee knows, public broadcasting is a collection of locally based stations that serve both local and national needs.

Public broadcasters offer coverage of national news—and of local high school and college sports. They bring the world's greatest artists and performances into our living rooms, and they collaborate with local arts and cultural institutions. Public broadcasting reaches children just learning to read, and often these children are sitting in front of the television with parents who are themselves learning to read in a new language.

Public broadcasting is not one size fits all. What you see and hear depends upon where you live and what the communities needs are.

—in Pennsylvania, you can explore your state's history with *Marking Pennsylvania History on WHYY*;

—in Iowa, you can tune in to *Living in Iowa*, a monthly statewide magazine show;

—and in North Dakota, you can keep up on all the doings with *Dakota Datebook*, daily on North Dakota Public Radio.

All across the country, stations are bringing different services and programming, informed by community attitudes and concerns, to their audiences. They are able to do this so effectively because they are locally owned and operated. They know their communities, what their neighbors want in terms of programming, what their local organizations need in terms of support. In a word, they are connected. And that connection is one that distant commercial media simply can't or won't provide.

Mr. Chairman, with your permission, I'd like to turn now to our funding requests and the ways in which those federal dollars benefit citizens and communities across the country.

These requests were of course submitted before I came aboard last week, but I have had the opportunity to review them with staff and believe they merit strong support.

CPB is requesting \$430 million in advance appropriations for fiscal year 2008, the vast majority of which will flow directly to local public television and radio stations for locally based, locally relevant operations.



Additionally, the corporation requests \$45 million in fiscal year 2006 for the ongoing conversion to digital technology. Mr. Chairman, this is so important. As the result of the investment made by Congress so far, hundreds of public television and radio stations are offering digital signals, and we have recently begun making grants to develop new digital services for local communities.

Digital is the future of broadcasting and the future is here. Mr. Chairman and members of the Committee, public broadcasting must be enabled to participate fully in that future, and thanks to your ongoing support, it is well on the way.

Finally, CPB is requesting \$40 million in fiscal year 2006 to fund replacement of the public television interconnection system. Given the scheduled expiration of public television's satellite leases, we must not miss this opportunity to develop a system that is both more efficient and compatible with the new digital technologies.

Mr. Chairman, I recognize that we make these requests in a time of great pressure on the federal budget. The requested funds, however, represent an investment of only about \$1.75 per American—and the return on investment is far greater in terms of value to older citizens, urban and rural residents, and minority audiences. If this were a stock, I would argue it is one of the best investments the American people have ever made.

Public broadcasting serves every one. There are no qualifications of age and income; no requirements for matching funds; no copays. Instead, public broadcasting is available to virtually every American, free of charge, in every community across the country. And every week, more than 100 million of our fellow citizens take advantage of the opportunity to tune in.

In fact, this July 4th I began my day in Washington, D.C. listening to *Morning Edition* and the reading of the Declaration of Independence. My day ended at the Capitol Fourth concert and fireworks on the Capitol steps. Public television covered this event, which meant that my 90-year-old mother and so many others like her throughout the country could share in the celebration of America's birthday without leaving home.

Of every dollar CPB receives from the federal government, 95 cents goes to local stations, either directly, or indirectly to support radio, television and on-line programming, research and technology.

The largest amount by far—72 cents of every dollar—goes directly to local public television and public radio stations. As I said, these stations are uniquely connected to their communities. They determine their own program schedules, and often produce their own programming; they respond to community needs and leverage local support.

CPB also supports the creation of programming for radio, television, and new media. Probably every American is familiar with signature programs like *Masterpiece Theater* and *Sesame Street*, but today, we're funding tomorrow's classics. If you've heard any of the new *StoryCorps* or *This I Believe* segments on public radio or listened to Philadelphia's own Terry Gross, you know what I mean. And we have similarly high hopes for our newly announced children's programming initiative, which will continue public broadcasting's leadership in high-quality, non-commercial, educational programming for children; for America at a Crossroads, which will explore the issues facing us in the wake of the 9/11 attacks; and for the American History and Civics Initiative, which will capitalize on today's technology to reach and teach middle and high school students.

To carry out its mandate to serve the underserved, CPB provides support to five minority consortia—representing the unique points of views of Latinos, African-Americans, Native Americans, Asian Americans, and Pacific Islanders. We also fund the Independent Television Service, through which the work of innovative, independent filmmakers is made available to the public television audience.

And we also work to ensure that the programs we support have a life long after the television and radio are turned off. Materials are available on website and for classroom use and often prove enduringly popular as the years go on. Radio material, too, is available for download or web-based listening. And programming is frequently supported with direct, person-to-person outreach, something distinguishes public broadcasting from our commercial counterparts. In other words, our impact resonates well beyond the broadcast.

Another six cents of every dollar go to projects that benefit the entire public broadcasting community. We negotiate and pay music royalties for all of public broadcasting, for example, allowing audiences nationwide to enjoy new and classic recordings, and we recently completed the most comprehensive audience research project in public television history, information that producers and broadcasters will use to guide programming decisions for years to come.

With special appropriations from Congress, CPB helps local public broadcasters provide the advanced public service digital technology makes possible. We are fund-

ing the upgrade of the public television interconnection system that delivers programming to stations. And we are funding station purchases of digital equipment that they will use to provide new and needed streams of news, music, and public service programming. From homeland security information to special streams of programming for kids, the public investment is creating a deeper, richer mix of services available to people across the country.

CPB's administrative expenses are limited by law to five percent, but we normally hold them even lower. Less than a nickel of every federal dollar stays in Washington; the rest is spent to benefit stations across the country.

The Federal appropriation accounts for only about 15 percent of the entire cost of public broadcasting, and stations and other organizations must work very hard to raise the money to fund their activities. In fact, CPB funded the Major Giving Initiative, which has helped stations sharpen their community-based fundraising skills and improve their balance sheets.

The Federal dollars are critically to leveraging all the other resources. It opens the door for funding from state and local governments, universities, businesses, foundations, by providing a "seal of approval" from the Federal Government.

The funding we receive from Congress ensures that public broadcasting continues to offer programming and services that are superior across the board to those offered by commercial competitors. As Ken Burns has said, "The programming on PBS, in all of its splendid variety, offers the rarest treat amidst the outrageous cacophony of our television marketplace—it gives us back our attention and our memory. And by so doing insures that we have a future."

Public broadcasting attracts the support of viewers and listeners nationwide—people from all walks of life, who add their dollars to the vital core of Federal support, writing the checks to fund programs and services that are important to their lives, leisure, and careers.

The Public Broadcasting Act describes public television and radio stations as "valuable community resources" that can help address local concerns. The American public has already invested a great deal in creating, preserving and now modernizing these resources. With the requested funding, we will work to fulfill their hopes and expectations by continuing to deliver high quality, high value services.

Mr. Chairman, members of the subcommittee, on behalf of all my colleagues in public broadcasting, let me say how much we appreciate the vital support Congress continues to provide. And let me say personally that I understand how valuable public broadcasting is. Plain and simple, strong public broadcasting means a stronger democracy. I take that responsibility extremely seriously. Thank you, and I will be happy to try to answer any questions you may have.

Senator SPECTER. Thank you very much, Ms. Harrison.

We have been joined by the distinguished Senator from Hawaii, Senator Inouye, who has been in the Congress as long as Hawaii has been a State, initially in the House of Representatives and in the Senate, 1960?

Senator INOUE. 1963.

Senator SPECTER. 1963.

Would you care to make an opening statement, Senator?

Senator INOUE. I thank you very much, Mr. Chairman. But at this moment I would prefer just to ask questions.

Senator SPECTER. Thank you. Thank you very much.

Our third witness is Ms. Pat Mitchell, President and CEO of Public Broadcasting Service. She has a broad and distinguished background as a journalist, television executive, and educator. During her 3-decade career, she has been recognized at her work at NBC, CBS, ABC, and CNN; a graduate of the University of Georgia.

Thank you for joining us, Ms. Mitchell. We look forward to your testimony.

**STATEMENT OF HON. PAT MITCHELL, PRESIDENT AND CHIEF EXECUTIVE OFFICER, PUBLIC BROADCASTING SERVICE**

Ms. MITCHELL. Thank you very much, Mr. Chairman, and I welcome Senator Inouye on behalf of the PBS Board Chair Mary Bidderman, who hails from Hawaii, as you know.

I am very grateful for this opportunity to be here to support the appropriations request for the Corporation for Public Broadcasting. Mr. Chairman, allow me to welcome Pat Harrison to the community of public broadcasting. Last week Pat and I shared the PBC Fourth of July Concert and we celebrated both our country's independence and also the value of a Public Broadcasting Service who can independently bring such a celebration through our local station, WETA, and its leader, Sharon Rockefeller, who is with us as well, into every American home.

We understand the enormous responsibilities we all have in leading such a valued media enterprise at such a time of transformational change, a time when our mission, which is to use the power of media to serve the public good, is more needed than ever. And we are grateful, Mr. Chairman, that in such a time when you have such challenging choices to appropriate public funds that you continue to appropriate them for public media.

Public media must have the public's trust. It is our rating system, our currency, our measure of achievement. In a recent Roper poll, Americans named public broadcasting the most trusted national institution in this country. The result of this trust is the collective good work of public broadcasting producers, stations, and the collective goodwill of the American people we serve. It is also, Mr. Chairman, the result of a collaborative, constructive relationship between the management of the public broadcasting organizations seated at this table.

It is a great affirmation to know that Americans indicate in independent surveys they consider public television to be their best value for their tax dollars, second only to military defense.

So what is PBS's role, then, in using these funds? We are not a network like ABC or CBS, but we do provide nearly 3,000 hours of top-quality educationally-based programs to 170 public television stations, who distribute them to 350 communities. These are the programs that define public television, but they come through essentially local institutions, built on local values, serving public and local community interests.

During my tenure at PBS, I have visited more than 100 of these stations and on these visits I have seen the positive results of public service media in our communities up close and personal. I wish I had the time to share the smiles and appreciative thank-you's that have come from parents and caregivers and teachers and home schoolers in every community. I meet these people and for them PBS is not a luxury or a burden; it is an important part of their lives.

Let us not forget the 40 million Americans without cable or satellite. It also matters that, even in homes where there are 300 channel choices, PBS is still among the top six media choices, viewed by more than 70 percent of Americans every month. Add to that the millions of visitors to pbs.org and station websites every day, learners of all ages, taking advantage of 175,000 pages of edu-

cational content. Then add the millions more that are reached through educational services and community partnerships, and you begin, Mr. Chairman, to get a picture of the true scale, the unparalleled power of reach and power that PBS and our stations in our community are bringing to communities in this country.

We do it in ways that have earned the public's trust: children's programs that educate, science programs that illuminate, history that is definitive, memorable, news and documentaries that are trustworthy and reliable, because of the editorial standards that ensure accuracy, fairness, and balance across our schedule, all of our programs produced in the public interest, not to motivate consumers.

PBS's management, Mr. Chairman, not the PBS board or any other party, is ultimately responsible for ensuring these standards guide our decision-making and public opinion polls verify that the public perceives we are doing it, free of bias and any undue influence from any source.

Then beyond being a broadcaster that is so valued, we are also this Nation's largest educational service, the leading source of on-line lesson plans, 3,500 free on-line, the number one choice of educational content in classrooms. More than 5 million adults receive their GEDs through public television stations; workplace essential training; and over the past 10 years a partnership with the Department of Education has changed the lives of hundreds of millions of parents and caregivers through Ready To Learn and Ready To Teach. We have prepared children for school achievement and we have prepared teachers to use the latest technology to meet today and tomorrow's learners.

#### PREPARED STATEMENT

With your support, we will continue to build on this foundation of trust and use all the new technologies to deliver even more public service.

Thank you, Mr. Chairman. I look forward to your questions.

[The statement follows:]

#### PREPARED STATEMENT OF PAT MITCHELL

Mr. Chairman, members of the Subcommittee: I welcome this opportunity to be a witness on behalf of the Public Broadcasting Service, this country's largest public service media enterprise, which is also this country's most trusted national institution, according to a recent Roper Poll.

Public media must have the public's trust. Trust is our ratings system. Our currency. Our measure of achievement.

And like public education, public health programs, and public libraries, public broadcasting is supported by public funds—another reason why it is essential to be sure that we have earned the public's trust.

I am pleased to share that Americans have said in independent surveys that public television is the best value for their tax dollars, second only to military defense. This may surprise some, just as many are surprised to learn that the amount of those tax dollars is about one tax dollar per citizen per year, totaling less than 20 percent of the costs of operating public radio and television stations in communities across the country.

This investment of public funds is the foundation upon which public broadcasting has built a national/local, public/private partnership that is unique in the world, and it is crucial that we maintain that foundation. Therefore, we are asking this committee to fund \$430 million to the Corporation for Public Broadcasting for fiscal year 2008 to support local stations' operations and public broadcasting programming.

Only in America with our strong philanthropic culture would a media enterprise such as PBS meet its mission year after year by leveraging every tax dollar with three or four private dollars from foundations, corporations, and yes, viewers like you, voluntarily adding their personal dollars to ensure that the programs and services of public broadcasting continue in their communities.

Those viewers come from every sector of our communities, closely aligned in age, ethnicity, education and income with the overall demographic picture of this country. It is a committed constituency who believes—as Congress has historically indicated through its appropriations votes—that in a media landscape of hundreds of media businesses with fewer and fewer owners, with more choices than ever but fewer real options, that this country needs, perhaps more than ever, one media enterprise that resists the race to the bottom for profits and popularity, that respects the intelligence of its audience and responds to the need for programs that reflect our values and both celebrate and document the best of our history and culture.

We need one media enterprise, as originally conceived over 35 years ago, that is not using its power to sell, cannot be bought or influenced and that truly does belong to all of the American people. It is those people's voices that have been heard in these halls and around the country to protect a service that is open to voices from every perspective, that tackles the tough, complex issues they want and need to understand, that puts them on the frontlines of the news and in the front rows of the theatre and that teaches their children letters and numbers as well as respect and other pro-social behavior.

Those are the “viewers like you” who never ask the question, “Who needs PBS in today's media landscape?” And yes, among them, are the often forgotten 40 million Americans who cannot afford or do not choose the options of cable or satellite. For them and for most rural communities, the funds to support a new interconnection system are critical to the sustainability of the national public broadcasting service that connects all 348 member stations to PBS and to each other.

Because of their unique national/local structure, PBS and its member stations also offer a unique and important means of communicating during a crisis. Trials are under way to determine how best to serve first responders and how to ensure communities get what they need in times of disaster. The interconnection system must be updated to fully optimize this additional service for Americans.

Therefore, we are asking that this committee fund the \$40 million needed to build out the interconnection system so that we can ensure the universal reach that is our mandate and the delivery of national and local programs that serve our mission.

“Serve” is the operative word because PBS and its 348 member stations have a mission to serve, not to sell, to inform and engage citizens, not to motivate them as consumers.

This is a distinction with a big difference and the difference can be measured by results. I'd like to share a few of them with you today.

The most obvious and most celebrated are the programs, consistently among the most honored for educational value, excellence in quality and journalistic standards, and—even in the midst of 300 media choices—still among the top choices every week in most households and still viewed by nearly 70 percent of American households. In addition, PBS was chosen again this year as the number one television and video resource for classrooms by teachers across the country.

Those who question whether there is still a need for PBS when there are so many other choices need to take a closer look at those other choices. I think you would agree that “Monster Garage” is not really a substitute for “Masterpiece Theatre.” And while distracting and amusing, “Dancing with the Stars” will not have the long lasting value of PBS's series on Broadway, a Ken Burn's history of jazz or baseball or the upcoming World War II program.

At PBS, we do not begin with questions like, Will this program sell a product? We begin with questions like, What's the educational value of the content? How can teachers use it? Will it have lasting value to learners of all ages? Is it comprehensive, well researched? Does it contribute to a diversity of perspectives on the subject? Does it add to the understanding of our community, our country and our world? Will it open a mind, change a life, strengthen a family, teach a skill, connect a community? Will it comply with PBS's editorial standards for reliability, transparency, objectivity and balance?

PBS recently updated its editorial standards with the help of a blue ribbon panel of journalism experts and also created the position of PBS ombudsman to ensure both transparency and responsiveness to the public. A search is under way to fill that new role.

Every year, PBS distributes almost 3000 hours of programs that meet our high standards:

- Children’s programs that teach the concepts of literacy and math, which foster respect and pro-social behavior, which get our youngest and most disadvantaged ready to learn and prepared for school.
- Science and history programs that set the standard for accuracy and comprehensiveness and are, along with the rest of our programming, the most used TV and video curricula in American schools.
- Drama and performance programs that celebrate our country’s great cultural diversity and inspire the artists, the dancers, the writers and musicians of tomorrow.
- News and investigative journalism programs that Americans turn to for an understanding of the complex issues of our times.

And this is just the tip of the iceberg.

Many of these programs and additional educational content go to PBS.org, which learners of all ages visit more than one million times a day to view 175,000 pages of content—web sites that extend the value of PBS and that link users seamlessly to their local PBS station web sites for local information, programs and educational services. Teachers across the country use nearly 4,000 highly credible, freely available lesson plans and study guides based on PBS content in their classrooms, all customized to national and state curriculum standards.

Beyond broadcast and the Internet are the extensive and diverse outreach activities that engage PBS and stations in additional community service for which our content is perfectly suited: Through a Department of Education grant, Ready To Teach, our PBS TeacherLine service has been training teachers in reading, math, science, curriculum & instruction and technology integration. Everywhere I go around this country, teachers express appreciation for this professional development training, which is available through online courses, videoconferencing and face-to-face workshops, and for the state-of-the art digital technology PBS and its member stations are deploying to America’s classrooms and school systems. The committee’s support of these programs is essential, and we are requesting that this committee fund \$17 million to enable PBS and its member stations to continue providing this critical service.

In addition to providing teachers with access to training, PBS and its stations are meeting another community need, offering training to workers who have faced layoffs or hold jobs in industries in transition. KET, a statewide network of PBS member stations in Kentucky, is addressing the need to keep Americans fully engaged in the economic lives of their communities by offering through PBS distribution and to other stations a program that teaches workplace skills.

Together with stations and partnerships with institutions of learning, PBS also offers video curriculum and materials for Americans seeking to complete their high school education and take college classes. More than 2 million Americans have received their GED certificates through PBS programs, and PBS and its local stations have helped more than 6 million adults earn college credit using PBS courses.

When he signed the law creating public broadcasting in 1967, President Johnson said we should “use the miracles of communication to create the miracles of learning.” PBS and its member stations are doing this every day in every community, making us the single largest educational institution in the country.

Education is a significant part of what we do, and the return on investment of tax dollars can be measured in the number of children better prepared to read and to succeed in school and in the number of Americans in every community who are being informed and educated through public service media.

Traveling the country as the president and CEO of PBS, I have seen these results up close and personal.

In rural Pennsylvania, I spoke with a young woman who thanked me for her high school diploma and the college degree she expects to earn through her PBS station.

I have met teachers in Iowa who use our videos and DVDs who look to us to train all teachers in the best uses of technology.

I have visited kindergartens and have seen caregivers in Mississippi, some with few educational resources, put in a DVD of our PBS KIDS program “Between the Lions” and I have watched the joy on children’s faces when they used that program to connect the letters to a word they’re learning.

I have been in homes in Texas where there were no books until our Ready To Learn program provided books for the children learning to read and taught the parents how to support literacy in the home.

And I have talked with hundreds of homeschoolers for whom PBS content comprise their core curriculum.

Education is our mission and we need your support to ensure that we can sustain this service, particularly through Ready To Learn, for which we are asking this committee to fund \$32 million for programs and community outreach. Developed in co-

operation with the Department of Education, Ready To Learn has helped nearly one million parents and teachers prepare eight million children for success in school using local public television stations as outreach partners.

We are working to strengthen our educational offerings in the future through an effort called the Digital Future Initiative (DFI), led by former Netscape Chairman Jim Barksdale and former FCC Chair Reed Hundt. The panel, made up of experts from inside and outside public broadcasting, is examining the future of learning and technology, and analyzing where PBS and its member stations fit into that future.

The DFI will recommend new services we can deploy in the digital future for learners of all ages, but nothing will be possible without current funding, which we hope you will support. With that, we will solicit new partners who share our education mission, once again leveraging the private funds to make the public funds go even further.

With your help in securing the foundation of public funds—the all-important investment of public dollars—PBS and its member stations are the best positioned media enterprise to succeed in the digital future—in fact, to lead it. Eighty-nine percent of our stations have converted at least their transmission facilities, but some remain in need and cannot be left behind. We are asking this committee for \$45 million to help stations fund the conversion to digital broadcast technology.

For PBS and for those stations that have converted, the transition to digital means a transition to a new way of serving the American people by deploying our already considerable offerings across platforms that respond to our audience's needs in this media landscape. And that is what this is all about. Harnessing the current power of media—unprecedented in its capability to do good—on behalf of the American people.

In a media landscape transformed by technology, consolidating in ownership and power, this country needs one media enterprise:

- where education comes first;
- where partisanship is checked at the newsroom door;
- where editorial guidelines ensure that all content produced for us is fair, transparent in the process and accurate. We have recently updated our editorial guidelines to ensure that we continue to achieve these goals at every level.

In a media landscape where fewer and fewer Americans trust the press, we maintain our high level of trust because the public believes that we are independent of pressures that come from the marketplace and the influence of any funding source.

And in a media environment where our children are spending 4 to 6 hours a day interacting and engaged with media of some sort, we offer a media experience that is committed to the values of family and the values of this democracy.

We are this country's only media enterprise that invests public funds in a public-private partnership through a strong national program service and an interconnected community of locally owned media institutions, public radio and public television stations. And we are this country's only media enterprise that delivers programs and services that meet community needs and that measures our value and relevancy by how many minds we open, how many lives we change, how many ways we strengthen communities and how well we serve this democracy.

Senator SPECTER. Thank you. Thank you very much, Ms. Mitchell.

Our next witness is Mr. John Lawson, President and CEO of the Association of Public Television Stations. He served on the board of the National Coalition for Technology in Education and Training, was appointed to the Federal Communications Commission's Media Security and Reliability Council in 2002, a graduate of the University of South Carolina.

Thank you for coming in this morning, Mr. Lawson, and the floor is yours.

**STATEMENT OF JOHN M. LAWSON, PRESIDENT AND CHIEF EXECUTIVE OFFICER, ASSOCIATION OF PUBLIC TELEVISION STATIONS**

Mr. LAWSON. Thank you, Mr. Chairman and Senator Inouye. Thanks for inviting me to testify on behalf of America's 356 local public training stations. In an era of media consolidation, our stations are among the last of the locally controlled media and that fact alone makes them vital to our democratic society.

With all that has been said and written about public broadcasting, especially over the past few weeks, my concern is that we not lose sight of who we really are and, more to the point, who we really serve. It is not the media, it is not the pundits, and it is not us here in this room. It is viewers and listeners who turn to public TV and radio as their most trusted source for news and public affairs. It is children, whose public education is improved by programs in reading, math, and science. It is parents, who depend on public television for home schooling and for family-friendly and non-violent programming. And it is people living in Russell, Kansas, and Cumming, Iowa, Hooper Bay, Alaska, and other rural communities who depend on public TV and radio as information lifelines.

Senator SPECTER. Why special concern about Russell, Kansas?

Mr. LAWSON. I understand that is where you were born, sir.

Senator SPECTER. Close. Bob Dole was born there. I was born in Wichita, moved there when I was 12.

Mr. LAWSON. Okay, where you grew up.

Senator SPECTER. Glad to have Russell included. You can have some extra time for mentioning that.

Mr. LAWSON. I will take it.

So these are the real people, Senator, that public broadcasting serves. But make no mistake, our viewers challenge us and we challenge ourselves to keep pace with a changing society. With the support of this subcommittee, we are converting to digital, DTV. In practical terms, that means that, instead of broadcasting a single program, stations can reach nontraditional learners, kids, the elderly, Spanish speakers, and rural Americans with multiple news services simultaneously.

I am also pleased to report that the Department of Homeland Security has turned to our stations as the backbone for upgrading the Cold War-era emergency alert system and overcoming the communications bottlenecks we saw on 9–11 both here and in New York City.

Mr. Chairman, just over 2 weeks ago the House of Representatives voted by a two to one margin to restore \$100 million that the House Appropriations Subcommittee cut from CPB. While we are grateful for that bipartisan vote of confidence, funding for four critically important programs still was completely eliminated in the House bill. Tomorrow this subcommittee will take on the different task of allocating scarce resources.

So please let me summarize what our stations believe is needed to continue serving their communities. First and foremost, CPB funding is irreplaceable for our stations. It is the foundation. It is the seed money on which all the other money we raise stands.

Also very important is the longstanding practice of this subcommittee to provide these funds 2 years in advance. This allows for good planning, provides a buffer from politics, and does not cost the Federal Government any more than a current year appropriation.

For CPB, we urge you to appropriate \$430 million for fiscal year 2008, an increase of \$30 million over what was appropriated last year and the year before. These additional funds are needed, among other reasons, because stations are required to transmit



both analog and digital signals and added cost for electricity alone is \$30 million per year.

#### NEXT GENERATION INTERCONNECTION SYSTEM

Two years ago, this subcommittee recognized that our current satellite system is wearing out. We have planned a 4-year phase-in of a new system that will allow local stations, wherever they are, to share programming with one another across their State and across the country. For this year's installment we are requesting level funding, \$40 million.

#### CPB DIGITAL TRANSITION FUNDS

This is another temporary line item. Next year the FCC requires stations to deliver full power digital signals and have their final DTV channel allocations in place. To help stations meet these Federal mandates and complete their digital buildup, we are requesting \$45 million. This augments State and private funding.

#### READY TO LEARN, READY TO TEACH

If I can characterize CPB funds as the foundation for our stations, I would describe these programs as the crown jewels. Ready to Learn provides educational programming for tens of millions of American children and its outreach component has helped to further prepare eight million children to enter school. Ready to Teach uses technology to help train teachers in core subjects and provides grants to stations to create world-class curriculum content. We are requesting \$32 million for Ready to Learn and \$17 million for Ready to Teach.

#### PREPARED STATEMENT

In conclusion, Mr. Chairman, Senator Inouye, you and ranking member Harkin and Chairman Cochran and Stevens and your colleagues on this subcommittee have provided steadfast support for public broadcasting. Through good times and bad, you have made it possible for public stations to serve uniquely their local communities. We are deeply grateful for your lifetime support.

Thank you.

[The statement follows:]

#### PREPARED STATEMENT OF JOHN M. LAWSON

Mr. Chairman and members of the Subcommittee: Thank you for the opportunity to testify on behalf of our members—representing the 356 local public television stations across the nation. In an era of mergers and acquisitions, our stations are among the last of the locally-controlled media and, in that regard, perhaps best reflect one of the central tenets of our democratic society.

With all that's been said and written about public broadcasting, especially over the past several weeks, my concern is that we not become distracted from our core issues. More to the point, I think it's important that we not lose sight of who we serve.

It's not the media. It's not the pundits. And it's not really us in Washington.

—It's the viewers and listeners who turn to public TV and radio as their most trusted source for news and public affairs.

—It's the children whose public education is improved by programs in reading, math and science.

—It's the parents who depend on public television for home-schooling, and who want to be assured that what their children watch on TV is family-friendly and non-violent.

—And it's the people living in Russell, Kansas, Cumming, Iowa, Tunica, Mississippi, Hoppers Bay, Alaska and other rural communities, who depend on public TV and radio as a lifeline for news and weather alerts. These are the real people public broadcasting serves.

#### THE DIGITAL AGE

But make no mistake. We are not resting on our laurels. Our viewers challenge us—and we challenge ourselves—to keep pace with a changing society.

With the support of this subcommittee, we are converting to digital television broadcasting [DTV]. In practical terms, this means that instead of transmitting a single program over the airwaves, stations can now broadcast a wide range of new services, including standards-based education, all-day channels for kids, and expanded public affairs and local programming, simultaneously. DTV means we can reach non traditional learners, the elderly, Spanish language speakers and Rural Americans as never before.

I'm also pleased to report that the Department of Homeland Security has turned to our stations for help with upgrading the aging Emergency Alert System [EAS]—using our digital signals to overcome the communications bottlenecks we saw on 9/11, both here and in New York City.

Last year, in fact, my association and DHS signed a cooperative agreement to begin a pilot project in the National Capital Region to demonstrate the capabilities of public television's infrastructure to support the distribution of digital EAS messages. The goal was to prove that we could distribute digital EAS messages (such as audio, video, and/or data messages) wirelessly to any number of communications devices: TVs, radios, PCs, cell phones, pagers and wireless networks.

The pilot has been a success, and I am gratified to make an important announcement today. Building upon the success of this pilot project here in the National Capital Region, DHS has signed a new cooperative agreement with APTS to plan the national roll-out of the Digital Emergency Alert System. We will use the PBS satellite system and the local public television stations as the backbone for this significantly upgraded public warning system.

#### HOUSE ACTION

Just over two weeks ago, the House of Representatives voted—by a 2 to 1 margin—to restore \$100 million cut from the Corporation for Public Broadcasting by the House Appropriations Committee. While we are grateful for that bipartisan vote of confidence, unfortunately, the House bill still fails to fund four critically important programs: next generation interconnection, digital conversion, ready to learn and ready to teach. In other words, the bill sent by the House to the Senate falls more than \$103 million short of what is required to sustain public broadcasting's mission in the 21st century.

Moreover, we believe the House cuts presented a great fiscal contradiction. On the one hand, two authorizing committees—Budget and Commerce—have made the digital conversion of the television industry a major priority. This is because the Federal Government can recover and auction off the nation's analog television spectrum for billions of dollars in new revenue, without raising taxes. Some of these channels have already been promised to public safety. On the other hand, this will occur only when consumers all make the switch and broadcasters cease analog transmission.

Public television has clearly led the broadcasting industry in driving the digital conversion. Yet the House cuts would severely damage our digital transition at precisely the moment in history when Public Television is doing the most to make the auctions feasible by a date certain. In purely financial terms, cuts to public television are penny-wise and pound foolish.

Tomorrow, this subcommittee will take on the difficult task of allocating scarce resources across a range of important programs. So, if I may, I'd like to briefly review what our local stations believe is needed to continue serving their communities.

#### CPB ADVANCE FUNDING

First and foremost, the Corporation for Public Broadcasting is the lifeblood of funding for our stations. Federal funding is the foundation, the seed money on which we raise all other money.

As you know, there has been a long-standing practice of providing CPB funds two years in advance, so that stations can more effectively plan and manage their operations, as well as leverage non-Federal funds. Doing so does not cost the Federal Government any more than a current-year appropriation would.

For CPB, we ask that no funds previously appropriated for fiscal year 2006 be rescinded. We suggest that the outpouring of popular support for public broadcasting that compelled the full House to restore a \$100 million cut by the House Appropriations Committee is the clearest expression of opposition to any rescission.

We further urge you to appropriate \$430 million for fiscal year 2008, an increase of \$30 million over what was appropriated last year. This represents an annualized increase over two years of three and three-quarters percent. These additional funds are needed because stations are required to transmit both analog and digital signals. Just the added cost for electricity amounts to \$30 million—annually.

#### NEXT GENERATION INTERCONNECTION SYSTEM

Two years ago, this subcommittee recognized that our current satellite interconnection system is wearing out and badly in need of replacement. We set out a four-year phase-in of a new system that will allow local stations—wherever they are—to share programming with one another, across their state, and across the country.

For this year's installment, we are requesting level funding—\$40 million.

We call this system the Next Generation Interconnection System, or NGIS. Like its predecessors, NGIS will serve as a distribution system linking PBS to local stations. Yet this time, stations will be equipped with servers that will store programming, digitally, to be aired—or shared—at the station's discretion.

In engineering-speak, NGIS will give public broadcasters station-to-station connectivity, on demand. Let me give you an example of what that capability means in the real world.

Let's assume that WHYY in Philadelphia has produced a program on the history and preservation of the Liberty Bell. In the NGIS world, WHYY will be able to distribute the program to any station in the country that wants it with the ease of a few clicks of a mouse. But that's just the beginning. Perhaps a station in say, Bethel, Alaska, is working with their local school district to put together some multimedia history content. A station employee in Alaska gets online to search public television archives and, lo and behold, not only finds what WHYY has produced on the Liberty Bell, but can choose just a small segment of that program—whatever works best for them. Think of this station-to-station sharing feature as connecting hundreds of local digital libraries that house local content.

#### CPB DIGITAL

Next year, the Federal Government requires that public television stations deliver a full digital signal to their entire viewing area, and that the final digital channel selection for stations be in place. To help meet these Federal mandates, we are requesting \$45 million to help stations complete their digital build-out. This augments the DTV conversion funds that have come from State governments and private fundraising. With funding for fiscal year 2006, our request will ramp down to zero over the next few years. Without this funding, rural and smaller public television stations are at real risk of going dark when the digital clock strikes 12:00.

#### READY TO LEARN/READY TO TEACH

If I can characterize CPB as the lifeblood of our stations, I would describe the Ready To Learn and Ready To Teach programs as the crown jewel in public broadcasting. These programs are what the term "educational" in our governing statute are all about.

Ready To Learn provides educational programming for tens of millions of American children, including *Between the Lions*, *DragonTales*, *Clifford*, and *Sesame Street*. The unique national-local partnership between PBS and local stations supports both the development and distribution of educational programming and the extension of this programming into the community, using specially developed curriculum and community outreach activities. The Ready To Learn service is designed to build partnerships with local community organizations such as childcare centers, schools, libraries, businesses, civic groups, and government agencies facilitated through local public television stations.

Through this extensive national-local partnership, approximately eight million children have benefited from the outreach component of the program, better prepared to enter school ready to succeed. This year, Public Television is requesting \$32 million in fiscal year 2006 to expand the reach and programming supported by Ready To Learn.

Ready To Teach uses technology to help train elementary and secondary school teachers in core curriculum subjects. It is a teacher professional development program that joins the power of multimedia content with facilitated training modules

in conjunction with local accredited higher ed institutions. To date, the 80 Ready To Teach stations have reached tens of thousands of teachers. Ready To Teach continues to grow in terms of both station and teacher participation; thus for fiscal year 2006, we request \$17 million to continue this effective program.

In conclusion, Mr. Chairman, I want to thank you, Senator Cochran, Senator Stevens, Senator Harkin, and your colleagues on this subcommittee for your unswerving support of public broadcasting. Time and again—through good times and bad—you have made it possible for public television and radio to fulfill their role to the local communities they serve. Thank you.

Senator SPECTER. Thank you very much, Mr. Lawson.

The final witness on this panel is Mr. David Boaz, Executive Vice President of the Cato Institute. Prior to joining Cato in 1981, he was Executive Director of the Council for a Competitive Economy. He has played a key role in the development of the Cato Institute and the libertarian movement, a graduate of Vanderbilt University.

We appreciate your coming in this morning, Mr. Boaz, and we look forward to your testimony.

**STATEMENT OF DAVID BOAZ, EXECUTIVE VICE PRESIDENT, CATO INSTITUTE**

Mr. BOAZ. Thank you, Mr. Chairman. Mr. Chairman and Senator Inouye. Thank you for the opportunity to provide a little diversity on this table and to explain why I think taxpayer funding for the Corporation of Public Broadcasting should be eliminated. I will touch briefly on several arguments in my oral discussion and I will save the most important for last.

First, we have a \$400 billion deficit and Congress and the Appropriations Committees should be looking for opportunities to cut nonessential spending. In a world of 500 channels and the World Wide Web, government-funded radio and training networks are nonessential.

Second, public broadcasting is welfare for the rich. In their public defenses, officials of CPB wax eloquent about bringing “Sesame Street” and Shakespeare to poor and isolated children. In talking to their advertisers, however, they are more candid. The audiences for PBS and NPR are the best educated, most professional, and richest audiences in broadcasting. Their cultural programming reflects elite tastes and I like a lot of it myself. But I think that we upper middle class people should pay for our own art and entertainment.

Third, NPR and PBS can survive privatization. As they often remind us, they get only 15 percent of their revenue from the Federal Government. Mr. Chairman, families and businesses in Pennsylvania often deal with 15 percent losses in their income. It is not fun, but they do it. The \$2.5 billion public broadcasting complex can survive and prosper without Federal tax dollars.

Fourth, in news and public affairs programming, bias is inevitable. Any reporter or editor has to choose what is important. It is impossible to make such decisions without a framework, a perspective, a view of how the world works. A careful listener to NPR would notice a preponderance of reports on racism, sexism, and environmental destruction, reflecting a particular perspective on what is most important in our world. David Fanning, the executive producer of PBS’s “Front Line,” responds to questions of bias by saying: “We ask hard questions to people in power. That is anathema to some people in Washington these days,” unquote. But there has

never been a “Front Line” documentary on the burden of taxes of the number of people who have died because Federal regulations keep drugs off the market, or the way that State governments have abused the rule of law in their pursuit of tobacco companies, or the number of people who use guns to prevent crime. Those hard questions just do not occur to liberal journalists.

Anyone who got all his news from NPR would never know that Americans of all races live longer, healthier, and in more comfort than ever before in history or that the environment has been getting steadily cleaner.

That brings me to my major concern. We would not want the Federal Government to publish a national newspaper. Neither should we have a government television network and a government radio network. If anything should be kept separate from government and politics, it is the news and public affairs programming that informs Americans about government and its policies. When government brings us the news, with all the inevitable bias and spin, the government is putting its thumb on the scales of democracy.

Journalists should not work for the Government. Journalists should not have officials of the Government looking over their shoulders. And taxpayers should not be forced to subsidize news and public affairs programming.

Therefore I urge you, not merely to reduce, but to eliminate taxpayer funding for public broadcasting. Now, even if this committee comes to my conclusion that taxpayer funding for radio and television networks is imprudent and constitutionally unfounded, I recognize that you may hesitate to withdraw a funding stream that stations count on. Even though Federal funding is only about 15 percent of public broadcasting revenues, you might choose to phase out the funding, perhaps on a 5-year schedule.

#### PREPARED STATEMENT

The total funding request for this year is about \$500 million. Congress could reduce it by \$100 million a year, leaving the CPB entirely free of taxpayer funding and of Federal intervention in what journalists do at the end of 5 years.

Thank you for your attention, Senators.

[The statement follows:]

#### PREPARED STATEMENT OF DAVID BOAZ

Thank you for the opportunity to testify on taxpayer funding for the Corporation for Public Broadcasting and by extension for National Public Radio and the Public Broadcasting System. I shall argue that Americans should not be taxed to fund a national broadcast network and that Congress should therefore terminate the funding for CPB.

We wouldn't want the Federal Government to publish a national newspaper. Neither should we have a government television network and a Government radio network. If anything should be kept separate from Government and politics, it's the news and public affairs programming that informs Americans about Government and its policies. When Government brings us the news—with all the inevitable bias and spin—the Government is putting its thumb on the scales of democracy. Journalists should not work for the Government. Taxpayers should not be forced to subsidize news and public-affairs programming.

Much of the recent debate about tax-funded broadcasting has centered on whether there is a bias, specifically a liberal bias, at NPR and PBS. I would argue that bias is inevitable. Any reporter or editor has to choose what's important. It's impossible

to make such decisions without a framework, a perspective, a view of how the world works.

As a libertarian, I have an outsider's perspective on both liberal and conservative bias. And I'm sympathetic to some of public broadcasting's biases, such as its tilt toward gay rights, freedom of expression, and social tolerance and its deep skepticism toward the religious right. And I share many of the cultural preferences of its programmers and audience, for theater, independent cinema, history, and the like. The problem is not so much a particular bias as the existence of any bias.

Many people have denied the existence of a liberal bias at NPR and PBS. Of course, the most effective bias is one that most listeners or viewers don't perceive. That can be the subtle use of adjectives or frameworks—for instance, a report that "Congress has failed to pass a health care bill" clearly leaves the impression that a health care bill is a good thing, and Congress has "failed" a test. Compare that to language like "Congress turned back a Republican effort to cut taxes for the wealthy." There the listener is clearly being told that something bad almost happened, but Congress "turned back" the threat.

A careful listener to NPR would notice a preponderance of reports on racism, sexism, and environmental destruction. David Fanning, executive producer of "Frontline," PBS's documentary series, responds to questions of bias by saying, "We ask hard questions to people in power. That's anathema to some people in Washington these days." But there has never been a "Frontline" documentary on the burden of taxes, or the number of people who have died because federal regulations keep drugs off the market, or the way that state governments have abused the law in their pursuit of tobacco companies, or the number of people who use guns to prevent crime. Those "hard questions" just don't occur to liberal journalists.

Anyone who got all his news from NPR would never know that Americans of all races live longer, healthier, and in more comfort than ever before in history, or that the environment has been getting steadily cleaner.

In Washington, I have the luxury of choosing from two NPR stations. On Wednesday evening, June 29, a Robert Reich commentary came on. I switched to the other station, which was broadcasting a Daniel Schorr commentary. That's not just liberal bias, it's a liberal roadblock.

In the past few weeks, as this issue has been debated, I've noted other examples. A common practice is labeling conservatives but not liberals in news stories—that is, listeners are warned that the conservative guests have a political agenda but are not told that the other guests are liberals. Take a story on the Supreme Court that identified legal scholar Bruce Fein correctly as a conservative but did not label liberal scholars Pamela Karlan and Akhil Amar. Or take the long and glowing reviews of two leftist agitprop plays, one written by Robert Reich and performed on Cape Cod and another written by David Hare and performed in Los Angeles. I think we can be confident that if a Reagan Cabinet official wrote a play about how stupid and evil liberals are—the mirror image of Reich's play—it would not be celebrated on NPR. And then there was the effusive report on Pete Seeger, the folksinger who was a member of the Communist Party, complete with a two-hour online concert, to launch the Fourth of July weekend.

And if there were any doubt about the political spin of NPR and PBS, it was surely ended when a congressional subcommittee voted to cut the funding for CPB. Who swung into action? Moveon.org, Common Cause, and various left-wing media pressure groups. They made "defending PBS" the top items on their websites, they sent out millions of emails, they appeared on radio and television shows in order to defend an effective delivery system for liberal ideas. Public broadcasters worked hand in glove with those groups, for instance linking from the NPR website to those groups' sites.

There are many complaints today about political interference in CPB, PBS, and NPR. I am sympathetic to those complaints. No journalist wants political appointees looking over his shoulder. But political interference is entirely a consequence of political funding. As long as the taxpayers fund something, their representatives have the authority to investigate how the taxpayers' money is being spent. Recall the criticism directed at PBS in 1994 for broadcasting *Tales of the City*, which has gay characters. Because of the political pressure, PBS decided not to produce the sequel, *More Tales of the City*. It appeared on Showtime and generated little political controversy because Showtime isn't funded with tax dollars. Remove the tax funding, and NPR and PBS would be free from political interference, free to be as daring and innovative and provocative as they like.

One dirty little secret that NPR and PBS don't like to acknowledge in public debate is the wealth of their listeners and viewers. But they're happy to tell their advertisers about the affluent audience they're reaching. In 1999 NPR commissioned Mediamark Research to study its listeners. NPR then enthusiastically told adver-

tisers that its listeners are 66 percent wealthier than the average American, three times as likely to be college graduates, and 150 percent more likely to be professionals or managers.

But perhaps that was an unusual year? Mediamark's 2003 study found the same pattern. As NPR explained, based on the 2003 study:

Public radio listeners are driven to learn more, to earn more, to spend more, and to be more involved in their communities. They are leaders and decision makers, both in the boardroom and in the town square. They are more likely to exert their influence on their communities in all types of ways—from voting to volunteering.

Public radio listeners are dynamic—they do more. They are much more likely than the general public to travel to foreign nations, to attend concerts and arts events, and to exercise regularly. They are health conscious, and are less likely to have serious health problems. Their media usage patterns reflect their active lifestyles, they tend to favor portable media such as newspapers or radio.

As consumers, they are more likely to have a taste for products that deliver on the promise of quality. Naturally, they tend to spend more on products and services.

Specifically, the report found, compared with the general public, NPR listeners are

- 55 percent less likely to have a household income below \$30,000
- 117 percent more likely to have a household income above \$150,000
- 152 percent more likely to have a home valued at \$500,000 or more
- 194 percent more likely to travel to France
- 326 percent more likely to read the New Yorker
- 125 percent more likely to own bonds
- 125 percent more likely to own a Volvo.

PBS has similar demographics. PBS boasts that its viewers are:

- 60 percent more likely to have a household income above \$75,000
- 139 percent more likely to have a graduate degree
- 98 percent more likely to be a CEO
- 132 percent likely to have a home valued at \$500,000 or more
- 315 percent more likely to have stocks valued at \$75,000 or more
- 278 percent more likely to have spent at least \$6000 on a foreign vacation in the past year.

Tax-funded broadcasting is a giant income transfer upward: the middle class is taxed to pay for news and entertainment for the upper middle class. It's no accident that you hear ads for Remy Martin and "private banking services" on NPR, not for Budweiser and free checking accounts.

Defenders of the tax-funded broadcast networks often point out that only about 15 percent of their funding comes from the Federal Government. Indeed, NPR and PBS have been quite successful at raising money from foundations, members, and business enterprises. Given that, they could certainly absorb a 15 percent revenue loss. Businesses and nonprofit organizations often deal with larger revenue fluctuations than that. It isn't fun, but it happens. In a time of \$400 billion deficits, Congress should be looking for nonessential spending that could be cut. Tax-funded broadcasting is no longer an infant industry; it's a healthy \$2.5 billion enterprise that might well discover it liked being free of political control for a paltry 15 percent cut.

Finally, I would note that the Constitution provides no authority for a Federal broadcasting system. Members of Congress once took seriously the constraints imposed on them by the Constitution. In 1794 James Madison, the father of the Constitution, rose on the floor of the House and declared that he could not "undertake to lay his finger on that article of the Federal Constitution which granted a right to Congress of expending, on objects of benevolence, the money of their constituents." In 1887, exactly 100 years after the Constitution was drafted, President Grover Cleveland made a similar point when he vetoed a bill to buy seeds for Texas farmers suffering from a drought, saying he could "find no warrant for such an appropriation in the Constitution." Things had changed by 1935, when President Roosevelt wrote to Congress, "I hope your committee will not permit doubts as to constitutionality, however reasonable, to block the suggested legislation." I suggest that this committee take note of the fact that no article of the Constitution authorizes a national broadcast network.

Even if this committee comes to the conclusion that taxpayer funding for radio and television networks is imprudent and constitutionally unfounded, I recognize that you may hesitate to withdraw a funding stream that stations count on. In that regard, I would note again that federal funding is only about 15 percent of public broadcasting revenues. But you might also phase out the funding, perhaps on a 5-year schedule. The total funding request for this year is about \$500 million. Con-

gress might decide to reduce it by \$100 million a year, leaving the CPB entirely free of federal taxpayer funding at the end of 5 years.

But Congress's resolve in such matters is not trusted. Recall the 1996 Freedom to Farm Act, which likewise promised to phase out farm subsidies. Barely two years had passed when Congress began providing "emergency relief payments" to make up for the scheduled reductions. This time, if Congress pledges to phase out broadcasting subsidies, it needs to make sure that its decision sticks.

A healthy democracy needs a free and diverse press. Americans today have access to more sources of news and opinion than ever before. Deregulation has produced unprecedented diversity—more broadcast networks than before, cable networks, satellite television and radio, the Internet. If there was at some point a diversity argument for NPR and PBS, it is no longer valid. We do not need a government news and opinion network. More importantly, we should not require taxpayers to pay for broadcasting that will inevitably reflect a particular perspective on politics and culture. The marketplace of democracy should be a free market, in which the voices of citizens are heard, with no unfair advantage granted by Government to one participant.

Senator SPECTER. Thank you very much, Mr. Boaz.

We have been joined by Senator Durbin. Would you care, Senator Durbin, at this point to make an opening statement?

Senator DURBIN. I can put it in the record. I would just like to ask some questions.

Senator SPECTER. Without objection, his statement will be put in the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR RICHARD J. DURBIN

Thank you, Mr. Chairman, for holding this hearing today. I want to welcome all the witnesses, and look forward to their testimony.

Like millions of parents around the nation, I am a strong supporter of public broadcasting for all the great educational opportunities it provides to our children. Over one third of all public broadcasts aired on weekdays are dedicated to children's programming. More important than what children see on public television is what they don't see—commercials about junk food and toys, interruptions throughout a program, violence, adult themes, and content simply not suitable for children.

Public Broadcasting Service provides more than just a wide range of programs for children's learning. PBS also provides online learning games and activities for children, as well as resources—including workshops and free books—for parents, caregivers, and educators to further enhance the academic and pro-social skills-learning experience for the children. These high quality tools, many of which are developed jointly with the U.S. Department of Education, have been proven to help build our children's literacy and school-readiness skills.

I am also a supporter of public broadcasting because of the value it adds to smaller towns and rural counties throughout Illinois and elsewhere. Sixty-five million Americans live in rural areas, yet many of these households do not have cable and broadband access. Free, over-the-air, public educational television continues to be a critical asset to rural Americans.

Thus, there is no question in my mind when it comes to fully funding the Corporation for Public Broadcasting and the other requests made by the public broadcasting community. It is a bargain to think that we can have such an abundance of quality programs for the entire year at the cost of a little more than \$1 of public funding per person in America.

Public funding is especially important for smaller or rural stations that depend on the federal funding as seed money to plan out their operations for the upcoming years. For these stations, the federal funds we provide each year make up a larger portion of their annual budget than stations in other parts of the country. But, unlike their counterparts in big cities, rural public stations simply do not have the fundraising bases—such as large pool of individual, corporate, and foundation donors—that could potentially replace any shortfall in federal funding.

I look forward to working with the Chairman and the members of this subcommittee to ensure that every item asked for by our local stations can be met in our appropriations process this week and beyond.

I also look forward to clearing the air today of several controversies surrounding recent activities at the Corporation for Public Broadcasting. I am very concerned to read in the press that there may be partisan political activities taking place at CPB,



and I hope we will receive some straight answers to these lingering questions from representatives of CPB.

Mr. Kenneth Tomlinson, who appears before us today as CPB's chairman of the board of directors, has been associated with many of these allegations. There are reports that he has made personnel decisions based on partisan or political factors and that he has influenced the content of programs that are aired on public broadcasting. These allegations rise to such a serious level that CPB's own inspector general has initiated an internal investigation.

One episode is particularly troubling. According to press reports, Mr. Tomlinson paid an outside consultant over \$14,000 of taxpayer funds to have him monitor certain public broadcast programs to determine the political ideology of guests who appear on these shows. The consultant's report is now in the public domain, and its conclusions are suspicious, at best. For example, according to Mr. Tomlinson's consultant, my Republican colleague, Senator Chuck Hagel, is a "liberal" because he happened to disagree with some of President Bush's positions on a show that aired on public broadcast. The report is full of such ridiculous assertions.

I have also read that Mr. Tomlinson personally advocated for the addition of a program to the PBS lineup hosted by editors of the Wall Street Journal's editorial page, in his self-described attempt to balance the perceived liberal bias of "NOW" with Bill Moyers. This comes at the same time when CPB is insisting on tying new funding for PBS to an agreement that PBS would commit to strict new standard of "objectivity and balance" in its programs.

Apparently, Mr. Tomlinson believes public broadcasting is too liberal, even though a series of focus groups and two national surveys conducted at CPB's own request concluded that the public perception is otherwise. Specifically, the survey of over 1,000 adults found that only 21 percent thought the Public Broadcasting Service had a liberal bias and 22 percent thought the National Public Radio had a liberal bias. The survey found that 12 percent thought PBS had a conservative bias and 9 percent thought the same of NPR. This means that two-thirds of those surveyed believed there was no apparent bias on PBS or NPR.

Additionally, the survey conducted on CPB's behalf found that 80 percent of respondents had a "favorable" opinion of public broadcasting, while only 10 percent had an "unfavorable" opinion. More than half of the respondents (55 percent) also said that PBS programming was "fair and balanced," while NPR received an even higher approval rating of 79 percent.

The internal survey results and the overwhelming support expressed by the public as evidenced by the recent vote in the House of Representatives to restore funding for public broadcast seem to indicate that perhaps Mr. Tomlinson should rethink what he believes is in the best interests of the consumers of public broadcasting.

Senator SPECTER. Mr. Boaz, let us start with the question that you raised, that public broadcasting can survive without Federal funding. Ms. Mitchell, can public broadcasting survive without Federal funding, as Mr. Boaz suggests?

Ms. MITCHELL. Mr. Chairman, I would respectfully disagree with the principle of Mr. Boaz's arguments. It is a principle of this democracy that, while we have very successful private bookstores, we still invest in private—in public libraries. And we have private schools, but we invest in public schools.

This Congress saw the benefit of setting aside public spectrum for public service broadcasting and that is, it seems to me, a great use of public funds, using the power of media to inform and engage citizens so that the great work of this democracy might go forward.

Senator SPECTER. Ms. Mitchell, I am not quite sure of your answer. Can public broadcasting survive without Federal funding?

Ms. MITCHELL. The taxpayer dollars, Mr. Chairman, are leveraged with private money. So that 15 percent is a hugely important critical foundation for not only the station services, because most of the money, as Ms. Harrison represented, goes directly to the stations, and there they leverage from the 15 or 20 percent of their budget that is provided by appropriations, they leverage all of this private investment from foundations, corporations, and, yes, view-

ers like you, who still voluntarily support at a level that is the largest single percentage.

Senator SPECTER. Mr. Lawson, the point is made by Mr. Boaz that there ought not to be a national newspaper and analogizes that to public broadcasting. Let me ask you a two-part question. Would you agree that there ought not to be a national newspaper, part one? And part two, does public broadcasting—and I am going to give Mr. Boaz a chance to respond to this, too—come anywhere in the range of constituting what would be a national media organ?

Mr. LAWSON. No, sir, I do not think there should be a national newspaper and I do not think public broadcasting in any way constitutes a national media organ. As I said in my statement, we are the last of the locally controlled media. That is a characteristic of American public broadcasting that is different from any other country. We are not the BBC, we are not NHK, we are not centrally managed. It is about local control.

I can tell you, if the 15 percent went away, first you would see stations serving rural America go dark. Secondly, even for the big market stations there would be so much pressure on them to replace that money. The Federal money is the foundation, it is the seed money. All the other money we raise is based on that, and you would see enormous pressure on even the largest stations to become more commercial.

So localism is the key to public broadcasting in the United States.

Senator SPECTER. Mr. Boaz, you raise a very fundamental point here on the kinds of programming and have identified a series of subjects which you note that the "Front Line" documentary has never addressed, such as burden of taxes or the regulatory system or pursuit of private companies. Has "Front Line" or other similar programs on public broadcasting addressed any of the issues which you think would provide balance on the kind of hard questions which ought to be asked?

Mr. BOAZ. I am sure that no program has been completely unbalanced. But I am not aware of "Front Line"—I did actually check with "Front Line" on these specific claims and they acknowledge that, no, they have never done a documentary on those. Certainly some of the questions that "Front Line" deals with I think are important and sometimes "Front Line's" programming is I think balanced.

But I do not think you can watch it or listen to National Public Radio, which I do at least twice a day, and not get the impression that there is a particular perspective guiding it. As I say in my written testimony, I agree with some of that perspective. I am sympathetic to NPR's skepticism about the religious right, its support for social tolerance and freedom of expression. But I do think that is a perspective.

I have a political opinion and so do the editors and producers at NPR. So I do think it is impossible to avoid some sort of perspective or theme running through your programming and I think that "Front Line," the other documentary series, NPR, have not avoided that bias.

## HOUSE APPROPRIATION BILL

Senator SPECTER. Ms. Harrison, the Appropriations Committee is going to have to consider the issue of digital transition. The House did not provide a direct appropriation for digital transition, but instead gave CPB authority to carve out funds from station grants.

To what extent would the absence of a direct grant for digital transition and a requirement that the money come out of station grants be problematic for you?

Ms. HARRISON. Mr. Chairman, if I could answer that question by folding in some of the things that we have been discussing here today. Public broadcasting is our strongest connected community at a time when we need an informed citizenry. Even though we have multiple channels, it seems amazing; the more channels we have, the more dumbing down occurs through programs, whether it is aimed at children or it is aimed at people who are older.

If we have to give up the money for this very, very important digital technology, it will come directly out of the sole purpose for which public broadcasting exists, and that is to be a network of knowledge. We will have to meet with the stations, the general managers, and the cuts will be very bad.

I feel so strongly about the purpose of public broadcasting as an educator, and now as we have increasingly more young people in this country who do not understand our history or civics, we have new Americans—and you know, sometimes those moms and their kids are sitting in front of these children's programs and they are learning English, they are learning about our country. If we did not have public broadcasting today, we would have to re-invent it.

I come to this job from a former position where in the early 90s exchanges were cut. We thought technology was going to enable us to increase mutual understanding between the people of the United States and other countries. What we found out is the people to people connection is important. This community connection is vital to our country's strength and I think to the strength of our democracy.

Senator SPECTER. We have since been joined by Senator Stevens, formerly the chairman of the full committee. Before going to Senator Inouye for his opening round of questions, Senator Stevens, would you care to make an opening statement?

## STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. Thank you very much, Mr. Chairman. I am sorry to be late. To confess, my mind is still in Alaska on the fishing stream, and there is 4 hours time difference, too. But I do appreciate the opportunity to come here and I hope I can stay through a round of questioning.

I believe that the full amount of the request should be supported by the subcommittee and moneys deleted by the House be restored. But I also believe that what Mr. Boaz has just said is true, that there are signs in portions of the Corporation for Public Broadcasting and the Broadcasting Service which indicate that there are unfortunate trends in some places to take on political issues in a way that demonstrates a bias.

It is my judgment that there should be no bias, no leaning to the right or to the left by management or by those who operate the stations. The answer that I think you should have given, Ms. Mitchell, to the chairman's question are the Federal dollars necessary, can these organizations survive without Federal money, the answer has got to be no. In my State there are many places where you do not have sufficient base for public support. Our State helps by paying in some areas the telephone services for these various stations. But there are other areas in the country which do not have public support capability, financial support capability.

I do believe that the Federal money is not only seed money for the system, but it is absolutely necessary to assure that the system will be extended to wherever there is a need, rather than wherever there is the public support base for financial contributions.

But I thank you for holding the hearing. I do think that members of the Congress ought to calm down. This system needs our support. I remember so well when we started some of the concepts of matching funds. We took away the actual matching fund requirement that existed for a little while. But I do believe that this is an essential service.

My mind goes back to "The Adams Papers" or to the rebroadcasting of some of the BBC programming that we would not have had otherwise. I know this system is needed by the country, but I deplore the fact that there are some people within it that want to exercise their political bias in delivering it. That is your problem. I think the board's problem is to get rid of that and restore the balance that existed in the past in the system and really not look to the left or the right, but just look wherever there is bias going either direction and set the record straight so we will not face this challenge that the House has delivered.

I think they were right in delivering it, because I think you are all here today to really react to the cause of that deletion. I think our job is to put the money back and convince them that there has been a wakeup call, that the bells have rung and that people have heard the message, and we are all going to make this system work.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Stevens.

Senator Inouye.

#### STATEMENT OF SENATOR DANIEL K. INOUE

Senator INOUE. Thank you very much.

#### AUDIENCE DEMOGRAPHICS

I would like to assure the panel here that I fully support full funding of what you are requesting. I would like to ask Ms. Harrison or Ms. Mitchell, do you believe that in the case of your operation monies—funded by the taxpayers—are they being spent to cater only to the rich and the educated? That is what was said here.

Ms. MITCHELL. Our viewers and our supporters, Senator Inouye, reflect and mirror very closely the demographic makeup of our communities, and that is in terms of income and education and ethnicity and cultural background. I would like to take Mr. Boaz on some of my visits to our stations, where he would meet these

people and see their faces, the faces of caregivers in rural Mississippi who have no books in the home, who are unprepared themselves, and often, as Pat said, even without the literacy skills they need, much less the skills to pass it on to the children in their care.

In those places and the rural places in this country, all over this country, we are there providing caregivers with materials they would not have otherwise: free books, training for these caregivers, literacy skills that prepare those children, usually the most disadvantaged.

I would also point out that among all the other children's programs that are on television, ours are the only ones that begin with educators, that begin with clear learning objectives, and that are based in every way, through characters, scenarios, to appeal to every child in this country, so that no parent or caregiver is left behind.

Mr. Chairman, may I take this moment also to say that in a time when, as Senator Stevens referenced, the trust in media has never been lower in this country—and I think there is good reason for that. And since our trust level is so high, we felt it very important for us to review the editorial standards that guide our program decisionmaking. More than a year ago we put together a blue ribbon panel of journalists and we asked them to look at our programming from every perspective: Was it reflecting the needs of our communities that we knew from the public opinion polls, and then the editorial standards, were they ensuring that we complied, not only with the statutory obligations for objectivity and balance, but that we went beyond that and clarified what we mean by accuracy, reliability, transparency.

Those new guidelines are in place and we believe that they will further ensure that on all subjects—and those subjects that Mr. Boaz referenced I am going to pass along to "Front Line" this afternoon; they sound like subjects we should be looking at—that on all subjects we represent the diversity of perspectives that is in this country.

Ms. HARRISON. Senator Inouye, I welcome this opportunity to address your question and also in an oblique way Mr. Boaz. CPB is the only organization within public broadcasting that really is cast to look at the concerns you expressed: Are we taking care of minorities? Are we looking at rural communities? Are we doing the outreach which only public broadcasting can do, prior to a program and after, involving communities?

My father when he died had Alzheimer's. I only wish that my mother had been able to access a recent program that public broadcasting did on Alzheimer's that was not just a program; it had a shelf life long after the program was over. It involved caretakers and organizations. After you watched this series, you felt there was some light at the end of the tunnel.

Commercial television cannot do this. This is the focus that CPB has and the mandate that we have, that it is not an elite programming entity, that we look at the big picture. Children more and more—I keep harping on that—if we do not focus on children, we are not going to have a very positive big picture for anyone across the line of all issues.

Thank you.

## IMPORTANCE OF FEDERAL FUNDING

Senator INOUE. Do you believe that our funding, Federal funding, is in our national interest?

Ms. HARRISON. I certainly do. You know, I do not want to appear as an instant expert. I have only been on this job for 4½ working days. But what surprised me was that in 1975 in an amendment to the Public Broadcasting Act President Ford at the time not only wanted Federal funding, he suggested it be 5 years out. Also, there is the authority to fund up to 40 percent, and the percentage has been going down. So we are at 15 percent now. I think the highest was 19 percent. 15 percent is modest, and I think all credit to the stations who have raised 85 percent of what they need to do, which keeps it local.

## PREPARED STATEMENT

Senator INOUE. I notice my time is up, sir.  
[The statement follows:]

## PREPARED STATEMENT OF SENATOR DANIEL K. INOUE

Since its creation as part of the 1967 Public Broadcasting Act, public broadcasting has pursued an ambitious mandate to provide educational, cultural and informational programming that takes creative risks while serving traditionally unserved and underserved populations.

Public broadcasting is a unique voice in the local community that we have come to trust and depend on. A recent survey conducted by The Roper Center for Public Opinion Research determined that public broadcasting is one of America's most trusted institutions.

Public television has set the standard with award-winning documentaries, outstanding children's programming, and in-depth news and public affairs programming that cannot be found on commercial television channels. The current audience for National Public Radio programming is 26 million listeners each week, up 97 percent over the past decade, as more and more Americans seek thoughtful analysis of the important issues facing our nation and our communities.

I am proud to be a long-time proponent of public broadcasting and believe that public broadcasting has been a tremendous success.

The funding cuts proposed by the House are ill-advised and poorly timed. As this Committee is well-aware, massive consolidation in the media industry along with a general coarsening of public discourse on the commercial airwaves is making it more and more difficult for families to find quality programming that is suitable for children. It makes no sense to undermine the primary place on the channel lineup that parents and families trust the most.

I am concerned not only about the funding cuts but also about the recent controversies reported in the press over possible misuse of taxpayer funds and the lack of transparency in decisions made by the Chairman of the CPB Board.

As a result of the current budget deficit, many important programs face funding cuts. These are not easy choices to make. While I am pleased that some of the funding for public broadcasting was restored by the House, funding for several important programs has been eliminated.

Funding for "Ready to Learn," which supports high quality children's programming, and grants supporting the transition from analog to digital broadcasting and the interconnection services that link public broadcasting stations together were all canceled out by our House colleagues. Traditionally, the Senate has restored this funding and I hope that Senators Specter and Harkin will continue to champion these important programs.

In particular, I question the wisdom of eliminating the funding to help local stations make the transition from analog to digital television, while at the same time, the Commerce Committees in both the House and Senate are considering legislation to complete the digital transition.

Public broadcasters are leading the way in the digital transition. More than 87 percent of public television stations are operating in digital. Public television licensees have embraced new services enabled by digital technology. Many stations already utilize multicasting capabilities to provide "PBS Kids" programming as a dedi-

cated children's channel and to provide educational services through "PBS You" as a dedicated channel.

Even without a government mandate, public radio stations are moving quickly to implement digital technology with 79 public radio stations broadcasting in digital and over 300 with licensed digital technology.

The use of taxpayer funds by the Chairman of CPB to hire lobbyists and consultants raises serious concerns. Not only do such actions potentially violate the prohibitions against advocacy in current law, but the fact that these steps were apparently taken without consultation with either the full Board or the President and CEO of CPB is extremely troubling.

The Inspector General is currently investigating whether these decisions violate the law and the CPB's bylaws, and I will look forward to his full report on those concerns. Without accountability and transparency in the use of taxpayer funds, the legitimacy of these actions is rightly questioned.

Concerns have also been raised that the CPB is straying from its statutory obligation to act as a heat shield between Congress and programming decisions. The Public Broadcasting Act requires the CPB "to carry out its purposes and functions and engage in its activities in ways that will most effectively assure the maximum freedom of the public telecommunications entities . . . from interference with, or control of, program content or other activities."

Thank you Mr. Chairman and I look forward to the testimony of the witnesses today on these important issues.

Senator SPECTER. Thank you very much, Senator Inouye.

Senator Stevens.

Senator STEVENS. Senator Durbin.

Senator SPECTER. Well, the early bird rule would go to Senator Durbin, but the practice of the committee has been to alternate between the sides.

Senator STEVENS. I am not prepared yet.

Senator SPECTER. Senator Durbin, you have the floor.

#### POLITICAL BALANCE IN PUBLIC BROADCASTING

Senator DURBIN. Thank you, Mr. Chairman, and I thank the panel. I especially thank you, Mr. Chairman, for calling this hearing because if your experience is like mine, this is an issue on the minds of a lot of people, what is happening to public broadcasting. Are we going through some effort now to politicize this, to change the nature and philosophy of something that we value very much in this country?

I am a fan, have been for a long time. Obviously, I am not alone. When you read the surveys of people asking them what they think about public broadcasting, it is pretty good. Over a thousand adults polled, PBS and NPR had an 80 percent favorable rating. Not a single one of us on this side of the panel would look askance at that number. 80 percent favorable is pretty good.

When you ask if it is fair and balanced, not to steal a line from some other company, 55 percent said PBS programming is, 79 percent said NPR is fair and balanced.

That is why it strikes me as odd, Mr. Tomlinson, that we are on this crusade of a sort here, this mission, to change what is going on. I do not quite get it, understand what your agenda is here and what you are trying to achieve.

I read and I watched over the break Mr. Moyers' speech in St. Louis, ordered a copy online, read it twice. It is troubling to me. I think Bill Moyers' program now is a balanced program and I think most people would agree with it. Now, Mr. Mann that you hired or someone hired to monitor this program came up with some

rather strange conclusions about who is a liberal and who is a conservative and who is a friend of the President and who is not.

Even I think in your opening statement you have tried to clarify that you do not stand by his conclusions, for example on Senator Hagel, the characterization of Senator Hagel as liberal and such. Maybe you do think he is a liberal. I do not know what that conclusion might be.

But the point I would like to get to is this. Let us go to a specific question. Under section 19 of Public Broadcasting Act you are required to mandate political balance on all shows. It has been reported that you have championed the addition of "Wall Street Journal Editorial Report" to the PBS lineup and that you have raised money for that purpose. I would like you to clarify. If you did that, how much money was raised? What was your purpose in bringing in the Wall Street Journal, which, as has been noted, is a publication owned by a company that has been very profitable and would not appear to need a subsidy to put on a show?

Mr. TOMLINSON. I think Senator Stevens hit the nail on the head: no bias. No bias on the left, no bias on the right. If we have programs, like the Moyers program, that tilt clearly to the left, then I think according to the law we need to have a program that goes along with it that tilts to the right and let the people decide.

Senator DURBIN. Let me ask you about this "clearly to the left" bias on the Moyers show. How did you reach that conclusion? Did you watch a lot of those shows?

Mr. TOMLINSON. I watched a lot of those shows, and I think Mr. Mann's research demonstrates that the program was clearly liberal advocacy journalism. It was good broadcasting. Bill Moyers is a very capable broadcaster. But it seems to me we should be able to agree that we do not want bias, and if we do in the interest of provoking debate, if we have some bias on public television, let us balance it out in the course of the evening.

Senator DURBIN. So what was Mr. Mann's expertise? Why did you happen to hire him? According to Senator Dorgan, who has seen the raw data, he was paid thousands of dollars. His data, riddled with spelling errors, was faxed to you from a Hallmark store in downtown Indianapolis. What is this man's background for judging a program like Moyers' program and whether it is liberal or not?

Mr. TOMLINSON. He worked for 20 years for the National Journalism Center, which is a 401(c)(3) organization.

Senator DURBIN. National Journalism Center?

Mr. TOMLINSON. National Journalism Center.

Senator DURBIN. What is that?

Mr. TOMLINSON. But the point of watching—

Senator DURBIN. Excuse me. What is the National Journalism Center?

Mr. TOMLINSON. It is a center here in Washington that funds internships for—

Senator DURBIN. And they are straight down the middle of the road, moderate, centrist group, right and left?

Mr. TOMLINSON. I think it qualified for 401(c)(3) support. I do not think it was regarded as right of center.



But the point is, it is like Bob Dylan said, you do not need a weather vane to see which way the wind is blowing. It was very clear that the Moyers program was liberal advocacy journalism. I wanted a statistical basis because I did not think people were responding appropriately. We got the statistical basis, and as soon as—

Senator DURBIN. From Mr. Mann?

Mr. TOMLINSON. From Mr. Mann's research. And as soon as we got the statistical basis, it turned out other people had determined that that program should be balanced. It was balanced. All this took place something like a year and a half ago.

Senator DURBIN. Well, let me—I have got to get to the basic question here. I will not go through the list of some of Mr. Moyers' more liberal guests—Frank Gaffney, Grover Norquist, Richard Viguerie, Paul Gigot—on his liberal program.

Mr. TOMLINSON. It was our experience—

Senator DURBIN. But let me ask you this if I can.

Mr. TOMLINSON. Yes, sir.

Senator DURBIN. Did you feel that it was your responsibility or authority to go out and put together the Wall Street editorial page show and to find subsidy for that? Did you feel that that was your responsibility to do?

Mr. TOMLINSON. I felt that the law required us to reflect balance in our current affairs programming. I was not the only one involved in encouraging a program that represented a diverse point of view from the Moyers show.

Senator DURBIN. So following Mr. Moyers' comments in St. Louis, can we expect you to do the same for "The Nation Magazine?" Are you going to raise \$5 million to make sure they have a show?

Mr. TOMLINSON. I do not see, I do not see today we have a balance problem. We have a 30-minute show "Now" and we have a 30-minute show, "Wall Street Journal." That is balanced. Let the people decide. Balance is common sense.

Senator DURBIN. But Mr. Tomlinson, the people I said at the outset already decided. They thought that the Corporation for Public Broadcasting was presenting balance and they thought that—they gave a high approval rating. You have perceived a problem here which the American people obviously do not perceive.

Mr. TOMLINSON. Well, certainly in terms of "Jim Lehrer News Hour" there is no balance problem. That is great journalism. Public broadcasting has a great reputation in these areas.

We had a period of time a few years ago where I think we were all asleep at the switch in terms of the Moyers program. I never wanted to take the Moyers program off the air.

Senator DURBIN. What do you mean by "asleep at the switch" with the Moyers program? I would like you to tell me a little bit more.

Mr. TOMLINSON. Because we should have been aware that on Friday evening if you presented liberal advocacy journalism for an hour you really should present conservative advocacy journalism for an hour, just for a matter of balance. The law requires balances.

Senator DURBIN. This was your conclusion based on Mr. Mann's investigation?

Mr. TOMLINSON. This was my conclusion when I found that there was a dispute over my view of this program and the general view of this program. I quite frankly have run into next to no serious people who regarded the Moyers program as anything other than good liberal advocacy programming.

Senator DURBIN. Will you accept his invitation to take an hour, go on the air on public television, and to debate that issue?

Mr. TOMLINSON. Absolutely. But you know—

Senator DURBIN. Oh, you will accept it?

Mr. TOMLINSON. Oh, absolutely. But you know, Senator Durbin, Bill Moyers and I both have concluded that this debate is not good for public television.

Senator DURBIN. No, it is not.

Mr. TOMLINSON. There were things that Moyers said in that speech about me that were most inaccurate and unfair. It saddened me to see that. I could have come back in kind. I chose not to. We are for public broadcasting, we are for no bias in public broadcasting. We do not want bias on the right and we do not want bias on the left.

Senator DURBIN. I have gone over my time. I thank the chairman for giving me a couple extra minutes and I will wait for the next round.

Mr. TOMLINSON. Thank you, sir.

Senator SPECTER. I thought we had a little more leeway here, Senator Durbin, than we do on the Judiciary Committee. So the red light was flexible.

Senator STEVENS, would you care to question?

#### PUBLIC TELEVISION INTERCONNECTION SYSTEM

Senator STEVENS. Well, I would clear up the Senator from Illinois' confusion. I think Bill Moyers is biased and I respect him for it. I think he is a very talented spokesman for his point of view in the political spectrum. I applaud you for recognizing that and counterbalancing it. I think your support will demonstrate that in the long run.

But the main thing is I want to get back to the financing of this, because that is the question before us, really. I just was waiting for the information, Mr. Chairman. My State contributed \$5.3 million as a State to public broadcasting stations in Alaska because we recognize the need for the system and to maintain it. I do believe that all States that have similar dependent communities should recognize it and should come forward and support it.

I would like to know whether you can tell me about the concepts that have been left out of this bill this year. The satellite upgrade of \$40 million, the request from the President was deleted. The digital programming of \$45 million was deleted. Each of those had had money in the fiscal year 2005. And the Ready to Learn program of \$32 million was deleted.

Now, those are the items that we are really concerned with. CPB's request was \$430 million. The House brought it down to \$400 million. There are lots of small adjustments that have to be made in these bills this year. I am not as disturbed about that as I am disturbed about the deletion of satellite upgrading, digital programming, and the Ready to Learn program, which I think has

been eminently successful in places like the rural stations that I mentioned in my State.

Who among you would be willing to talk about the satellite upgrade and its necessity? Mr. Lawson, is that you?

Mr. LAWSON. Yes, sir, I will take that one. It has been a Federal responsibility since day 1 to provide for this interconnection between the stations for the distribution of programming. Congress last, with your support, last funded that in the early 1990s. That system is becoming obsolete. The satellite leases are expiring. If that system is not renewed, then we are FedExing tapes around.

This is a system, this is the glue that holds our whole system together in terms of technical infrastructure. The exciting thing about the next generation, right now we are feeding a lot of programming to tape machines. It is expensive, it is very labor-intensive. This system will allow more peer to peer, station to station interaction. They will literally be emailing programs around as attachments to emails.

So you are going to see Alaska and stations all over this country with this new system not only receiving the PBS programming over the satellite, but they themselves will be able to move programming around and share it with other stations, without even having to go through a national organization like PBS.

So the infrastructure for the satellite interconnection is absolutely crucial. Without it we are not connected.

Senator STEVENS. Let me tell you a little history. When I moved to Alaska our programming, such as sports and weekly programming, they were sent up by tapes to Alaska. So if you had a baseball game on Friday on the 1st in Washington, D.C., you would see it on the 8th in Alaska. You know, I soon got out of the habit of watching baseball.

My point is right now what this means is real-time delivery to the country as a whole. Satellite interconnections are available in the South 48. In many places you can use fiber or you can use other connections. But in the rural part of the country that satellite connection is absolutely important.

So I want to assure you that is one thing, and I think in my colleague's State in Hawaii those small stations around the islands—actually, if you put a ring around Hawaii it would be bigger than Alaska; did you know that? We do not let them count the water. Ours is frozen in between, but his is open water.

But the point is is we need that.

Now, digital programming, who is going to tell us about the digital programming and the reason for even the President increased it by \$6 million? Who wants to comment on that? Is that yours too, Mr. Lawson? Ms. Harrison?

#### DIGITAL CONVERSION

Ms. HARRISON. Well, again jumping in probably where I should not, but I, as somebody new to this position, I come with a fresh eye, I do believe. And I am just so impressed. Just to give you an example, there is something called the Think Bright Digital Content Initiative, and that is going to be programming targeted to address five community needs: family literacy, success in school, fam-

ily health, learning disabilities, civic engagement. It is going to also include research and development.

What is really happening as we move into this new technology—and again, that is part of the 1967 mandate—as we keep up with changing technology, so we can be that connector to the community, we are now facing almost a different viewer and listener, not the passive viewer or listener, but the viewer and listener who wants to really have input, who wants to participate.

Now, right now we are saying this is the younger generation. They are learning. In many cases they are way ahead of us. The technology is ahead of us. For public broadcasting to be vital and, as we said, this important connector to community, the technology must be there. We cannot have the programming without the advanced technology. It is going to enable us to do things we had not thought possible before.

I think it is one of the most exciting developments. As we look at the successor generation and how they are involved with computers and downloading on their MP3's, we are going to have a growing group of listeners and viewers who are really going to be there on some of these issues that I mentioned earlier.

Senator STEVENS. My time is up, but if I could I would like to ask one question about Ready to Learn. Ready to Learn money also went up by \$8.7 million, I believe—no, \$7.7 million. Who can explain Ready to Learn to us now?

Ms. MITCHELL. The Ready to Learn grant, Senator, as you know has been a very successful partnership with the Department of Education. Over the last 10 years PBS, our children's programming producers, and our stations have leveraged this grant again to provide new series that are based on educational learning objectives, teaching the most disadvantaged, as well as all of our Nation's preschoolers, the skills that they need for literacy.

In addition, we work with the Department of Education to provide these educational programs and then stations take the largest percentage of these Ready to Learn funds and use them to provide, through experienced educational teams at every station, the kind of workshop, training, and programs that are making the difference in the lives.

We looked at the number. It was 100 million families have been affected by the Ready to Learn programs. Going forward, CPB, PBS, and other teams of producers worked together on our new proposal, looking at how we might engage these new digital technologies to enhance what we are already doing.

If I might augment what Pat said about our leadership in the digital arena, we know how to use these technologies and we know how to use them for public interest and public education.

Senator STEVENS. I am sorry, my time is up. I am informed I made a mistake. I was looking at your request rather than the President's request.

But let me tell you this. Alaska has the highest rate of computer literacy in the Nation on a per capita basis, despite our isolation. The reason is our young people get the computers from the second grade up. But they also, through the local stations that they are watching, have these programs. That makes them relevant to their lives even though they in most instances do not have modem capa-

bility, they do not have the ability to go up. Now, the schools, libraries, and health facilities do, but individual citizens do not have that same access.

So it is very important to us that this kind of concept of Ready to Learn be supported also.

Thank you very much, Mr. Chairman.

Senator SPECTER. Thank you, Senator Stevens.

BILL MOYERS

Senator Harkin, who is the ranking Democrat on the subcommittee, could not be here this morning. But he asked me to ask this question on his behalf and on his time, although it retraces some of what Senator Durbin has had to say. This question is for you, Mr. Tomlinson.

Mr. Bill Moyers' comment was made in a speech in St. Louis about 2 weeks ago and Senator Harkin would like to know whether you would be willing to take up Mr. Moyers' expression of an interest in a public debate between you and him on the questions you have raised about him and his objectivity. The question that Senator Harkin has is is that a conversation or debate which you would be prepared to engage in with Mr. Moyers publicly?

Mr. TOMLINSON. Absolutely, Mr. Chairman. Let me say, though, that in that speech in St. Louis Mr. Moyers said some most inaccurate things about me. He charged or he implied that in the early 1980s when I was chairman, when I was director of Voice of America, that I was somehow involved in some blacklist scandal. I have never been associated with anything like that.

He implied I was forced out of office because of that. I left my years of service at VOA with general acceptance that I had been a success, as it were.

Now, this thing between Mr. Moyers and me could be a lot of fun. We would have a lot of fun debating on television for an hour about that. It would not be good for public television and I think Mr. Moyers and I both agree that in recent weeks we stopped—we now have balance on that Friday evening offering and we did not think it was in the interest of public broadcasting for us to continue.

Senator SPECTER. Do you think it would be a lot of fun?

Mr. TOMLINSON. It would be a lot of fun.

Senator SPECTER. Would you think it ought to be broadcast on "Saturday Night Live?"

Mr. TOMLINSON. That is probably where it belongs.

Senator SPECTER. How about on public broadcasting, where you have a little more control? I do not think you can control "Saturday Night Live," but would you be willing to have it on public broadcasting?

Mr. TOMLINSON. Yes. As I say—

Ms. MITCHELL. Mr. Chairman, if I might, Mr. Tomlinson would have to—

Senator SPECTER. Do you want to join in the debate, Ms. Mitchell?

Ms. MITCHELL. No, I just thought it was important to clarify that that is not Mr. Tomlinson's decision, what would go on PBS. That decision is made by PBS management.

Senator SPECTER. We may come to PBS management here. But Mr. Tomlinson has standing to express a view as to whether he would like to have it there or not.

Ms. MITCHELL. We would consider it.

Senator SPECTER. Now that you have considered it, what is your decision?

Ms. MITCHELL. I think your suggestion of "Saturday Night Live" might be a better place.

But in all seriousness, Senator, it just seems important to, as Mr. Tomlinson has said and I think you are hearing from all of us, to focus on the fact that, as Senators on this committee have already indicated, the American public looks at all of our programming and they trust it and they value it, and they do not judge it only in terms of political balance. There are a lot of other balances that we are concerned about.

We are concerned in media about the balance between what is important, what matters in this country, as well as what just amuses us. What entertains us is not as important as what is educating us. Our role as public service media is to use this enormous power to educate, to strengthen family values, and to contribute to the strength of this democracy, and that judges and that guides our decisions about programming.

Senator SPECTER. Well, Senator Harkin is almost out of time. I would perhaps—well, your acceptance of the debate challenge is fine, Mr. Tomlinson. We will now have to find a venue, and perhaps if you cannot find any other venue we can have a hearing before the subcommittee. But I do not know that C-SPAN would be willing to do any more on this subject, but we could see.

Senator Harkin wants to yield back 53 seconds.

#### CPB INTERCONNECTION REQUEST

Coming back to my own 5 minutes of time, I have asked the question about the digital transmission and the lack of funding in the House bill. Senator Stevens has covered this to an extent, but I want to be sure about your response. The interconnection 10-year lease expires on October 1 next year for the satellite that transmits public radio and television programs. It is going to cost \$120 million. We have already put up almost \$50 million and CPB is requesting an additional \$40 million. The President and the House have both proposed diverting \$52 million from 2006 grants.

Ms. Mitchell, Mr. Lawson, I take it your answer would be the same as on the issue of digital transition, if you did not get funding that it would be very, very problematic?

Mr. LAWSON. Yes, sir, it would. That would come—that money would come directly out of the station operational money and programming money. I would like to point out that the conversion to digital is a Federal mandate and our stations have raised and spent \$1.1 billion to do that. Half of that came from State legislatures. Congress has been generous in the last few years with Federal support and we are sort of over the hump in terms of getting this thing built out. But that final money for the next couple of years is needed, especially for stations serving rural America that do not have the kind of matching money that some of the other stations have.

Senator SPECTER. Thank you very much, Mr. Lawson. We do not have much time. I want to move on to some other questions.

Mr. Boaz, in your written statement you say: "As a libertarian, I have an outsider's perspective on both liberal and conservative bias and I am sympathetic to some of the public broadcasting's biases, such as its tilt toward gay rights, freedom of expression, and social tolerance and its deep skepticism of the religious right."

Picking up on your statement about being sympathetic toward gay rights, let me ask you about the request from Education Secretary Margaret Spellings in January of this year to PBS asking that it not distribute an episode of the children's program "Postcards from Buster" that featured a family with two lesbian moms. PBS agreed not to distribute the program. What is your view of that?

Mr. BOAZ. Well, I am not personally offended by Buster's trip to Vermont. I think it is good to teach social tolerance. But I understand that there are a lot of Americans who do not appreciate that, who did not like the program or would not have if they had seen it. So I understand why Secretary Spellings thought it was her responsibility to interfere.

What I would say in relation to public television is this is why it is a bad idea to have a government-run television station, because Secretary Spellings can write a letter to Fox or CNN saying, hey, I wish you would not run this program, but she has no authority over them. Here, because of the government's funding, the taxpayers fund these networks, therefore the taxpayers are occasionally going to exercise their authority to look at what the stations are running.

I think that is not good. I think it is not good to have political overseers. I am sure that Senators would exercise more oversight if they saw these things more often. I am sure Senators, for instance, are usually in transit or visiting community affairs on Friday nights, so they have not actually seen the Bill Moyers program, because if they did I think it would be difficult to sustain the argument that it was not advocacy journalism, though good advocacy journalism.

But I think the basic point that "Buster" illustrates is the danger of having political oversight of a news and public affairs program.

Senator SPECTER. Ms. Mitchell, who made the decision with respect to "Postcards from Buster" and Secretary Spellings' request?

Ms. MITCHELL. The decision not to distribute the program on the national program service that goes from PBS to our stations was made by PBS management and was made before the letter from Secretary Spellings.

But might I speak just a moment more about this unique partnership and why it has worked so well? The Ready to Learn teams, who include PBS children's producers, a PBS team, station teams, as well as the team at the Department of Education, sit down and very carefully review the objectives of these programs, and they review the subjects that are going to be treated. But when this subject came in we felt that it was of such controversial nature for some of our communities that it was best to go back to what you have heard us all say all morning: public broadcasting is a local institution.

Senator SPECTER. Do you share Mr. Boaz's—my red light just went on, but I want to finish this subject up with a very brief question and then you can expand on your answer. Do you share Mr. Boaz's comment about his concern about the regulatory approach or the decision being made by a public agency on this kind of an issue?

Ms. MITCHELL. No, indeed I do not. The money that has come to PBS and our producers from the Ready to Learn partnership with the Department of Education has made it possible to prepare millions of children in this country for school.

Senator SPECTER. Senator Inouye.

#### CPB USE OF CONSULTANTS

Senator INOUE. Thank you.

I would like to ask Mr. Tomlinson a few questions. Do you believe it is legal or appropriate for the chairman of the board, CPB board, to hire a consultant at Federal funds in excess of \$14,000 without the consultation or approval of the board?

Mr. TOMLINSON. Senator Inouye, I observed every procedure that I had seen used over my 5 years on the board in the hiring of this consultant. These decisions were made in the CPB front office. I went to the president of CPB, I went to the general counsel. I asked that this contract be handled like any consultant's contract through the business office. It was handled by the general counsel.

In my 5 years on the board, the board had never been asked about contracts. I certainly was not trying to hide this from the board and I would have taken it to the board in a minute if anyone had pointed to me that this should have been done.

Senator INOUE. In the case of Mr. Mann, did you get the approval of Ms. Mitchell?

Mr. TOMLINSON. I am CPB. She is PBS. I got the approval of the president of CPB, the general counsel, and the business office. The consultant's contract was handled no different—

Senator INOUE. The law does not require you to consult with the board?

Mr. TOMLINSON. No, sir. I was certainly not trying to hide it from the board and if I had known of any tradition that the board should be involved I certainly would have involved the board.

#### CPB POLLING

Senator INOUE. There are also press reports that allege that you refused to make public CPB's own research that had been conducted by two polling firms, Terrence Group and the Lake Snell and Perry Associates.

Mr. TOMLINSON. That is simply not true. On the day that charge was made, you could go to the CPB website and find all the results of these polls.

Senator INOUE. Well, I am giving you the opportunity.

Mr. TOMLINSON. Yes, sir. I appreciate it.

We also share the friendship of Mary Bitterman, who did an outstanding job at Voice of America and has done an outstanding job for public broadcasting.



## CPB USE OF CONSULTANTS

Senator INOUE. Did you use \$15,000 of taxpayers' funds to hire two Republican lobbyists without the knowledge of the board to defeat amendments to the reauthorization bill?

Mr. TOMLINSON. The board was stunned to discover that there was a serious proposal in the authorization process to require that four of our nine members come from the community of public broadcasters. The board unanimously opposed this. We have a very small staff relative to other agencies at CPB. Our legislative person was on vacation when we made this discovery. Our leadership, the leadership, again our president, general counsel, were involved in hiring at least three consultants to help us communicate, determine what the situation was on Capitol Hill in that time frame.

I was an indirect part of the process. The decision again was made by the chain of command.

## JOURNAL EDITORIAL REPORT

Senator INOUE. Is it appropriate for the chairman of the board to secure private funding from the corporate world for the "Journal Editorial Report" hosted by Mr. Paul Gigot?

Mr. TOMLINSON. The decision to add Paul Gigot and the "Wall Street Journal Editorial Report" was one that involved a lot of people at both PBS and CPB. It was a decision that I saw no opposition to, and I was not directly involved in negotiating any contracts involving it.

Senator INOUE. You had no role to play in that?

Mr. TOMLINSON. I certainly thought it was a good idea and I thought it was an important idea because of the importance of having balance in current affairs broadcasting. I would never have put the Wall Street Journal show on alone. Again, as Senator Stevens said, no biases; make it neutral, make it common sense. If you have a liberal show, have a conservative show, one in the middle. If you have a conservative show, have a liberal show.

This is to me common sense and it is good for public broadcasting.

Senator INOUE. So your position is that these press reports are false?

Mr. TOMLINSON. The press reports, yes, sir.

Senator INOUE. Thank you.

Senator SPECTER. Thank you, Senator Inouye.

Senator Durbin.

## "NOW WITH BILL MOYERS"

Senator DURBIN. Mr. Tomlinson, I am going to follow up on that. So let me understand what you are saying. You had to get "Now" off the air because of liberal advocacy—

Mr. TOMLINSON. No, no. I never wanted to take "Now" off the air.

Senator DURBIN. No pressure on Mr. Moyers?

Mr. TOMLINSON. No, no, sir. No, sir. In fact, if I had put pressure on Mr. Moyers you know exactly the way Mr. Moyers would have responded.

Senator DURBIN. So let me ask you this question. Mr. Moyers has said that when rumors began to circulate regarding hiring a con-

sultant to monitor his show he tried three times to meet with the CPB board to hear their concerns and answer their questions three times, and every time he was refused. So let me ask you to clarify then. If you had no axe to grind with Mr. Moyers, no problem with Mr. Moyers, why is it he could not get to meet with you?

Mr. TOMLINSON. Well, I did have a problem with his show. In terms of at the time—and I would have to go back and reconstruct about his requests to meet with us. At the time I remember discussing it with the president of CPB and he did not think it was appropriate to have such a meeting because our purpose—you are not going to change Bill Moyers. He has got a wonderful record of public service, but you are not going to change the politics of Bill Moyers, nor were you going to change the politics of that show. Frankly, I did not want to change the politics of—

Senator DURBIN. Well, I wish you would check, because he said he tried to reach out to you three times and could not get a meeting.

The point I want to get to is this. Assume for a second this was, as you called it, liberal advocacy on the “Now” show. Now we have something from the Wall Street Journal. Would you call that conservative advocacy?

Mr. TOMLINSON. Yes.

Senator DURBIN. Would you?

Mr. TOMLINSON. Yes.

Senator DURBIN. Okay.

Mr. TOMLINSON. So now we have a 30-minute show, a successor to Moyers’ called “Now,” and a 30-minute Wall Street Journal show. That is balanced.

Senator DURBIN. You do not expect within the content of each show that there be a balanced presentation, or do you?

Mr. TOMLINSON. No, I do not think that is realistic. I am old school. I think you should have the kind of programming that gives you back and forth. I think that you should have liberals and conservatives on these shows and let the viewer decide.

Senator DURBIN. I guess what troubles me then is why you had to put this pressure on Mr. Moyers. I do not understand that. If you just wanted to put a conservative show on next to him, you could have done that all along.

Mr. TOMLINSON. I do not quite understand how I put pressure on Mr. Moyers.

Senator DURBIN. You do not think you put any pressure on Mr. Moyers?

Mr. TOMLINSON. No, no. In fact, I think if I had he would have responded in kind. He does not respond well to pressure.

#### VOICE OF AMERICA

Senator DURBIN. Let me say that you made some references to your service at the Voice of America quite a few years ago and also the fact that it was referred to in Mr. Moyers’ speech. I would like to make sure the record reflects that Mr. Moyers said this about your service at Voice of America and the controversy involving Mr. Frick, and I quote Mr. Moyers’ speech:

“Let me be clear about this. There is no record apparently of what Ken Tomlinson did. We don’t know whether he supported or

protested the blacklisting of many American liberals or what he thinks of it now.”

That is a direct quote from his speech. So I do not know if that is all of the things that he said there, but that was included in his remarks.

If I might ask you, too——

Mr. TOMLINSON. There was an earlier reference that linked me to——

“NOW WITH BILL MOYERS”

Senator DURBIN. That you were working there at the time Mr. Frick was involved in some of these activities, that is true.

Let me ask you this. The board leadership, you say in your testimony: “The board leadership of PBS recognized that Friday evening programming should reflect different points of view. When it was clear that PBS was following through on its commitment, I ended the Mann study and did not make it public because to do so would have called attention to the fact that for nearly 2 years public broadcasting ignored our legal responsibility for presenting diverse viewpoints on controversial views.”

I am trying to follow what you are saying here. Without your study—in other words, without your study alleging liberal bias in PBS programming, people would not have noticed it? Is that what you are saying?

Mr. TOMLINSON. I did not need a study to document that the Moyers program was biased.

Senator DURBIN. Then why did you pay Frederick Mann 14,000 taxpayers’ dollars?

Mr. TOMLINSON. Because I was facing people, not unlike you, who were saying at the time: Gee, there is nothing wrong with the Moyers program; this program is balanced. Statistically—you know, Warner Wolf used to say: “Let’s go to the videotape.” We took 6 months of Moyers programs and demonstrated that it was left wing advocacy journalism.

As I said, it is outstanding stuff. He is a great broadcaster. But the show was biased from the left.

Senator DURBIN. I do not understand how this gentleman is competent to make that conclusion, and some of the things that he characterizes on here are clearly off the wall. But at the risk of——

Mr. TOMLINSON. He had, for example, Bob Barr, a Republican former Congressman, was on the Moyers show to attack the Patriot Act. He was not on the Moyers show to take any of his traditional positions.

Senator DURBIN. Sounds pretty balanced to me.

Mr. TOMLINSON. He was on the show to balance the Patriot Act. That is how he got on the show. Conservatives and Republicans got on the Moyers show by and large when they took positions which agreed with Mr. Moyers.

Senator DURBIN. Are you familiar with the fact that the bill to reform the Patriot Act is co-sponsored by me and Senator Larry Craig.

Mr. TOMLINSON. Well, I certainly welcome reform of anything, Senator. I am just talking about journalism here.

Senator DURBIN. That is what I am talking about, too.

Mr. TOMLINSON. I am talking about how he came to be on that show.

Senator DURBIN. Ms. Harrison, are you familiar with Bill Moyers' program? Did you watch it?

Ms. HARRISON. I have to admit I have not. I have been working 24-7 in my previous job. But I guess I should let you ask the question before I answer a question you have not asked yet.

#### PATRICIA HARRISON BACKGROUND

Senator DURBIN. I just want to try to understand your familiarity with Corporation for Public Broadcasting, NPR, PBS.

Ms. HARRISON. I understand the mission and that we have two tracks here. One is to ensure that public broadcasting is not pressured or interfered with by the Federal Government in any way or the board. The other mission is to ensure that there are a diversity of views.

I do believe in just looking at a lot of material in the last several days that one of the answers to this—and I too would like to get back to the mission of public broadcasting—is the Office of the Ombudsman, an independent office. They really have no authority to pre-censor, to censor, but they just do what many ombudsmen do for newspapers, and to take it out of this whole controversial range and have it as something that is just ongoing; I know PBS has their own ombudsman, and to start focusing on the real issue here, which is the importance of public broadcasting.

Senator DURBIN. Mr. Chairman, if I could ask one last question of Ms. Harrison.

Ms. HARRISON. Yes.

Senator DURBIN. If we matched up our résumés, very few things would come out the same, but—

Ms. HARRISON. I have a feeling where you are going.

Senator DURBIN. But it would demonstrate that we are both political animals. We both from our partisan perspectives have been pretty actively involved in our partisan beliefs. Clearly the concern over what is happening with Mr. Tomlinson is that we are politicizing public broadcasting, and the fear is now that if it reaches the point where the average viewer, who now thinks so highly of public broadcasting by radio or television, begins to believe that it has now been taken over by people with a political agenda, who want to spare this administration or any administration of criticism, who want to make certain that those who are the most effective advocates for one point of view are silenced or diminished, it is going to really tear at the heart of what is good about public broadcasting.

Now, you come in with a strong Republican résumé. I in the same spot would have a strong Democratic résumé. The obvious question is, can you put this aside? Do you feel like you have got water to carry here for the White House and the administration in this new position?

Ms. HARRISON. That is a three-part question and it is actually a very important question. First, let me say before I am a member of any party I am an American. For the last 4 years, as I alluded to, I ran a bureau. During that period of time the OIG did its first review in 50 years of the Bureau of Educational and Cultural Af-

fairs. I am very proud of the fact that what they found was that my leadership style, my management style, was inclusive, I am a team-builder.

I have a track record in the private sector. Running a company, I could not tell you who is Republican and Democrat. When I take on, let me just call this a mission, I am looking at best achievable outcome and I think about the last day that I am going to be on the job. I have a strong enough ego to want to say because I took this job the entity, the organization, was stronger than before I came here.

I am committed to this. Without going into braggadocio too much, I did have other opportunities, but I believe in the mission of public broadcasting. And I believe that the people who are concerned need to not only listen to what I say, but to watch what I do. I am going to fight for this. I am here fighting for this budget. I am now the CEO of the Corporation for Public Broadcasting and I know what my clear mission is.

I fought for similar things. One of the reasons I wanted to do this, Senator, is I find a similar mission that I had at the Bureau of Educational and Cultural Affairs, where people look at exchanges and say, why do we need those people coming here. Basically, these things are the things that are really going to connect our country.

I do not know what else to say. I was president of Capital Press Women. I have been an advocate for women. I founded an organization, National Women's Economic Alliance. I have written two books really focused on helping women. I feel confident that I am a fair person, that I have a great deal of integrity, and that nobody owns me ever. Plus I come from Brooklyn, New York, and I am an Italian-American.

Senator DURBIN. I have a daughter living in Brooklyn now. Maybe she is picking up some of the same attributes.

Thank you to the panel. Mr. Chairman, thank you for your patience.

#### CPB USE OF CONSULTANTS

Senator SPECTER. Senator Durbin, I thought you would not have any question after that last response.

Mr. Tomlinson, the New York Times has reported a couple of payments, one for a lobbyist, \$10,000 into the insights of a specific Senator. Is that true?

Mr. TOMLINSON. I described that situation a moment ago and with your indulgence I would like to go over how we got to that point.

Senator SPECTER. Go ahead.

Mr. TOMLINSON. Our board discovered that there were interests in public broadcasting which wanted to put into the authorization bill language which would have required four of our members come from the public broadcasting community. The board was very concerned about this. We were unanimously opposed to this. When our board members, including our Democrats, called counterparts on Capitol Hill, they discovered quite a lot of work had gone into this on the part of the public broadcasting community.

We have a small staff at CPB. Our legislative person the week we discovered this was on vacation. Our front office turned and hired to my knowledge, or at least had three—brought in three different consultants to work that bill, to try to get to Capitol Hill—

Senator SPECTER. Mr. Tomlinson, that is all very interesting, but why pay \$10,000 to find insights into a Senator? Why not your picking up the phone and talking to him or going to pay him a visit, and save \$10,000 on a very tight budget?

Mr. TOMLINSON. If our legislative person had been in town that week, that might have been the direction we would have gone.

Senator SPECTER. Well, you had some protracted period of time to make the contact, did you not?

Mr. TOMLINSON. Yes.

Senator DURBIN. Do you not think the Senator would be a lot more impressed by having you in your position come talk to him, giving him your reasons, than the amorphous approach of somebody seeking insights into his background?

Mr. TOMLINSON. Absolutely. But the reason CPB has traditionally hired these consultants is because we have a small core staff and we tend to turn to the outside for help in these areas.

Senator DURBIN. And \$5,000 being paid to provide advice on the legislative process for a month, without having talking to any of the lawmakers; is that also accurate?

Mr. TOMLINSON. Yes, although we—because this thing was sprung on us overnight. Our board, both Democrats and Republicans, we were absolutely unaware that for apparently weeks leaders in public broadcasting had been working to require that four of our nine members be drawn from the public broadcasting community. We did not think that was right.

Senator SPECTER. Well, Mr. Tomlinson, when we see reports in the press about that and then have them confirmed by you, it raises a question at least in my mind as to the propriety of the expenditures. We Senators see a lot of people and I would repeat that if a man in your position came to see a Senator I think it would bear a lot more weight, or even a telephone call.

So as a little guidance to the future, when you are short on budget to bear that in mind.

Mr. Boaz, do you think that public broadcasting ought to take any further steps to seek the avoidance of what you consider to be political bias?

Mr. BOAZ. I think it is valuable to seek to avoid the bias, and I do think if you look at the examples—there is this report nobody has mentioned, that appeared in the newspaper "Current," the newspaper of public TV and radio, not by a conservative, that goes through looking at Bill Moyers show and points out several examples of heavy bias on the issues that mattered a lot to Mr. Moyers.

One way you balance that is by having different programs there. I do not think the addition of the "Wall Street Journal Editorial Report" is going to balance the overall thrust of prime time programming on PBS.

But as I say, I do believe that it is impossible to choose the topics and choose the speakers and choose the angles without having some perspective involved, and that is why, rather than seek political balance, put a Republican onto the CPB board, put a Repub-

lican somewhere into NPR or PBS, the better thing is to depoliticize the system, take it out of politics entirely.

My guess is that public radio and television might be more adventurous if they did not have a Republican administration and a Republican Congress looking over their shoulders. Some people would remember a few years ago when PBS broadcast "Tales of the City" and there was a lot of controversy because this was a fictional program that had some gay characters and some drugs involved in it. They decided not to do more "Tales of the City." The commercial network Showtime picked it up and nobody complained, because it was not taxpayers' money, it was not an official government imprimatur, and we understand that in a free society Showtime can pretty much show what it wants to.

So I think if you depoliticize you will avoid this problem of getting two ombudsmen or a new chairman, a new president. You take it completely out of the realm of politics.

Senator SPECTER. Ms. Mitchell, do you think there is any substance at all to Mr. Boaz's contention of political bias on the public broadcasting?

Ms. MITCHELL. The public opinion polls certainly substantiate our firm conviction that we are producing a schedule that meets our editorial standards and that meets the obligations of fairness and balance.

Might I also respond to something else I think you asked?

Senator SPECTER. Before you go on to another subject, I do not think that is quite responsive to my question. My question was do you think there is any basis for Mr. Boaz's contention that there is political bias on public broadcasting?

Ms. MITCHELL. We take every allegation of that very seriously. Last year, out of 3,000 hours there were less than 30 hours that rose to what we would consider any kind of question or controversy. But 2 years ago we looked at our editorial standards and said they need to be updated, we need to be very clear with our producers what we expect from them in terms of fairness and objectivity, accuracy, and transparency. So we clarified it.

Senator SPECTER. Is your answer no?

Ms. MITCHELL. The answer is we work very hard to ensure that there is not, and when there is an opinion or a point of view, Senator, we are very clear that that is what the viewer is hearing; it is someone's point of view, someone's commentary.

Senator SPECTER. Okay, I interpret that to mean possibly. To the extent that there is any possible bias, what you are saying is that you take every step you can to eliminate it?

Ms. MITCHELL. In dealing with controversial issues, we require of our producers that they do the most thorough, accurate, transparent process to examine—and we take on the complex issues, Mr. Chairman, as you know, many of which are not taken on by mainstream media. We do not attempt, except in our news programs, to balance everything within a segment or within a program, because that is what the law requires, and we believe that there is a better understanding and comprehension if you do it over a series of programs.

But we take very seriously any charge that our programs are not representing the diversity of perspectives in this country. We think

of ourselves as a big tent where a Bill Moyers and a Paul Gigot and a Travis Smiley and a Gwen Eifel all are welcome.

Senator SPECTER. Ms. Harrison, do you have anything you would like to add? We are about to conclude the hearing.

Ms. HARRISON. Just very briefly. There are some mechanisms in place, because public broadcasting, the word most important is the "public." So there is a toll-free number where viewers and listeners can call in. We direct them also to connected links. We have a very vigorous e-mail program.

So we are hearing from viewers and listeners all the time, and these are remarks and observations that are not just dismissed. I am very busy answering my own enormous mail right now and I have to tell you the interesting thing is I am getting about the same degree from people saying it is too left and the same degree it is too right, concerns on both sides. I think we have a very passionate listener and viewer audience, and I think the Office of the Ombudsman is a good step.

Senator SPECTER. Mr. Lawson, anything you care to add?

Mr. LAWSON. Yes, sir. My association was the author of the amendment in question that prompted Mr. Tomlinson to hire the two lobbyists. That just speaks to the need for—

Mr. TOMLINSON. I did not hire the lobbyists, John. They were hired by the front office.

Mr. LAWSON. Mr. Chairman, it just speaks to the need for greater transparency in the way that CPB operates. We would like to pick up the conversation we had with the Senate Commerce Committee last year and the rest of Congress to work out some reforms to the way CPB operates.

Senator SPECTER. Mr. Tomlinson, awaiting the Moyers-Tomlinson debate, do you have anything else to add now?

Mr. TOMLINSON. No, Mr. Chairman. Thank you so much for your support of public broadcasting.

Senator SPECTER. Mr. Boaz, we will give you the last word if you want it.

Mr. BOAZ. I feel like Daniel in the lion's den. But I am glad to have the last word. I believe that the controversies that—

Senator SPECTER. Daniel did not do too badly and neither have you.

Mr. BOAZ. I believe the controversies that we are discussing are an illustration of the problem I raised, that it is inevitable that you are going to have politicization if you have government funding. That is why I think public radio and television would be better off without government funding.

#### ADDITIONAL SUBMITTED STATEMENT

Senator SPECTER. We have received an additional submitted statement that will be included in the record at this point.

[The statement follows:]

#### PREPARED STATEMENT OF AMERICANS FOR THE ARTS

On behalf of Americans for the Arts, I am pleased to provide you this statement in support of funding for the Corporation for Public Broadcasting (CPB). As you know, recently the fiscal year 2006 funding for CPB was threatened during House subcommittee consideration. The House bill was substantially improved during full



committee debate and floor action, but it is still inadequate. I write to you today to ask for your support in keeping CPB fully funded.

Americans for the Arts is the service organization for the nation's 4,000 local arts agencies, which provide \$1 billion of annual funding and support for the arts and humanities at the local level. It is important to note at the outset that many local arts agencies are important partners, and funders, of local public television and radio stations. We are asking the federal government to continue to honor its commitment to public broadcasting, just as local arts agencies continue to honor theirs.

CPB supports public television and radio through its partners, the Public Broadcasting Service (PBS) and National Public Radio (NPR). These organizations provide important access to the arts for millions of Americans. With both community-based arts programming, and nationally televised shows such as "On Stage at the Kennedy Center" and "Austin City Limits," public broadcasting is often a primary source of arts programming in many rural parts of the country. Public broadcasting also serves as an important source of information about live arts performances and exhibitions. Any reduction to its budget would drastically reduce the access that many Americans have to the arts.

Public broadcasting's national programs are probably well known to members of the Committee. While you are probably familiar also with local programming in your own state, I would like to provide a few examples of local arts programming from around the country.

—In Pittsburgh, WQED, the nation's first community-owned television station, airs "Performance in Pittsburgh" featuring recorded-in Pittsburgh concert highlights as well as interviews with Pittsburgh musicians and presenters. The WQED-FM, the radio station produces "Pittsburgh Symphony Radio" presenting the Pittsburgh Symphony Orchestra's recent concerts at Heinz Hall, archival tapes and tour performances.

—Iowa Public Television (IPT) has a show named, "A Century of Iowa Architecture," which uses high definition cameras to capture the details and drama behind the construction and design of Iowa's most significant buildings. Also, as part of its School-to-Careers programming IPT has programming specifically on becoming an artist. The National Employer Leadership Council (NELC) highlighted Iowa Public Television in its publication Best Practices in School-to-Careers: Rural Issues.

—The Mississippi Arts Council and Mississippi Public Broadcasting produced a seven-part radio show titled, "Sounds From Around the Corner" which included gospel and old-time fiddling, as well as more recent immigrant traditions such as Latino music and classical Indian singing—all performed by Mississippi artists.

—In Alaska, CPB has provided funding for the weekly "AK" cultural magazine show produced by the Alaska Public Radio Network. In 2003, Public Radio News Directors International voted AK second place nationally for "Best Public Affairs Program".

Budget cuts would heavily impact public radio broadcasting, as CPB funding represents 15 percent of the budget for many individual member stations of NPR. If they lose that support, many of them will have to make severe cuts to their programming and local services. This will especially impact rural areas and stations serving minority populations, as they heavily rely on federal funding for their operating budgets. While local and state arts agencies also support these stations, they could not make up for a loss of federal funding on this scale.

While the House partially restored CPB funding, its legislation, as passed, eliminated \$39 million to help local stations switch to digital transmission, \$40 million to upgrade aging satellite technology, and made a \$23 million cut to the "Ready to Learn" program, which provides money for the creation of shows such as "Sesame Street" and "Reading Rainbow." These are all important items for CPB operations. We hope you will fully fund these programs in your subcommittee consideration, and that you will fight for them in conference with the House.

With your leadership, we can insure that CPB funding is adequately funded, and that public television and radio can continue to provide high quality arts and cultural programming to our nation.

#### CONCLUSION OF HEARINGS

Senator SPECTER. Thank you all very much for coming in. Let me tell you, drawing four Senators on a Monday morning in Washington is high praise for this panel and this subject. That concludes our hearings.

[Whereupon, at 12:39 p.m., Monday, July 11, 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 2006**

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

MATERIAL SUBMITTED BY AGENCIES NOT APPEARING FOR  
FORMAL HEARINGS

[CLERK'S NOTE.—The Social Security Administration and the Railroad Retirement Board were unable to testify and the following information was received in support of their fiscal year 2006 budget requests.]

[The information follows:]

SOCIAL SECURITY ADMINISTRATION

QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

HUMAN CAPITAL PLANNING

*Question.* In January 2001, the General Accounting Office identified strategic human capital management as a government wide high-risk area. What steps are you taking to acquire, develop, and retain an appropriate mix of agency staffing/talent, particularly in light of the Agency's impending retirement wave? What is the Agency's plan for creating an organizational culture that promotes high performance and accountability and empowers and includes employees in setting and accomplishing programmatic goals? How does the fiscal year 2006 budget support these activities?

*Answer.* SSA has a long history of successful human capital planning. We first analyzed the impact of our impending retirement wave in 1998. This prompted development of a Future Workforce Transition Plan (FWTP) which laid out the strategies to ensure that a highly skilled staff was in place.

We update our analysis of projected retirements annually and make appropriate adjustments to our recruitment, retention and succession strategies. We expanded upon the FWTP to publish a comprehensive and strategic Human Capital Plan in January 2004. The plan lays out how SSA will use human capital to meet the Agency's mission and goals and ensure that we have employees in place with the skills necessary to continue SSA's tradition of excellent citizen service. Employees across the Agency work together to accomplish these initiatives and, as a result, SSA received a President's Management Agenda score of "green" for the Strategic Management of Human Capital in June 2004.

To date, we have maintained our green status by successfully completing planned activities, continuing with initiatives underway and adding new ones that will further improve our management of human capital.

Since 2001, we have implemented a new national recruitment strategy with the following key elements: (1) an integrated marketing campaign with a new SSA brand entitled "Make a difference in people's lives and your own;" (2) emphasis on the Inter/Intranet; (3) coordinated on-campus college recruitment; (4) automated staffing/recruiting; (5) practical methods for diversity recruitment; (6) streamlined hiring; and (7) maximum use of hiring flexibilities. We have expanded on these key

elements through other key recruitment successes, including the release of a National Recruitment Guide to ensure consistency and excellence in our recruitment activities and the establishment of partnerships with other Federal agencies to assist veterans with transitioning to civilian employment.

We are maximizing the use of technology to improve recruitment and hiring. SSA is in the process of transitioning to a new web-based staffing automated system. We are also working to improve methods of submitting, collecting, and processing electronic job applications. Improving the application process in those areas is expected to improve the hiring process by encouraging a larger number and more qualified applicants to apply for Federal positions and by facilitating more timely selections.

Our recruitment efforts have proven successful in attracting quality hires. We hired over 15,000 employees in fiscal years 2001–2004. For fiscal year 2005, we have hired 2,616 through March 2005. This includes employees who were recently hired in support of the recent Medicare legislation which will provide drug benefit subsidies to the elderly.

We develop employees from entry-level through the Executive level. Our orientation programs for new employees emphasize our organizational culture and public service values.

SSA has received many accolades for its national leadership development programs that have often been referred to as the “best in government.” This reputation is based upon our use of competency-based programs that include a rigorous selection process and a variety of program features that produce well-rounded graduates. The programs include the Senior Executive Service Candidate Development Program for executives, the Advanced Leadership Program for middle- and senior-level employees, the Leadership Development Program for employees at the journeyman level, and the Presidential Management Fellows Program for entry-level professionals.

SSA has redesigned entry level training, developing job-specific training competencies and delivering related training for about 24,000 positions in the claims representative, service representative, and teleservice representative occupations. In fiscal year 2006, SSA will develop competency-based training that will be used for another 4,000 positions in the benefit authorizer, claims authorizer and technical support technician occupations.

SSA is also delivering training to prepare employees for the new Medicare legislation. The intent of this training is to ensure all employees understand and can process the workloads associated with the new legislation.

We are also maximizing the use of technology in the training arena by implementing a project development plan to migrate to a common, government-wide electronic-learning service.

Our 2-year retention rate for new hires has been gradually increasing from 84 percent for 1998 hires to 89.9 percent for 2002 hires; a rate which is considered outstanding in the private and public sectors. We have enhanced our orientation process and are improving our exit interview processes to further support our high retention rate.

We are promoting high performance and accountability by improving our performance management systems. We implemented new multi-tiered appraisal systems for Senior Executive System employees in October 2002 and for GS–15s in October 2003. We are further improving our performance management systems by implementing a new multi-tier performance appraisal model for union-represented employees that, when implemented, will differentiate between levels of performance and enhance managers’ ability to hold employees accountable for results.

Full funding of the fiscal year 2006 President’s budget will allow us to continue to carry out our Strategic Human Capital Plan activities.

#### DIRECT SERVICE POSITIONS

*Question.* What is your plan to increase the number of direct service positions, while maintaining appropriate levels of technical, policy, and administrative support staff? The Subcommittee is aware that SSA met its long-term goal of reallocating 5 percent of headquarters positions to direct service in fiscal year 2004. Specifically, how was this accomplished? What does the budget assume for such redirections in fiscal year 2005 and fiscal year 2006?

*Answer.* We met our goal through a combination of redeployments and overall attrition in staff components. For example, 71 employees transferred from staff components to direct service positions in the Office of Central Operations in November 2002. The fiscal year 2006 budget request assumes no additional redirections for fiscal year 2005 or fiscal year 2006. The fiscal year 2006 budget request does assume an increase in full-time equivalents from fiscal year 2005, attributable mainly to the

2,200 direct service employees hired in fiscal year 2005 to handle workloads related to the new Medicare prescription drug program. Although hired initially to deal with this new Medicare workload, these employees will be trained on all of SSA's programs so they can ultimately help backfill for the 3,000–4,000 employees we lose each year due to retirements and resignations.

#### ENRICHMENT OPPORTUNITIES AND LEARNING

*Question.* One long-term outcome identified in SSA's Agency Strategic Plan is ensuring ongoing enrichment opportunities and training. Specifically, how does the fiscal year 2006 budget support this long term outcome?

*Answer.* SSA is dedicated to improving its training and development programs in order to build the skills our employees at all levels need to deliver quality customer service in the 21st century's technological environment. To fill emerging skills gaps, SSA is focusing on improving the training it provides all its employees—from the lowest levels to the top. We are using the lessons we learned from "getting to green" to stay focused on our commitment to improve learning at SSA so all of our employees are prepared to support SSA's mission.

Currently, SSA's Office of Training is moving forward to:

- Develop and implement a competency-based training approach to ensure that our employees on the front-line doing mission critical work have the skills and knowledge they need to effectively address the concerns of the American public.
- Ensure that the Agency has the number of well-rounded, competent leaders it needs by implementing a new leadership development strategy that will enhance SSA's nationally acclaimed career development programs.
- Open up more learning opportunities for SSA's employees by moving from SSA's Online University to the government-wide GoLearn online learning system. SSA employees nationwide will be able to select from over 2,000 courses that are designed to make the most of their potential.

Of the many influences that are shaping SSA's future, none may be more fundamental or influential than the training we provide our employees. Our shared learning helps us to forge a sense of common purpose nationwide and provides us with the knowledge and skills we need to do our jobs. SSA's future success at meeting the public's increasingly varied needs depends on our ability to open up learning opportunities that make the most of our employees. Because of this, SSA is continuing to reassess the needs of its workforce and investing in workforce learning and performance for each of our employees and the Agency as a whole.

- SSA provided an average of 48 hours of training per employee over SSA's Interactive Video Teletraining (IVT) network and Online University. SSA employees were particularly interested in new IVT broadcasts that covered the new Medicare policy, security in SSA's offices, and the growing use of the Internet.
- The Office of Training is continuing to work with Operations to redesign the training for new or recently promoted employees in our mission critical positions. In redesigning our training, SSA has been using results from private sector source surveys and studies to develop a competency-based training program. This approach provides our students with the knowledge, skills, and abilities they need to do their jobs in an environment that is becoming increasingly automated.

By the end of last year, the entry-level training for Title II and Title XVI Claims Representatives (CRs), Service Representatives (SRs), and Teleservice Representatives were redesigned to reflect this competency-based approach.

Redesigned training lessons improve the way our new employees learn their jobs by integrating information regarding SSA's programs and policies with structured off-air activities and on-the-job-training. This plays a key role in helping new employees master the technology and automated processes that are a critical element of today's SSA work environment. Mentors help guide and support students as they develop new skills by practicing on SSA computer systems, taking part in role-playing, and having on-the-job experiences that will serve them well when they take on their new roles full time.

The Office of Training has also been developing training for specific groups of employees. Working with Operations' offices across the country, they have completed the development of competency-based training for Benefit Authorizers, Claims Authorizers, and Technical Support Technicians in the Program Service Centers by 2006. They have also improved fundamentals training for employees who do not provide direct services to the public. This training gives general information about the Title II and Title XVI programs and strengthens our commitment to work purposefully together in shaping and managing these programs.

Because of the continuing changes in the disability programs, SSA is working to update and expand the disability training materials for new or recently promoted disability adjudicators. SSA also provides a significant amount of training for OHA employees who process disability claims at the appeals levels. Topics that SSA provides on its IVT network focus on OHA's Case Processing Management System, Speech Recognition Software, Digital Recording, Dismissals, Remands, and Docket Management.

The Office of Training is evaluating the training needs of SSA's Executive Officers and expects to develop a core curriculum for that position by the end of the fiscal year.

Technology has also played an important role in SSA training.

—During fiscal year 2004 and into fiscal year 2005, Social Security continued to move forward towards realizing its vision of providing IVT nationwide. By the end of 2004, employees in more than 100 additional offices were linked to the IVT network. Today, over 98 percent of Agency and Disability Determination Service (DDS) employees have access to IVT.

—The IVT network continues to play an important role in ensuring that our employees learn what they need to know, when they need it. The first part of the Medicare Part D subsidy training on policy was developed and successfully delivered over the IVT network. The second part of this training, which will cover systems and subsidy changing events, is being readied for delivery this May.

—SSA is working behind the scenes to improve the delivery of its IVT broadcasts. With the conversion of the headquarters' practice studio, SSA now has a fully functional digital broadcast facility in Baltimore that helps us improve our ability to get up-to-date programs to our employees. SSA is also upgrading its other six broadcast facilities and enhancing our automated scheduling and evaluation procedures as well in an effort to better ensure that our IVT programs reach the employees who need them.

—SSA is expanding the benefits and values of online learning through the SSA GoLearn training site. SSA GoLearn replaces SSA's current Online University (OLU). All employees and their managers will have unprecedented opportunities to take over 2,000 courses at their workstations or at home, at no cost to them or their offices. Each employee will learn at his or her own pace and be able to select courses that will help them learn and perform better or become eligible for other, more rewarding work. Successful learners will automatically get credit for completed courses on their personnel records, without filling out any paperwork.

—IVT provides disability policy training to SSA and the DDS employees. IVT broadcasts provide these employees with help in handling a host of difficult technical issues, including electronic disability, evidence in childhood cases, disability fraud detection, and disability onset. SSA also broadcasts vocational and adjudicative tips in case development and processing for employees who handle SSA's disability workloads.

Since 2004, SSA has ensured that it has the talent it needs to lead the Agency by supporting the expansion of the national leadership development programs.

—60 employees have been selected to take part in the Leadership Development Program (LDP) that will begin mid-year. The GS-9 through GS-11 employees who will participate in the program will have the opportunity to move forward in the Agency by making the most of the training and rotational assignments available to them in the 18-month program.

—The Senior Executive Service Candidate Development Program (SES CDP) is expected to be announced later this year. The SES candidates are expected to begin their program in 2006. In order to develop the qualifications they need to become the government's top executives, SSA's SES candidates will take a variety of Agency rotational assignments and some will spend time at other Federal agencies to prepare them to successfully lead change within the Federal Government.

—Approximately 26 top graduate students are expected to be selected at the end of this calendar year for the Presidential Management Fellows (PMF) 2-year development program.

SSA is continuing to seek new ways to ensure that the Agency has the leadership it needs to succeed in the 21st century. Earlier this year, a national workgroup of manager and trainers in headquarters and from the field worked together to establish a new strategy for developing leaders at SSA. The Office of Training is getting nationwide comments on the strategy which is designed to foster competencies that leaders and managers need to effectively manage people, achieve results, and promote performance management. SSA anticipates implementing this new, improved approach to leadership by the end of this year.

Full funding of the fiscal year 2006 President’s budget request for SSA will permit us to continue to carry out these training and development programs.

INITIAL DISABILITY CLAIMS

*Question.* Over the period fiscal year 2000–fiscal year 2004, initial disability claims pending have increased by more than 16 percent and now total more than 620,000, despite an increase in agency resources from \$6.6 billion to \$8.3 billion, or almost 26 percent. Please provide a breakout of DDS (Disability Determination Service) resources (dollars and staffing) over this period. What explains this growth in backlogs, despite increasing Agency resources? What specific actions are underway or planned in fiscal year 2005 and fiscal year 2006 to ensure more timely adjudication of disability cases and more cost-effective expenditure of agency resources?

*Answer.* The growth in initial disability claims pending is the result of a dramatic growth in initial claims receipts. Over the fiscal year 2000–2004 period, DDS initial claims receipts increased almost 24 percent.

SSA responded within available resources to this increase in receipts by: (1) increasing DDS resources; (2) initiating fewer continuing disability reviews in fiscal year 2003 and fiscal year 2004 and redirecting those resources to process initial claims; and (3) improving productivity in the DDSs. In spite of these efforts, we were unable to keep up with the growth in receipts.

In fiscal year 2005, we implemented a plan to lower initial pending levels to 592,000 by the end of the fiscal year. Thus far this year, we have succeeded in lowering pendings to 608,000. To help achieve the pending goal, increased funding was provided to the DDSs, and DDSs were authorized additional hiring and increased overtime. In addition, where requested and needed, Federal assistance in case processing is being provided to some DDSs. In fiscal year 2006, the President’s budget request reflects productivity and processing time improvement for the DDSs, mainly through an electronic disability claims process (eDib).

Despite not receiving the full President’s budget request for the last two fiscal years, my Service Delivery Budget goal is still to reduce disability claims pending to 400,000 by 2008. To achieve this, we need the Committee’s support, including full funding for the President’s budget request of \$9.403 billion for SSA’s administrative expenses.

A breakout of DDS resources (dollars and staffing) for fiscal year 2000–fiscal year 2004 is provided in the chart below.

[Dollars in millions]

Year	Workyears	Amount
2000 .....	14,231	\$1,461
2001 .....	14,397	1,513
2002 .....	14,947	1,588
2003 .....	14,700	1,593
2004 .....	14,772	1,672

eDIB AND IMPLEMENTATION

*Question.* The Government Accountability Office (GAO) added Social Security’s disability programs to its list of High-Risk programs. SSA’s fiscal year 2006 budget request supports complete implementation of an electronic disability process—eDIB—as a means to improving the timeliness of and efficiency associated with disability decision. How much funding is included in the fiscal year 2006 request to support the eDIB? In several recent reports, GAO has raised concerns about the cost-benefit analysis, risk assessment and mitigation, and implementation plan for this initiative. Given the difficulties experienced in previous attempts to improve this process, what contingencies are in place to deal with challenges in implementing eDIB? Specifically, what resources are available and supports in places to deal with any potential implementation challenges?

*Answer.* SSA has requested approximately \$50 million in fiscal year 2006 for information technology (IT) hardware/software services, as well as internal IT staff to support eDib.

The most important thing to note is that eDib functionality was implemented by January 2004 and has been working effectively since that time. This includes the Internet Disability Report, the Electronic Disability . . . Collect System (EDCS), new hardware and software for the State legacy systems, the Document Management Architecture (DMA), and the Office of Hearings and Appeals (OHA) Case Proc-

ess Management System (CPMS). We are well on our way to the completion of the eDib rollout to all of the Social Security and State offices.

SSA has put many controls and resources into the process to assure our success as we implement these features, as we build upon them, and as we continue to roll-out full electronic folder capability across the nation to all components involved in processing the disability workload. This includes regular high level monitoring of the project status. There is frequent contact among all of the SSA components involved in eDib including staff from systems, policy and operations. SSA also deploys policy, systems, workflow, and usability experts to field offices, Disability Determination Service (DDS) offices, OHA offices, and Office of Quality Assurance (OQA) sites to learn first-hand about the issues faced by staff working with the eDib applications and works to resolve any problems quickly.

In addition, SSA is conducting an Independence Day Assessment (IDA) before moving a DDS, OHA, or OQA office to a fully electronic process (i.e., new cases can be processed in the electronic folder with no new paper folder created). This assessment ensures that everything is working properly before going fully electronic by validating the business process, the systems functionality, and other processes and procedures. The assessment also makes sure the electronic folder meets all documentation standards set forth by SSA and the National Archives and Records Administration (NARA).

SSA has assigned an "integrator" for each State. The integrator is responsible for tracking the progress of testing and implementation in each State and is the single point of contact for the DDS should they encounter issues. The integrator is responsible for identifying the component/person that can address and resolve each issue. This has proven to be a very successful model for eDib implementation. In addition, each DDS receives onsite support by their legacy system vendor and SSA Systems staff during testing and training, as well as during the first week of production.

We have placed a strong focus on risk management. We hired a contractor to work with our Project managers to develop Risk Management Plans for each of the major eDib projects. We have assigned each of the risks to the appropriate Project Managers for their use in addressing the risks. Our contractor updates these plans with the Project Managers to assure continued monitoring and mitigation of risks.

#### DISABILITY REDESIGN PROCESS

*Question.* According to SSA's service delivery assessment of the disability process completed in 2002, persons pursuing their disability claims through all levels of Agency appeal wait an average of 1,153 days for that final decision. Due to backlogs, cases that go through all levels of appeal spend nearly 50 percent of the time (535 days) waiting for SSA action. Commissioner, you have proposed an ambitious redesign concept for the disability determination process, and also have established a date of January 2006 as the earliest major changes in the disability determination process may become effective. Improvements to this process are needed, as the current process takes too long. What process will you follow for making final decisions about the redesign plan and what is the timeline for making those decisions? How much funding is proposed in the FY'06 budget associated with redesign implementation (OB) and what redesign activities do they support?

*Answer.* Improving the disability process is one of my highest priorities as Commissioner. I am close to making the final decisions that will convert my new approach for improving disability determinations into a proposed regulation which will provide the right decision as early in the process as possible and create work opportunities for people with disabilities.

When I announced my new approach, I stressed that the changes envisioned were predicated on successful implementation of our electronic disability system (which we call eDib) and that it was critically important to listen to the ideas of all interested parties as we developed the disability determination improvements.

I am pleased to report that our State-by-State roll out of eDib is on track. All of our field offices across the nation are now using the Electronic Disability Collect System (EDCS) that initially creates the electronic folder. This system was implemented at the first State Agency Disability Determination Services (DDS) in January 2004, and additional DDSs have continued to implement eDib ever since. Currently, eDib has been rolled out in all States except North Dakota, Alaska, Nebraska, New York and Washington, DC. With the exception of New York, all remaining States will be rolled out by the end of June 2005. At the same time, our Office of Hearings and Appeals (OHA) has begun using the new Case Processing and Management System (CPMS), which is a new software for processing cases and managing OHA office workloads. CPMS will enable OHA to work with the electronic file.



In view of the complexity and importance of the disability programs, my second strategy, having an open process, has been invaluable in my decision making. Last year, I launched a massive outreach effort to obtain and give thoughtful consideration to all comments on the current system and our proposed improvements. I created the Disability Service Improvement Staff within my immediate office to coordinate this effort and I have been taking a personal role in listening to those involved and interested in the disability process. I have personally participated in more than 60 meetings with more than 40 organizations—both within SSA and outside of the Agency. As I have been making decisions, I have carefully considered hundreds of views and suggestions received from the Congress, the general public, and many public and private sector groups and individuals.

With respect to fiscal year 2006 funding, I anticipate that our plan to roll out the new process region by region will enable us to implement these improvements without seeking additional resources beyond those the President requested for SSA from the Congress for fiscal year 2006.

#### SPECIAL DISABILITY CASES

*Question.* The Subcommittee is aware that SSA's latest plan is to complete the entire review of the special disability cases by 2010. What specifically is the Agency's plan for accomplishing this goal and how much funding will be required to review all of these cases?

*Answer.* As of fiscal year 2004, we have processed 96,600 cases of the estimated 300,000 individuals eligible for Supplemental Security Income (SSI) who are also entitled to (but not receiving) Social Security Disability Insurance benefits. In fiscal year 2005, we plan to process 30,500 cases at a cost of \$78 million. The fiscal year 2006 budget includes \$79 million for the processing of 30,600 special disability cases.

Through fiscal year 2004, SSA spent approximately \$175 million on the processing of Special Disability cases. Assuming full funding of the President's fiscal year 2006 budget request, as well as sufficient funding in future years to support continued processing of this workload, we expect to complete case processing by September 2010 at an administrative cost of about \$630 million.

#### CDRS

*Question.* The Subcommittee notes that one of the Agency's Long-Term Outcomes under its Stewardship goal is to remain current with Disability Insurance CDRs and to regain currency with SSI CDRs. What are the performance outcomes the Agency needs to achieve during the years fiscal year 2005 through fiscal year 2009 to meet this long-term outcome measure? What is SSA's plan for meeting this goal? What best practices did SSA develop during the period when Congress provided special funding that are being applied to the process currently that will ensure the most cost-effective expenditure of LAE resources? How will the Agency determine an appropriate balance between Continuing Disability Reviews processed through mailers and those cases requiring a full medical review?

*Answer.* To remain current in Title II CDRs and achieve currency in Title XVI CDRs by the end of fiscal year 2009, SSA would need to process over 7.5 million CDRs, including those that will come due during the period fiscal year 2006–fiscal year 2009 and CDRs that we have been unable to initiate through fiscal year 2005 because of funding limitations. While we are updating our CDR plan to reflect more current information, including the latest projections of initial disability claims receipts, we do not believe that we will be able to achieve Title XVI currency until after fiscal year 2009.

The President's fiscal year 2006 budget includes budget enforcement legislation that would place caps on net discretionary budget authority and outlays. The legislation would permit adjustments to these caps for spending above a base level for several government-wide program integrity activities, including SSA's CDRs. The amount of the adjustment for CDRs is \$189 million, which means if the President's proposal is enacted, \$189 million of SSA's budget request would not be counted towards the overall cap on discretionary budget authority.

Congress provided SSA with special funding for CDRs, outside the discretionary budget caps, from fiscal year 1996 through fiscal year 2002. During this period and continuing, SSA has worked continuously to improve the efficiency and effectiveness of the CDR program. The results are borne out by the following passage from SSA's most recent Annual Report to Congress on CDRs covering fiscal year 2003:

"SSA's CDR process has consistently yielded a favorable ratio of savings to costs in the Disability Insurance (DI) program. Prior to the implementation of the current process for case selection, it was estimated that we were achieving \$3 in DI program

savings for each \$1 in administrative costs invested in full medical CDRs. The addition of the mailer process beginning in 1993 was estimated to result in a doubling of this ratio to approximately \$6 to \$1.

“Actual results to-date for the period during which supplemental administrative funding has been available have been even better than anticipated. During this period, the number of cases processed has expanded significantly, especially in the review of SSI cases. This expanded process has yielded savings-to-cost ratios for the seven fiscal years 1996–2002 averaging roughly \$10.3 to \$1.”—From SSA’s Annual Report of Continuing Disability Reviews, fiscal year 2003; published October 27, 2004.

The breakthrough innovation was the implementation of a statistical profiling/ mailer process in 1993 which permitted SSA to reliably identify large cohorts of beneficiaries with a low probability of cessation due to medical improvement for whom the expensive full medical review process is not required. The CDR statistical scoring models are a series of mathematical formulas designed to predict the likelihood of medical improvement for each Retirement Survivors Disability Insurance (RSDI) beneficiary and SSI adult recipient. Based on the scores generated by these models and a statistical threshold which determines whether a mailer or full medical examination would be the most cost effective type of review to perform, cases scoring below the threshold are targeted for CDR mailers, and those scoring at or above the threshold are targeted for full medical reviews.

During the early years of the special funding we focused primarily on improving internal systems and operational processes needed to reliably control and track more than a million reviews annually. SSA engaged a statistical contractor in fiscal year 2000 to improve the performance of the statistical modeling. Since then, the contractor has updated and expanded the data and mathematical formulas upon which the statistical scoring is based.

SSA has been able to implement several processing improvements based on research findings by our statistical contractor. Since fiscal year 2002, SSA has been able to use the profiling/mailer process to identify RSDI disabled workers with a statistical model score signifying “medium” probability of medical improvement who do not require a full medical review. The process was extended to SSI disabled adult beneficiaries in fiscal year 2005. In fiscal year 2003, we were able to apply Medicare usage data to identify additional RSDI disabled workers with a low or medium probability of medical improvement. Altogether since fiscal year 2002, these innovations have avoided well over 500,000 full medical reviews, more than \$300 million in administrative costs, and significantly reduced unnecessary burden on our most severely disabled beneficiaries.

We continuously monitor the performance of the statistical models and can readily make enhancements that are suggested. In addition, the models have been scrutinized by several teams of auditors and found to be accurate and reliable. And, together with our statistical contractor, we continue to look for additional processing efficiencies that can be implemented in the future.

With respect to determining the appropriate balance between CDRs processed through mailers and those performed as full medical reviews, this decision is determined through the CDR statistical scoring models. For cases with medical re-examinations due to be scheduled in the particular fiscal year, we begin releasing CDR mailers and full medical reviews at the start of the fiscal year, and continue the release process throughout the year, with the goal of releasing all cases due for a CDR in that year.

#### TICKET TO WORK

*Question.* According to the “Justification of Estimates for Appropriations Committees” for the fiscal year 2006 budget request, the Ticket to Work Program will be expanded to all States and U.S. Territories by September 2004. Specifically, how much funding is available within the fiscal year 2006 request for the Limitation for Administrative Expenses account to support implementation of the Ticket to Work program and what activities are supported? How much funding from other sources within the fiscal year 2006 budget request support the program?

*Answer.* The administrative budget for fiscal year 2006 includes \$39.4 million for Return to Work activities. This funding is for Benefits Planning and Assistance Cooperative Agreements (\$23 million), Protection and Advocacy grants (\$7 million), and the Program Manager Contract (\$9.4 million).

The following chart summarizes other objects administrative costs of the Ticket to Work program by major category:

## RETURN TO WORK

[In millions of dollars]

	Fiscal year	
	2005 estimate	2006 budget submission
Benefits Planning & Assistance Cooperative Agreements (including training and technical assistance) .....	23.0	23.0
Protection & Advocacy Grants .....	7.0	7.0
Program Manager Contract .....	<sup>1</sup> 6.9	9.4
<b>Total</b> .....	<b>36.9</b>	<b>39.4</b>

<sup>1</sup> The fiscal year 2005 contract is only for nine months. The contract is being re-competed for fiscal year 2006. The President's budget estimates \$9.4 million for fiscal year 2006, the same as the full year cost for fiscal year 2004.

Benefits Planning and Assistance and Cooperative (BPAO) Agreements are intended to ensure that community based benefits planning and assistance outreach services are available across the United States and its territories. The law authorized \$23 million to be appropriated each year and the Social Security Protection Act of 2004 (Public Law 108-203) extended this authorization through 2009.

The Protection and Advocacy (P&A) grants are used to provide advice to beneficiaries and to provide an avenue for resolving disputes. The Social Security Protection Act of 2004 also extended authorization to provide funding for P&A grants through fiscal year 2009. The budget continues funding of \$7 million for P&A grants in fiscal year 2005 and fiscal year 2006.

The Program Manager Contract provides funds to an outside contractor to help SSA manage the Ticket to Work program. The contract will be re-competed and the required funding has been estimated to be \$9.4 million for fiscal year 2006.

The budget also includes program funding to cover outcome and milestone payments made to Employment Networks (ENs) under the Ticket to Work program. State Vocational Rehabilitation (VR) agencies have the option, on a case-by-case basis, to elect to be paid under the reimbursement payment system or as an EN. The Beneficiary Services Budget for fiscal year 2006 includes \$262 million to cover reimbursement payments to VR agencies and Ticket payments to ENs (see chart).

The chart below summarizes the estimated Beneficiary Services payments:

## BENEFICIARY SERVICES PAYMENTS

[In millions of dollars]

	OASDI		SSI	
	Fiscal year		Fiscal year	
	2005	2006	2005	2006
Reimbursement Payments (VR) .....	80	104	52	67
Ticket Payments (EN) .....	25	54	25	37
<b>Total Payments</b> .....	<b>105</b>	<b>158</b>	<b>77</b>	<b>104</b>

## DISABILITY PROGRAM NAVIGATOR

*Question.* How has SSA collaborated with other federal agencies and partners to increase the work opportunities of individuals receiving Social Security and SSI disability payments and what resources are included within the fiscal year 2006 budget request to carry out such activities? Specifically, what has been the experience in increasing work opportunities through the Disability Program Navigator housed in One Stop Centers and the Area Work Incentive Coordinators? Why is funding for the Disability Program Navigator position being discontinued in 2005?

*Answer.* On September 30, 2002, SSA and DOL entered into an interagency agreement to jointly fund a two-year pilot and evaluation of a new position within the One-Stop Career Center system, the Disability Program Navigator (DPN). This funding, in the form of cooperative agreements, was distributed to 14 States in fiscal year 2003. A primary objective of the Navigator is to increase employment and self-sufficiency for individuals with disabilities by linking them to employers and by facilitating access to programs and services that will enable their entry or reentry into the workforce.

SSA and DOL funded the DPN's for a second year which will support the project through June 2005. During the second year of this joint initiative, Navigators experienced increased activity in the area of relationship building within the One-Stop Center as well as with employers, Vocational Rehabilitation agencies, Benefit Planning, Assistance and Outreach (BPAO) providers, and SSA Area Work Incentive Coordinators (AWIC). Evaluation survey data is currently being collected and, based on the results, SSA will make a decision regarding funding for an additional year.

The SSA AWICs are the Agency focal point for public information outreach and education efforts for the Ticket to Work program. The fifty-five nationwide AWICs work closely with the external Ticket to Work partners, such as Protection and Advocacy representatives, BPAO representatives, Employment Networks (ENs), Disability Program Navigators, Vocational Rehabilitation and other disability advocates. In some regions AWICs are included in regional training events with the BPAOs and have partnered with Maximus to provide training to the ENs. AWICs, Plan for Achieving Self-Support (PASS) specialists and SSA regional office staff participate in the training and refresher training sessions.

In addition, SSA has entered into a number of interagency agreements and cooperative agreements which are focused on increasing work opportunities for individuals receiving disability benefits.

SSA has entered into a \$100,000 interagency agreement with HHS' Office of the Assistant Secretary for Planning and Evaluation (ASPE) to subcontract the evaluation of the Florida Freedom Initiative (FFI). The FFI is an expansion of a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS), which is targeted to a subpopulation of participants in the section 1115 waiver demonstration called Consumer-Directed Care Plus. This subpopulation consists of adults with mental retardation/developmental disabilities. In addition to the financial commitment to the evaluation of the FFI, SSA will be waiving certain SSI and SSDI program rules for FFI participants to test whether the combination of Social Security and CMS waivers fosters greater self-sufficiency among demonstration participants.

SSA's Youth Transition Demonstration (YTD) consists of seven cooperative agreements in six States (California, Colorado, Iowa, Maryland, Mississippi, and New York). The goal of these cooperative agreements is to find more effective ways to enable youth who receive SSI and SSDI as well as those who are at risk of receiving these benefits, to transition successfully to work or post-secondary education and ultimately to maximize their economic self-sufficiency. These seven cooperative agreements were awarded September 30, 2003 for up to five years. The latest budget estimate for fiscal year 2006 includes \$11.8 million for funding the demonstration projects, evaluation and technical assistance. These partners are collaborating at the State level with the Vocational Rehabilitation Services, Department of Education, Department of Labor One Stop Centers as well as other State and local agencies.

Since 2001, SSA has been working under an Interagency Agreement with DOL's Office of Disability Employment Policy (ODEP) to promote SSA's Ticket to Work Program within DOL's "Employer Assistance Referral Network" (EARN). DOL has incorporated Ticket to Work into a specialized unit of EARN called "Ticket to Hire" (TTH). EARN's primary purpose is to provide employers with a one-stop service to help them locate and recruit skilled candidates with disabilities for jobs. TTH matches employers' job openings with qualified, job-ready candidates from the Ticket to Work Program. Presently, there is \$600,000 budgeted for the continuation of this Interagency Agreement for fiscal year 2006.

#### OHA HEARINGS

*Question.* Over the period fiscal year 2000–fiscal year 2004, the number of social security hearings pending have increased by 90 percent to more than 590,000, despite an increase in agency resources from \$6.6 billion to \$8.3 billion, or almost 26 percent. Pending hearings grew by nearly 80,000 during the last fiscal year and the average processing time increased by almost 14 percent, despite the provision of additional staff support to OHA and the hiring of 103 administrative law judges. Please provide a breakout of Office of Hearings and Appeal resources (dollars and staffing) over this period. What accounted for this growth in backlogs, despite increasing agency resources? What actions are underway or planned in fiscal year 2005 and fiscal year 2006 to ensure more timely dispositions and more cost-effective expenditure of agency resources?

*Answer.* The inability to hire ALJs between fiscal year 2001 and fiscal year 2004 resulted in increased cases pending, even though we were able to hire 103 ALJs in fiscal year 2004. This ALJ shortage, along with a 14 percent increase in case receipts during the same time period, has also increased processing time. OHA has

hired an additional 100 ALJs during fiscal year 2005, and anticipates hiring additional ALJs during fiscal year 2006 which will, when these ALJs are fully trained, facilitate case processing. Other actions being implemented to decrease processing time include the:

- development of File Assembly Units for assembling files for hearings;
- establishment of a Centralized Screening Unit which reviews and prepares cases for potential On-The-Record Decisions;
- implementation of various initiatives at the hearing level to expedite the issuance of decisions. These include the following: screening cases for on-the-record allowances; issuance of fully favorable decision by the ALJ at the hearing (bench decisions); providing an easily prepared decision format for ALJs to prepare decision findings; and
- electronic developments such as eDib, the Digital Recording Acquisition Program and the Case Processing Management System (CPMS), are expected to expedite case processing and tracking.

Despite not receiving the full President's budget request for the last two fiscal years, my Service Delivery Budget goal is to eliminate the hearings pending backlog by 2010. To achieve this, we need the Committee's support, including full funding for the President's budget request of \$9.403 billion for SSA's administrative expenses.

The breakout of OHA's resources (dollars and staffing) over the period covering fiscal year 2001 through fiscal year 2004 is as follows:

(Dollars in millions)

Year	Workyears	Amount
2001 .....	7,945	\$692.8
2002 .....	8,049	751.1
2003 .....	7,903	815.7
2004 .....	8,204	867.0

HIRING ALJs

*Question.* What is SSA's plan for hiring Administrative Law Judges in fiscal year 2005 and fiscal year 2006? How does the fiscal year 2006 budget request support continued improvement in Administrative Law Judge productivity, one way to help reduce the growing average processing time for hearings, which is up 31 percent from fiscal year 2000 to fiscal year 2004? The Committee is aware of the more than 100 day decrease in average processing time for hearings associated with the use of the video teleconferencing capability. What are the savings associated with the expansion of these facilities proposed in the fiscal year 2006 budget request?

*Answer.* OHA hired 100 ALJs for fiscal year 2005 and plans to hire additional ALJs in fiscal year 2006 depending on the level of funding available. After the nine-month learning curve, we expect that the increase in ALJ resources will help reduce the hearings backlog, and as a result, reduce the average processing time.

Including the 80 additional sites installed this fiscal year, there now are a total of 240 video teleconferencing sites in operation. We have conducted nearly 12,000 video hearings this fiscal year through April compared to 4,000 through April of fiscal year 2004. Video hearing usage contributes to ALJ productivity improvements because fewer hearings are postponed, ALJ travel is decreased, and expert resources are more accessible.

OHA'S CASE PROCESSING MANAGEMENT SYSTEM

*Question.* The new Office of Hearings and Appeals Case Processing Management System was scheduled to be completed by September 2004. What training resources are being expended to support its successful implementation? What does the fiscal year 2006 budget assume about savings related to this new system in fiscal year 2005 and fiscal year 2006?

*Answer.* The Case Processing Management System (CPMS) conversion began in May 2004 and was completed in August 2004. The following training resources supported successful implementation of the Case Processing Management System (CPMS):

- CPMS training began in April 2004 and ended in July 2004;
- CPMS training took place "onsite" at each hearing office (HO);
- CPMS training was performed over a 40-hour week;
- Training was broken into several categories, general training for all staff then job specific training for each job type;

- The on-site trainers were in the HO to help with the conversion of all Hearing Office Tracking Systems data to CPMS;
- The trainers remained onsite the week after training to address any CPMS issues that arose; and
- Further support has been provided after the training was completed:
  - A CPMS help desk in Falls Church is now maintained full-time;
  - CPMS training manuals have been made available on the OHA's website;
  - CPMS training material is on the OHA Website;
  - Continual updates are made to the training materials on the website;
  - Net meetings are conducted with HO's on the use of CPMS; and
  - A series of three Interactive Video Teletraining sessions on the use of CPMS were completed in March 2004.

No specific savings were associated with implementation of CPMS. However, the system is an essential element for implementation of the electronic folder process at the hearings level and will assist us in our plan to achieve an annual productivity improvement of 2 percent.

#### ELECTRONIC SERVICE DELIVERY

*Question.* Given the focus SSA has placed on electronic service delivery as a means of providing appropriate service to growing workloads, how is the agency monitoring electronic service delivery use and experience to alter and build its electronic service delivery infrastructure in a secure and user-friendly way?

*Answer.* E-Government services within SSA are maturing as a service delivery alternative to face-to-face contact, mail, and telephone. Substantial investments in infrastructure have been made with the expectation that electronic services will continue to grow and become a viable, efficient channel for the delivery of SSA's services. In fiscal year 2004, over 611,000 electronic entitlement and supporting actions, i.e., applications, Medicare replacement cards, change of address, etc., were processed. This represents an increase of 179 percent over the fiscal year 2002 baseline.

Electronic services are monitored using management information data. This data is analyzed to identify usage trends and to determine the level of resources required for these workloads. Customer feedback using email, surveys and telephone calls are additional ways to monitor usage.

#### *Customer Feedback*

- We have general feedback mechanisms on most web-pages that allow customers to send us their comments or complaints via email.
- Some on-line applications on the SSA web site also allow general customer feedback through the use of surveys. In addition, SSA has incorporated several American Customer Satisfaction Index (ACSI) surveys on its web site. Sponsored by the Department of the Treasury's Federal Consulting Group, ACSI surveys use a standardized set of questions to measure user satisfaction.
- SSA's Office of Quality Assurance uses telephone surveys to measure customer satisfaction with the Agency's programs, including services available from the web site.
- SSA subscribes to demographic data services that allow us to identify who is visiting the SSA site, from where, how long they stay, how many pages they visit, etc. This data helps us identify both popular and problem pages/services on the web site, and to focus marketing of the web site and its services.

*Question.* What new electronic services will be supported by the fiscal year 2006 budget and how will current services be improved to enhance user experience and Agency efficiency?

*Answer.* The following services will be supported:

- SSA's Internet Change of Address application has been enhanced to allow access through Knowledge Based Authentication in addition to the pin/password access.
- Speech technology provides citizens with the option to use automated telephone applications on the National 800 Number Network to access claims, benefits and related programmatic information.
- Last year, we completed speech-enabled automation of the transcription process over the National 800 Number Network. Prior to this conversion, callers left a message which was manually transcribed by SSA employees. Now callers hear a message confirming that their request was received and is being processed. If the request was not successful, the caller is directed to an agent for assistance.
- SSA's Electronic Wage Reporting initiative encourages employers to report their employees' wages electronically rather than via paper, magnetic tape or diskettes/CD ROMs. SSA offers online assistance and staffs an Employer 800 Num-

ber to provide information and technical support to employers. At least 70 percent of all W-2s will be filed electronically in fiscal year 2006, resulting in WY savings for the Agency and in more accurate, timely postings to the Master Earnings File.

- The Electronic Special Redetermination Mailer is an approved project in the Agency IT Systems Plan fiscal year 2005–2006. Under this project, High Error Profile (HEP) redeterminations will be processed using a new, expanded redetermination mailer that will be scanned in the Office of Earnings Operations (OEO). Mailer responses will be extracted electronically and compared to the Supplemental Security Record, and decision logic will be applied which clears cases or refers them for manual review/exception resolution in OEO or the Field Offices. Testing of the electronic special mailer is planned for April 2006 with implementation by October 2006.
- Social Security Number Verification Service (SSNVS) was recently approved by OMB. SSA plans to begin implementation in June 2005, with full nationwide implementation in October 2005. Employers who previously called the Employer 800 Number to verify employee SSNs will be able to obtain that confirmation via the Internet, instead. SSA plans extensive marketing of electronic SSNVS, which is expected to reduce SSN verification calls to the Employer 800 Number, verifications requested by tape/diskette, and the processing of paper listings.
- Electronic Freedom of Information Act (EFOIA) is expected to expand the use of the Internet to provide faster and better access to Government services and Information. The EFOIA system will employ technology that will automate SSA's internal FOIA processes to substantially reduce the FOIA processing time and allow us to respond to citizens within the legally required 20-day timeframe. The new system will accept electronic credit card payments and respond to requests via aggressive use of the Internet. EFOIA is expected to reduce the OEO unit time for FOIA actions by 20 percent effective with fiscal year 2006.
- The Microfilm/Microfiche Replacement Project was approved by the Information Technology Advisory Board in fiscal year 2004 after evaluation of Proof of Concept (POC) results. The processes SSA has used to produce, store, and access microfilm/fiche data have been among its most labor-intensive and costly. Microfilming technology is outdated and increasingly difficult to maintain. Online access by Operations employees from their workstations will enable SSA to process related workloads on a timely basis and ensure both the availability and integrity of SSA's databases. Based on POC results, the unit time required for employees in the PSCs, ODIO and OEO to access data will decrease from an average of 12 minutes to an average of 2 minutes.
- W-2C Online will continue to decrease the volume of W-2 corrections received in OEO for manual processing (examination, data entry/balancing, microfilming, etc.).
- As part of the e-Authentication initiative of the Presidential E-Government Initiatives, SSA has signed a Memorandum of Understanding with GSA to implement the federated authentication architecture with several SSA applications through fiscal year 2006. The federated authentication architecture will allow SSA to use the authentication of an online customer by a trusted partner (e.g., a financial institution whose authentication process has been certified by GSA) to conduct business online. The federated authentication architecture offers the potential for millions of online customers of banks and other financial institutions to use their existing pin/passwords to gain secure access to SSA electronic applications, improving and simplifying user access to our electronic applications without SSA (or any other government agency) having to establish or maintain pin/passwords.
- Development of the electronic folder to replace the paper disability folder will continue with processes to speed the request and retrieval of electronic evidence from medical, educational, and other third parties.
- SSA is studying ways to enhance the claims process to incorporate secure messaging with claimants as an alternative communication approach to the more-expensive telephone and in-person channels.

*Question.* What specific activities are supported in the fiscal year 2006 budget to promote the use of electronic services to employers, covered workers and current recipients/beneficiaries?

*Answer.* Through our network of field office managers and Public Affairs Specialists, we conduct ongoing outreach to raise awareness of online services and to encourage their use. Each year, working in their local communities, these professionals deliver speeches, submit newspaper articles, conduct workshops, lead seminars, and conduct radio and television interviews on all aspects of Social Security's programs, including the benefits of doing business with us online. We include infor-

mation about our online services in all our Social Security publications, including the Social Security Statement, which we send to all workers age 25 and older.

We also use a variety of other tools tailored to specific target audiences, as follows:

*General Public*

- An Online Services Marketing Kit, which includes:
  - A Fact Sheet (also available in Spanish);
  - Links to Special Places, a one-page handout that lists webpages such as the Glossary, the Immigration page, Most Popular Baby Names—items that draw people of all ages and ethnicities to the site;
  - A tri-fold leaflet, Apply Online for Social Security Benefits, that answers questions about our online retirement application;
  - A one-page “URL Handout” that provides addresses for the online retirement application, the Social Security Statement page, the Benefit Planners and Social Security card information; and
  - An Internet bookmark
- 800 Number on-hold messages promoting online services
- Partnerships with local libraries to distribute Social Security Online bookmarks and conduct educational seminars

*Third Parties With Clients Applying for Disability Benefits*

- PowerPoint overview of the i3368PRO (Internet Adult Disability and Work History Report)
- Instructional CD containing examples of the i3368PRO online application screens
- “eColleague letters” (email messages that formerly were paper-based “Dear Colleague” letters) to national organizations (advocates, attorneys, social service agencies, etc.)
- Webpage [www.socialsecurity.gov/i3368prohelp](http://www.socialsecurity.gov/i3368prohelp) that provides background information, helpful tips, etc.

*Covered workers*

- Cost-of-Living Adjustment (COLA) notices sent to all beneficiaries in January each year inviting them to visit [www.socialsecurity.gov](http://www.socialsecurity.gov)
- Panel on homepage promoting online retirement application
- Door signs that show office hours and encourage visitors to do business online
- Posters, tent cards, leaflets
- PowerPoint presentations
- PowerPoint overview of the i3368 (Internet Adult Disability and Work History Report)
- Instructional CD containing examples of the online application screens
- Draft redesign of Baby Names page to promote online retirement planners and calculators
- 800 Number on-hold messages promoting online services

*Current recipients/beneficiaries*

- Change of Address:
  - Articles for local news outlets, organizations’ house organs, etc.
  - Correspondence with people who wrote to the Commissioner, the Congress, or the White House
  - Fact Sheet
  - Partnership with USPS to place a link to SSA from their homepage
- Direct Deposit:
  - Partner with Fidelity to allow their online customers to set up direct deposit of their Social Security benefits into an eligible account
- 800 Number on-hold messages promoting all online services

*Employers*

- Articles in SSA/IRS Reporter
- Electronic Wage Reporting CD
- Posters, pamphlets, fact sheets
- Inserts for inclusion in IRS correspondence with employers
- Seminars at national conferences, such as the IRS Tax Forums the American Payroll Association and the National Restaurant Association to promote online wage reporting and filing for retirement online
- Partnerships with Chambers of Commerce across the country to encourage small business owners to file their wage reports online



- Partnerships with Human Resource Managers including the Society of Human Resource Managers to encourage their employees to file for retirement online
  - CD for Human Resource Managers promoting online retirement and providing useful tips
  - Screen calendars (calendar strips that people affix to their computer monitors)
  - Survey of non-electronic filers to identify (and help us overcome) barriers to online wage reporting
  - Website covering all aspects of online wage reporting
  - Toll-free call center specifically for employers with wage reporting issues
  - W2News e-mail specifically for employers discussing wage reporting issues
- Question.* How much savings does SSA expect through its electronic service delivery initiative in fiscal year 2005 and over the period fiscal year 2004–fiscal year 2007?

*Answer.* Although savings have not been specifically identified for most of these initiatives, we expect that the efficiencies gained through implementation and expansion of these efforts will be an essential element in our ability to reach a goal of a 2 percent annual improvement in productivity.

#### BI-PARTISAN SOLVENCY EDUCATION PROGRAM

*Question.* Please provide the Subcommittee with additional information related to the proposed bi-partisan solvency education program. What resources are requested within the fiscal year 2006 budget for these activities? How does this planned level of expenditure compare with fiscal years 1999–2004?

*Answer.* Among the many services provided by the Social Security Administration is educating the American public about the programs and finances of Social Security. One of the stated objectives in our Agency Strategic Plan is: “Through education and research efforts, support reforms to ensure sustainable solvency and more responsive retirement and disability programs.” No specific amount was included in SSA’s fiscal year 2006 budget request for solvency education. As in prior years, this effort is part of the ongoing educational program conducted by SSA to educate the public about the Social Security program, including the financing challenges facing them, through our ongoing communication efforts. As the national discussion continues on how best to strengthen Social Security for the future, we will work to continue to ensure that policymakers and the public have the information needed to assess the implications of all proposals under consideration.

Messages about the current status of the Trust Funds, as described in the Annual Report of the Board of Trustees of the Federal Old-Age and Survivors Insurance and Disability Insurance Trust Funds are included in a number of our public information resources, including:

- On our website—[www.socialsecurity.gov](http://www.socialsecurity.gov);
- In our publications—“The Future of Social Security” and “Understanding The Benefits” pamphlets;
- In the annual Social Security Statement mailed to all workers age 25 and older not currently receiving benefits; and
- When appropriate, as part of the presentation by our Agency communicators when speaking to groups and organizations.

#### SOCIAL SECURITY EARNINGS

*Question.* Each year approximately nine million wage records cannot be reconciled due to a mismatch associated with the name or Social Security Number of a person. According to the Inspector General of the Social Security Administration, as of July 2002, the Earnings Suspense File contained 236 million wage items totaling roughly \$374 billion. Of these amounts, roughly 80 million items worth \$13 billion are more than 30 years old. What activities are proposed in the fiscal year 2006 budget to update the records of wage earners whose current or future social security benefits would be lower than provided under current law due to processing mismatches? What steps are being taken to ensure that earnings are posted to the correct social security number upon initial submission and how does the fiscal year 2006 budget support these actions?

*Answer.* In fiscal year 2003, SSA began developing new matching software to associate earnings items in the Earnings Suspense File (ESF) with the correct individual master earnings file. The new routines use data housed on the ESF, enumeration records, benefit records and earnings records to confirm that the correct earnings records were identified. In fiscal year 2003 and 2004, SSA removed about 10 million items from the ESF and posted them to the correct earnings records for tax years 1937 through 2000. In fiscal year 2005, we are continuing to expand our

new software and are focusing on tax year 2001. The improvements will also be used to remove additional ESF items for years prior to 2001.

To prevent future earnings from going into the ESF, SSA works with employers to provide tools to allow them to determine if they have a name/Social Security number (SSN) mismatch on their payroll records prior to sending W-2s to SSA for processing. SSA provides a free Employee Verification Service where an employer can verify if a name and SSN match. SSA has piloted an Internet-based version of this service, the Social Security Number Verification Service (SSNVS). SSA anticipates offering this free Internet-based service to all employers.

SSNVS allows an employer to verify up to ten names/SSNs at a time with SSA over the Internet while receiving a response within seconds. In addition, an employer may submit a file over the Internet of up to 250,000 names/SSNs and receive a response on the next business day.

#### LEGISLATIVE PROPOSAL—SSI DISABILITY CLAIMS

*Question.* The fiscal year 2006 budget request includes a legislative proposal that would require SSA to review at least 50 percent of favorable decisions for adult SSI disability claims before starting payments. What are the administrative costs of this proposal in fiscal year 2006, and are these costs requested within the LAE account? What are the anticipated programmatic savings from this proposal?

*Answer.* Under current law, SSA reviews at least 50 percent of all Title II initial disability allowances made by State agencies on behalf of SSA. The budget proposal would apply the same requirement for adult disability allowances in the SSI program. When fully phased in, 50 percent of initial SSI disability allowances would be reviewed.

The administrative costs in fiscal year 2006 are estimated to be about 45 workyears and \$6 million which would be absorbed under the LAE account if the legislation is enacted.

The estimated program savings to general revenues of the preeffectuation proposal in the budget are about \$493 million over 10 years in the SSI program alone. Additional Medicaid savings from the proposal over 10 years are estimated to be about \$639 million.

#### SOCIAL SECURITY PROTECTION ACT

*Question.* According to the “Justification of Estimates for Appropriations Committees” for the fiscal year 2006 budget request, the LAE account includes resources needed to implement the Social Security Protection Act. How much funding is required to implement each activity required by the Act?

*Answer.* There are fifty-one sections of the SSPA enacted March 2, 2004. The fiscal year 2006 administrative budget includes \$14.7 million, and 211 workyears (WYs), to fund the following provisions:

- Expanding numbers of onsite representative payee reviews the Agency will need to conduct under Section 102(b).
- Processing suspensions of Title II benefits to persons fleeing prosecution, custody, or confinement, and/or those violating probation or parole as provided in Section 203. This section extends fugitive felon provisions currently applied to Title XVI beneficiaries to Title II beneficiaries.
- Issuing receipts to acknowledge submission of reports of changes in work or earnings status of disabled beneficiaries as provided in Section 202.

The SSPA also authorizes attorney fees to be paid directly out of individuals’ retroactive SSI benefits to the same extent and under the same processes as currently are in place for deducting attorney fees from retroactive OASDI benefits (Section 302). Additionally, it requires SSA to test the impact of establishing a fee payment process for non-attorney representatives that is similar to the current one for attorneys (Section 303).

#### RAILROAD RETIREMENT BOARD

##### PREPARED STATEMENT OF MICHAEL S. SCHWARTZ, CHAIRMAN

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board’s (RRB) fiscal year 2006 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit pay-

ments and Medicare coverage for railroad workers. During fiscal year 2004, the RRB paid \$9 billion in retirement/survivor benefits to about 649,000 beneficiaries, and \$83 million in unemployment/sickness insurance benefits to about 34,000 claimants.

We are respectfully requesting a total agency budget of \$103,398,240 in fiscal year 2006. This total includes \$102,543,040 for ongoing agency operations, which is the same as the amount included in the President's proposed budget for the year. In addition, we are requesting \$855,200 for critical elements of the RRB's Enterprise Architecture Capital Asset Plan.

#### ADMINISTRATIVE FUNDING ISSUES

The President's proposed budget would provide the same level of funding for the RRB's administrative expenses in fiscal year 2006 as the amount appropriated for fiscal year 2005. To operate at this level, RRB staffing has been significantly reduced. Early this fiscal year, 77 employees were separated from the agency through a program of voluntary separation incentives, and since that time, new hiring has been severely restricted. The agency's funded staffing level for fiscal year 2005 is currently 76 full-time equivalent staff years (about 7.3 percent) lower than fiscal year 2004.

Continuation of the same funding level from fiscal year 2005 to 2006 would effectively require the RRB to absorb all fiscal year 2006 cost increases for the goods and services required to administer the railroad retirement/survivor and unemployment/sickness insurance benefit programs. These rising costs include the January 2006 pay increase for the agency's employees, which would total approximately \$1.61 million at the currently estimated rate of 2.6 percent.

Under current law, the cost increases would require further cuts in agency staffing, because nearly 80 percent of the RRB's budget is used for employees' salaries and benefits. We estimate that the President's proposed budget would provide sufficient funding for a staffing level of 931 FTE's, which is 41 FTE's less than we expect to use in fiscal year 2005. In order to reach this level, we would need to conduct a reduction-in-force of about 18 employees at an estimated cost of \$233,000.

#### NONGOVERNMENTAL DISBURSEMENT AGENT

The President's proposed budget assumes that the RRB will contract with a nongovernmental agent for disbursement services, as provided under Section 107(e) of the Railroad Retirement and Survivors' Improvement Act of 2001 (Public Law 107-90). However, initial market research has indicated that the cost of doing so would be about three times the cost of having similar services provided by the Department of the Treasury. In addition, our Inspector General has questioned whether certain services provided by the Department of the Treasury, such as reclamations, would be provided as effectively by a nongovernmental disbursement agent.

We have concluded that outsourcing this function would be inconsistent with the President's policy of outsourcing only where the government would save costs. For fiscal year 2005, the Congress added language to our appropriations bill prohibiting this transfer: Section 516 of the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 2005 provides that none of the funds appropriated under the Act are to be used to contract with a nongovernmental disbursement agent. The RRB also submitted separate legislation to address this issue during the previous Congress, and we plan to again submit legislation on the subject during this Congress.

Current estimates indicate that the cost of contracting with a nongovernmental disbursement agent would be in excess of \$3 million for the first year and \$2.3 million in subsequent years. By comparison, the annual cost of having these services provided by the Department of the Treasury is about \$800,000. Enactment of legislation to remove this requirement would provide sufficient savings in fiscal year 2006 to enable the RRB to cover essential operating costs at the proposed budget level.

#### ENTERPRISE ARCHITECTURE CAPITAL ASSET PLAN

Our budget request includes funding for a key element of the RRB's Enterprise Architecture Capital Asset Plan, which addresses the major initiatives needed to implement the agency's target enterprise architecture. This request is highlighted separately because of its significance to the long-term, continued viability of agency programs, and the realization that movement toward the desired target architecture will be a multi-year effort involving special funding needs. We are requesting an additional \$855,200 in fiscal year 2006 to continue with an initiative to convert our processing systems to a relational database management system.

Gartner Consulting recommended that we investigate alternatives for our Computer Associates' Integrated Database Management System (IDMS) and prepare to actively retire the platform beyond 2006. The RRB's day-to-day operations are heavily dependent on application systems that are based on IDMS technology. Delaying the database management system conversion would create a high risk of loss for these systems, which would compromise the agency's ability to pay benefits and fulfill its mission in the future. For this reason, we have already begun project development for this initiative. We are currently developing specifications for contractual assistance, and we expect to release a request for proposals later in fiscal year 2005. Preliminary estimates indicate that a full conversion might be accomplished within 12 to 18 months, although our schedule will depend on the availability of resources.

In addition to the requests for administrative expenses, the Administration's budget includes \$97 million to fund the continuing phase-out of vested dual benefits, and \$150,000 for interest related to uncashed railroad retirement checks.

#### FINANCIAL STATUS OF THE TRUST FUNDS

*Railroad Retirement Accounts.*—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (NRRIT), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 to manage and invest railroad retirement assets. The RRB transferred \$586 million to the NRRIT in fiscal year 2004. This amount is in addition to the \$19.188 billion and \$1.502 billion transferred in fiscal years 2003 and 2002, respectively. In fiscal year 2004, the NRRIT transferred \$1.564 billion to the RRB for the payment of tier 2 benefits.

In June 2004, we released the annual report on the railroad retirement system required by Section 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The report, which reflects changes in benefit and financing provisions under the Railroad Retirement and Survivors' Improvement Act of 2001, addresses the 25-year period 2004–2028 and contains generally favorable information concerning railroad retirement financing. The report included projections of the status of the retirement trust funds under three employment assumptions. These indicated cash flow problems only under a pessimistic employment assumption, and then not until calendar year 2026. This is 4 years later than in the previous year's report.

*Railroad Unemployment Insurance Accounts.*—The equity balance of the railroad unemployment insurance accounts at the end of fiscal year 2004 was \$87.5 million, an increase of \$36 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system, issued in June 2004, was generally favorable. The report indicated that even as maximum daily benefit rates rise 35 percent (from \$55 to \$74) from 2003 to 2014, experience-based contribution rates are expected to keep the unemployment insurance system solvent. No loans are anticipated even under our most pessimistic assumption. The average employer contribution rate remains well below the maximum throughout the projection period, but a 1.5 percent surcharge is now in effect and is expected for calendar year 2006 and probably 2007. We did not recommend any financing changes based on this report.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. We recognize that fiscal year 2006 will be a tight budget year throughout the Federal government, and our budget request reflects our continued commitment to contain the RRB's administrative costs accordingly. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

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#### PREPARED STATEMENT OF MARTIN J. DICKMAN, INSPECTOR GENERAL

Mr. Chairman and Members of the Subcommittee: My name is Martin J. Dickman, Inspector General of the Railroad Retirement Board (RRB). I would like to thank you, Mr. Chairman, and the members of the committee for your continued support for the Office of Inspector General. I wish to describe our fiscal year 2006 appropriations request and our planned activities.

The Office of Inspector General requests funding of \$7,195,968 to ensure the continuation of its independent oversight of the RRB. The agency is responsible for managing benefit programs which paid \$9 billion in retirement and survivor benefits to approximately 649,000 beneficiaries in fiscal year 2004 and an additional \$83 million in net railroad unemployment and sickness insurance benefits to 32,000 claimants. The RRB also administers Medicare Part B, the physician services aspect

of the Medicare program, for qualified railroad retirement beneficiaries. Through this program, approximately \$923 million in annual Medicare benefits are paid to approximately 551,000 beneficiaries.

In fiscal year 2005, the Office of Inspector General will continue to concentrate its efforts on the performance of reviews of significant policy issues and program operational areas. We will coordinate our efforts with agency management to identify and eliminate operational weaknesses. We will also continue our investigation of allegations of fraud, waste and abuse, and refer cases for prosecution and monetary recovery action.

We also request the removal of the prohibition on the use of appropriated funds for any audit, investigation or review of the Railroad Medicare program. The RRB manages a nationwide contract for processing Medicare Part B claims for railroad beneficiaries. The agency is responsible for the enrollment of beneficiaries, premium collection, answering beneficiary inquiries and conducting the annual Carrier Performance Evaluation for the Medicare carrier.

The prohibition does not permit the OIG to fulfill its statutory oversight responsibilities for a major agency program. The prohibition is contrary to Federal government priorities to reduce fraud in one of the largest Federal programs.

We also request oversight authority to conduct audits and investigations of the National Railroad Retirement Investment Trust (NRRIT), the body responsible for the investment of approximately \$27 billion in trust funds used to support Railroad Retirement Act benefit programs. This office would ensure sufficient reporting mechanisms are in place and assess if the NRRIT members are fulfilling their fiduciary responsibilities. We have repeatedly expressed concerns about RRB management's passive relationship with the NRRIT, and identified the issue as a serious challenge for the RRB.

The OIG currently is required to reimburse the agency for office space, equipment, communications, office supplies, maintenance and administrative services. We are the only Federal OIG that cannot negotiate a service level agreement with its parent agency. We, therefore, request that the language in appropriation law be removed.

#### OFFICE OF AUDIT

Auditors will perform the audit of the RRB's 2005 financial statements and preliminary work for the 2006 financial statements to ensure the issuance of reliable financial information. The OIG will obtain the services of a consulting actuary to audit the statement of social insurance.

Audit staff will work with agency management to ensure detailed and verifiable financial information is available from the National Railroad Retirement Investment Trust (NRRIT). As discussed above, we believe RRB management should take a more active interest in NRRIT activities.

They will conduct the annual evaluation of the RRB's information systems security to meet the requirements of the Federal Information Security Management Act of 2002. We will also monitor the agency's information systems operations to determine if the agency is meeting the goals established in its Strategic Information Resources Management Plan and to ensure the agency is in compliance with the provisions of the Information Technology Management Reform Act.

Auditors will continue to monitor agency actions to address security deficiencies and complete corrective actions. They will ensure that network and system security safeguards are in place to protect the confidentiality of sensitive financial and personal information. Auditors will also perform assessments of the agency's e-government initiatives to identify and eliminate system vulnerabilities, and to ensure compliance with the E-Government Act of 2002. We will continue our monitoring efforts of the RRB's document imaging activities and the expansion of paperless processing to ensure the integrity of records.

Auditors will continue to review RRB benefit processes and procedures to identify ways to reduce administrative and adjudicative errors. They will offer recommendations to strengthen the agency's debt collection program to reduce the outstanding receivables.

#### OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) identifies, investigates and presents cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. In fiscal year 2006, OI will continue to focus its resources on the investigation of cases with the highest fraud losses. OI currently has approximately 500 active investigations involving fraudulent benefit payments and fraudulent reporting with fraud losses of approximately \$11 million. These cases involve all RRB pro-

grams that provide sickness and unemployment insurance benefits to injured or unemployed workers, retirement benefits, and disability benefits for workers who are disabled.

We will continue our efforts with program managers to address weaknesses in agency programs that allow fraudulent activity to occur, and will recommend changes to ensure program integrity.

We will concentrate our resources on cases with the highest fraud losses, those related to the RRB's retirement and disability programs as well as fraudulent reporting by railroad employers. OI will dedicate considerable resources to the investigation of nationwide schemes to defraud the RRB disability program. Disability cases currently constitute about 40 percent of our investigative caseload. These cases involve more complicated schemes and result in the recovery of substantial funds for the agency's trust funds.

In fiscal year 2006, we will continue to use the Department of Justice Affirmative Civil Enforcement (ACE) program for those cases which do not meet the criminal guidelines of U.S. Attorneys. Through this program, we are able to obtain civil judgements and recover trust fund monies for the RRB.

#### SUMMARY

In fiscal year 2006, the Office of Inspector General will continue to focus its resources on the review and improvement of RRB program operations and ensuring the integrity of agency trust funds. We will also continue to aggressively pursue individuals who engage in activities to fraudulently obtain RRB funds.

## 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 MOTIVATION, EDUCATION AND TRAINING, INC.

Honorable Chairman, Senator Arlen Specter, and Honorable Committee Members: It is with sincere appreciation that I convey our gratitude for your efforts on behalf of all hard working Americans, and for granting us the opportunity to share information about the nation's migrant and seasonal agricultural workers and the importance of the National Farmworker Jobs Program.

I am the executive director of Motivation Education & Training, Inc. (MET), the authorized National Farmworker Jobs Program (NFJP) operator in Louisiana, Minnesota, North Dakota, and Texas, which are all funded through Section 167 of the Workforce Investment Act (WIA). MET is a community-based organization headquartered near Houston, Texas, and has been actively engaged serving low-income populations and communities for almost four decades.

Since the 1960s, the affirmative efforts of both Congress and various Presidential Administrations have created and preserved a modest, though vital, system to aid farmworkers and their family members who seek improved economic prospects through career training and stabilization services. As you may know, a typical American agricultural worker faces some of the harshest working conditions in the United States, and yet their compensation is neither commensurate with the risks taken, nor sufficient for the work performed. During the most recently completed Program Year, MET served more than 3,000 migrant and seasonal farmworkers with reported average annual earnings of \$5,855 per client. Despite this shockingly low income, very few farmworkers, only 6.3 percent, seek and receive public assistance, preferring instead the path of self-reliance and an extremely meager existence.

Uncertainty, which is inherent in the agricultural economy, ensures the perpetuation of a cruel paradox wherein extended periods of joblessness due to lack of available work, are interspersed with fleeting spikes in labor demand as crops mature or weather conditions permit activity in the fields. The long distances that many farmworkers and their families travel represents the desperate tradeoff between the mere hope of income and the likelihood that any semblance of stability can be achieved and maintained. But members of this community face severe challenges when seeking to exercise other career options, and for many families, reliance on agriculture is passed along from one generation to the next, thus ensuring the inheritance of work, subsistence, and poverty for decades to come.

Historically, migrant and seasonal farmworkers have had relatively limited access to the public workforce investment system. A number of factors have worked in concert to discourage their participation, and even in the recently expanded One-Stop network, farmworkers can expect little assistance outside of the local systems where NFJP programs consistently offer high caliber career development and stabilization services. Yet despite both the need for the program and the phenomenal performance of the NFJP with respect to all other workforce investment programs, the current leadership at the US Department of Labor fails to see any value in preserving this most basic form of individual, family, and community economic development. Though duly authorized in WIA we now face the regular threat of elimination, but MET and our partners across the country continue to strive for better employment options for farmworkers and increased earnings that can move families out of poverty and into progressively higher tiers of economic stability and security.

Within the last year, a series of DOL-sponsored community forums in three regions of the country reinforced the necessity of preservation of the NFJP. The dialogues brought together local workforce boards, local and regional One-Stop partners, state agencies, federal stakeholders, and NFJP representatives in a setting

that encouraged analysis and discussion related to improved One-Stop access for migrant and seasonal farmworkers. The forum in Texas that I attended primarily served as the central U.S. regional dialogue, and ultimately delivered two resounding messages: (1) preservation of the NFJP is crucial if farmworker clients can expect any type of appropriate workforce investment service; (2) expanded farmworker access to the One-Stop system is an improbable, if not impossible, prospect in the absence of the NFJP or a substantially similar nationally-administered initiative.

Workforce board representatives affirmed the necessity of our experienced and capable administration of workforce investment services for migrant and seasonal farmworkers. Citing the complexity of the challenge that farmworker clients represent to the general system's core, intensive, and training delivery operations, as well as our singular expertise in working with these constituents, boards and other key stakeholders candidly expressed their concerns about some of the limitations within the evolving One-Stop system. I did not hear one dialogue participant state, suggest, or even imply that passing responsibility to the states and local boards would do anything except dramatically reduce farmworker access to public workforce services.

A reasonable evaluation of NFJP performance clearly places this critical workforce component in the highest echelon of WIA authorized partners, achieving better results than programs that receive substantially more funds per client, as well as those serving populations that are better equipped than farmworkers upon program entry to secure sustainable employment. We work hard to place our clients in permanent positions that will afford an opportunity for consistent long-term upward mobility, and that provide compensation packages consistent with the needs of today's families. Few jobs are permanent in the strictest sense, and given the nature of the evolving global economy, an individual's ability to acquire and retain employment is only as promising as that person's capacity to satisfy emerging skill demands and their facility in utilizing available resources to promote their employment. Without the individual attention and highly intensive case management intervention that is available to farmworkers only through the NFJP, most of this population would be unable to matriculate or complete a workforce development training program of the type necessary to secure and retain higher wage and higher skill employment.

Belt-tightening and budget reductions are inevitable considerations in light of the current federal revenue shortfall; however, we would do immeasurable injustice to a worthy few and an extreme disservice to our national character if, in our attempt to reduce expenditures, we place a heavier load on the backs of our already overburdened and less fortunate citizens. I would respectfully request your favorable consideration of full restoration for the NFJP in fiscal year 2006, and if that proves altogether too ambitious, at least the maintenance of current federal support for this crucial component in the struggle for economic self-sufficiency among the poorest of America's workers.

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#### PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF HOME BUILDERS

On behalf of the more than 220,000 members of the National Association of Home Builders (NAHB), as well as our workforce development arm, the Home Builders Institute (HBI), we thank you for the opportunity to submit this statement for the record on the Responsible Reintegration of Youth Offenders program, and the Prisoner Re-entry Program.

NAHB members are involved in home building, remodeling, multifamily construction, property management, subcontracting, design, housing finance, building product manufacturing and other aspects of residential and light commercial construction. Known as "the voice of the housing industry," NAHB is affiliated with more than 800 state and local home builder associations around the country. NAHB's builder members will construct about 80 percent of the more than 1.6 million new housing units projected for 2005, making the housing industry one of the largest engines of economic growth in the country, and vital to the nation's overall economic growth and prosperity.

Throughout the past two decades, one of the most pressing problems confronting our industry has been a shortage of skilled workers. Record numbers in the construction of new homes, retirements and lackluster interest in the construction trades by younger generations, compounded by insufficient training opportunities for those interested in construction, are among the many factors contributing to the shortages. According to the Bureau of Labor Statistics, some 240,000 workers are needed each year to meet the nation's demand for housing, and they anticipate that



over 1 million new jobs in the residential construction industry will be created in the next decade as builders attempt to keep up with demand for affordable housing.

#### HOME BUILDERS INSTITUTE (HBI) PROGRAM BACKGROUND

Each year, the Home Builders Institute (HBI) works through various programs to train and place several hundred youth in residential construction jobs. Through real-life, hands-on training, some of our nation's most at-risk young people, learn a skill, and earn a second chance at a productive and successful life and career. Since 1994, HBI has focused a significant portion of its effort and resources on one particular targeted population, adjudicated youth, through its Project CRAFT (Community Restitution Apprenticeship-Focused Training) program. Piloted in 1994 through a Department of Labor demonstration grant, Project CRAFT is targeted solely to adjudicated youth and youthful offenders. This program has successfully combined employers, the juvenile justice system, workforce development and other systems, in one overall approach, and has since been implemented at 15 sites in ten states (Colorado, Ohio, Florida, Maryland, Mississippi, New Jersey, North Dakota, South Carolina, Tennessee, and Texas). Funding for HBI's implementation of this program in the state of Tennessee has come largely through funds provided under the Responsible Reintegration of Youth Offenders budget line.

Project CRAFT incorporates the apprenticeship concept of hands-on training and academic instruction, utilizing its Pre-Apprenticeship Certificate Training (PACT), numeracy, literacy and employability skills curricula. Under the supervision of journey-level trade instructors, students learn residential construction skills while completing community service construction projects. Nearly 85 percent of Project CRAFT graduates achieve success through industry jobs each year.

Since 1994, Project CRAFT has helped more than 2,000 high-risk youth, and in addition to offering adjudicated youth trade skills and job placement, community service projects by students saved taxpayers nearly \$400,000 in labor costs in 2003–2004 alone. During 2003–2004, Project CRAFT graduates were placed in jobs with an average wage of \$8.58/hour and graduates performed over 49,000 hours of community service as part of their programs. Recidivism rates for Project CRAFT have averaged between 10–15 percent, an impressive rate when compared to the national average of over 50 percent. Additionally, students in the program tend to evidence one grade level of improvement in math and language skills attributable largely to the formal education component that includes contextual learning. Math and communication skills are continually reinforced as students are challenged to apply these skills to everyday situations in the field and in the classroom.

Project CRAFT efforts were recognized by the Department of Labor and the National Youth Employment Coalition when in September 2002, the program received a PEPNet (Promising and Effective Practices Network) Award. We are also grateful to the Senate Subcommittee on Labor, Health and Human Services and Education for its acknowledgement of Project CRAFT in fiscal year 2005 Report Language, as well as Congress' years of dedicated support for the Responsible Reintegration of Youth Offenders program.

#### RESPONSIBLE REINTEGRATION OF YOUTH OFFENDERS PROGRAM

NAHB and HBI's encouraging experience with Project CRAFT is an example of the enormous success of the Responsible Reintegration of Youth Offenders pilot program, and the reason why we very strongly support the continuation of funding for a youth-focused program targeting adjudicated youth with training that provides this at-risk population with important job- and life-skills. The Responsible Reintegration of Youth Offenders Program has helped to bring together industry and government in a partnership with tangible positive outcomes. Since 1994 the program has earned a reputation as a worthwhile investment of taxpayer dollars, a significant and important resource to the nation's building industry, and a major contributor to the future success of thousands of young people. It is a demonstration model that works, and as such deserves to be touted and replicated. We hope that its proven success and recognition as an effective intervention will help enable it to receive continued funding, whether through a stand-alone program, or as part of a youth-focused component of the Prisoner Re-entry Program.

#### PRISONER RE-ENTRY PROGRAM

In its fiscal year 2006 budget proposal, the administration proposes to fund the Prisoner Re-entry Program through appropriations to three federal departments (Department of Labor, \$35 million; Department of Justice \$15 million, Department of Housing and Urban Development, \$25 million.) We hope this joint funding level will provide more opportunities to train the nation's at-risk youth. The Prisoner Re-

entry Program continues to focus on “helping individuals exiting prison make a successful transition to community life and long-term employment” through programs to help ex-offenders find and keep employment, obtain housing, and take advantage of mentoring programs.

NAHB and HBI support the goals of the Prisoner Re-entry program, and agree that there is enormous potential for successful programming targeting ex-offenders. NAHB and HBI continue to believe that an important targeted community within the Prisoner Re-entry program must be adjudicated juveniles and we support extending Prisoner Re-entry program eligibility to adjudicated juveniles and youthful offenders ages 16–24, in addition to other age groups served by the program. We have found that these young people in particular are energetic, interested and engaged in learning the skills taught through our Project CRAFT program. We believe that any funding targeted to training those who are re-entering society must include a component targeted to the youth offender population.

As we have stated, the Prisoner Re-entry program has significant potential for helping the adult offender community receive important training and job skills. And we believe that HBI is well-positioned to participate in an adult-focused program through its Project TRADE (Training, Restitution, Apprenticeship, Development and Education) program—which is the sister program to the youth-focused Project CRAFT. Designed to train and place adult offenders in employment in the home building industry, TRADE is currently being implemented in Colorado Springs and Sheridan, Ill. Project TRADE has trained over 500 adult offenders in the residential construction trade since 1995 through programs in Maryland, North Carolina, North Dakota, Oregon, Pennsylvania, Washington, Tennessee, Colorado and Illinois. We believe that Project TRADE’s emphasis on adults complements the work done by Project CRAFT with younger offenders.

#### CONCLUSION

NAHB and HBI continue to strongly support the goals of the Responsible Reintegration of Youth Offenders program. We also support the Department of Labor’s interest in targeting a program to ex-offenders and adjudicated individuals through the Prisoner Re-entry program, and we very strongly support the inclusion of youth offenders and adjudicated juveniles in this initiative.

We believe that the Responsible Reintegration of Youth Offenders demonstration program has been highly successful, as evidenced by our own accomplishments with Project CRAFT. We fervently hope that any proposal supported by congressional appropriators will take into account the needs of both the youth and adult ex-offender populations, and will clearly lay out congressional intent to continue serving the youth ex-offender population.

Again, we thank the subcommittee for this opportunity to share our views on the Responsible Reintegration of Youth Offenders program, and Prisoner Re-entry Initiative. We look forward to working with you to promote training programs that help America’s at-risk youth acquire the skills they need for successful and productive careers in the home building industry.

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#### PREPARED STATEMENT OF THE NATIONAL COALITION FOR HOMELESS VETERANS

##### INTRODUCTION

The National Coalition for Homeless Veterans appreciates the opportunity to submit recommendations on fiscal year 2006 appropriations for and program management issues related to the U.S. Department of Labor (DOL).

The National Coalition for Homeless Veterans (NCHV), established in 1990, is a nonprofit organization with the mission of ending homelessness among veterans by shaping public policy, promoting collaboration, and building the capacity of service providers. NCHV’s nearly 250 member organizations in 46 states and the District of Columbia provide housing and supportive services to homeless veterans and their families, such as street outreach, drop-in centers, emergency shelter, transitional housing, permanent housing, recuperative care, hospice care, food and clothing, primary health care, addiction and mental health services, employment supports, educational assistance, legal aid and benefit advocacy.

More than 250,000 veterans are homeless on any given night; more than 500,000 experience homelessness over the course of a year. Conservatively, one of every three homeless adult males sleeping in a doorway, alley, box, car, barn or other location not fit for human habitation in our urban, suburban, and rural communities has served our nation in the Armed Forces. Homeless veterans are mostly males (2 percent are females). 54 percent are people of color. The vast majority are single,

although service providers are reporting an increased number of veterans with children seeking their assistance. 45 percent have a mental illness. 50 percent have an addiction.

America's homeless veterans have served in World War II, Korea, the Cold War, Vietnam, Grenada, Panama, Lebanon, anti-drug cultivation efforts in South America, Afghanistan, and Iraq. 47 percent of homeless veterans served during the Vietnam Era. More than 67 percent served our nation for at least three years and 33 percent were stationed in a war zone.

Male veterans are twice as likely to become homeless as their non-veteran counterparts, and female veterans are about four times as likely to become homeless as their non-veteran counterparts. Like their non-veteran counterparts, veterans are at high risk of homelessness due to extremely low or no income, dismal living conditions in cheap hotels or in overcrowded or substandard housing, and lack of access to health care. In addition to these shared factors, a large number of at-risk veterans live with post traumatic stress disorders and addictions acquired during or exacerbated by their military service. In addition, their family and social networks are fractured due to lengthy periods away from their communities of origin. These problems are directly traceable to their experience in military service or to their return to civilian society without appropriate transitional supports.

Contrary to the perceptions that our nation's veterans are well-supported, in fact many go without the services they require and are eligible to receive. One and a half million veterans have incomes that fall below the federal poverty level. Neither the VA, state or county departments of veteran affairs, nor community-based and faith-based service providers are adequately resourced to respond to these veterans' health, housing, and supportive services needs. The VA plays only a limited role in providing employment services to veterans, administering just one small supported employment program for veterans with serious disabilities.

The U.S. Department of Labor and state and local workforce agencies bear primary responsibility for ensuring that veterans are provided opportunities to prepare for and obtain productive employment. Accordingly, we urge Congress to provide full funding for the programs of the Department of Labor Veterans Employment and Training Service (VETS) in order to ensure that our nation's workforce services system is equipped to fulfill their obligations to our nation's veterans.

FISCAL YEAR 2006 APPROPRIATION RECOMMENDATION—HOMELESS VETERAN  
REINTEGRATION PROGRAM

The Homeless Veterans Reintegration Program (HVRP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides competitive grants to community-based, faith-based, and public organizations to offer outreach, job placement and supportive services to homeless veterans. HVRP is the primary employment services program accessible by homeless veterans and the only targeted employment program for any homeless subpopulation. Homeless veterans have many additional barriers to employment than non-homeless veterans due to their lack of housing. HVRP grantees remove those barriers through specialized supports unavailable through other employment services programs. Grantees are able to place HVRP participants into employment for \$2,100 per placement, a tiny investment for moving a veteran out of homelessness, and off of dependency on public programs.

DOL estimates that 14,750 homeless veterans will be served through HVRP at the fiscal year 2005 appropriation level of \$21 million. This figure represents just three percent of the overall homeless veteran population, which the Department of Veterans Affairs estimates numbers more than 500,000 over the course of a year. An appropriation at the authorized level of \$50 million would enable HVRP grantees to reach approximately 24,000 homeless veterans.

Additionally, HVRP is being used as the account to fund a joint Department of Labor and Department of Veterans Affairs initiative authorized by Congress to assist veterans incarcerated in their reentry to the community. This decision essentially adds a new purpose to the HVRP program, for which additional funds are needed.

We urge Congress to appropriate at least \$50 million for HVRP in fiscal year 2006 Labor-HHS-Education appropriations legislation.

## FUNDING FOR HOMELESS VETERANS REINTEGRATION PROGRAM

[In millions of dollars]

Fiscal year	Amount
2004 .....	19
2005 .....	20.8
2006—Administration .....	22
2006—NCHV .....	50

## FISCAL YEAR 2006 APPROPRIATION RECOMMENDATION—VETERANS WORKFORCE INVESTMENT PROGRAM

The Veterans Workforce Investment Program (VWIP), within the Department of Labor's Veterans Employment and Training Service (VETS), provides grants to states and community-based, faith-based, and local public organizations to offer workforce services targeted to veterans with service connected disabilities, with active duty experience in a war or campaign, recently separated from the service, or facing significant barriers to employment (including homelessness). At least 80 percent of total VWIP funds are distributed via competition. VETS may reserve 20 percent of total VWIP funds for discretionary grants. VETS uses these discretionary funds for studies, demonstration projects, and additional funding to supplement competitive grants. The fiscal year 2005 appropriation for VWIP is \$8.5 million.

Both those agencies that receive VWIP funds and those hoping to apply face the problem of resource scarcity. Due to funding limitations, agencies and organizations in less than half of states receive VWIP funds. The need for the type of targeted assistance that VWIP offers is clearly needed by veterans in all states. Additionally, caps on the size of grant awards make it difficult for existing grantees to recruit and retain staff. This limits program effectiveness and the collaborative process. Sadly, the President's fiscal year 2006 request is a step backward, reversing the one million increase that Congress appropriated just last year.

We urge Congress to appropriate at least \$33.5 million for VWIP in fiscal year 2006 Labor-HHS-Education appropriations legislation.

## FUNDING FOR VETERANS WORKFORCE INVESTMENT PROGRAM

[In millions of dollars]

Fiscal year	Amount
2004 .....	7.5
2005 .....	8.5
2006—Administration .....	7.5
2006—NCHV .....	33.5

## CONCLUSION

NCHV appreciates the opportunity to submit recommendations to Congress regarding the resources and activities of the U.S. Department of Labor. We look forward to continuing to work with the Appropriations Committee in ensuring that our federal government does everything within its grasp to prevent and end homelessness among our nation's veterans. They have served our nation well. It is beyond time for us to repay the debt.

## PREPARED STATEMENT OF THE OPPORTUNITIES INDUSTRIALIZATION CENTER OF WASHINGTON

Honorable Chairman Specter and members of the Subcommittee: Opportunities Industrialization Center of Washington (OIC) has been providing employment and training, educational, nutritional and other community services in Central Washington for over 34 years. Since July of 1999, we have been the U.S. Department of Labor National Farmworker Jobs Program (NFJP) grantee for the state of Washington. Agriculture is one of Washington State's principal industries; the value of major crops alone is approximately \$5.5 billion per year.

Our NFJP program operates six regional offices and three satellite offices in central and western Washington. OIC provides a full range of core, intensive, training, and related assistance services to eligible farmworkers and dependents. From July of 1999 to June of 2004, we provided direct services to approximately 3,200 farm-

workers, most all of whom had substantial barriers to employment. Approximately 41 percent of our customers had less than an 8th grade education and an additional 29 percent had only up to an 11th grade education. Also, 58 percent of customers were limited English proficient, 79 percent lacked significant work history outside of agriculture, 34 percent lacked transportation, and 20 percent were single head of household with children. Over 80 percent were unemployed at the time they entered our program. In light of these obstacles, our staff did an excellent job in obtaining year-round employment for approximately 1,200 of our customers, which was 114 percent of program goals during this time period.

OIC has been a part of the development of our state's WorkForce Development System (the OneStop system) and are partners in each of the Workforce Development Councils within the areas that we provide services. This includes participation on key committees as the voice of the farmworker, as well as out-stationing of staff in each area's WorkSource Center. It is our experience that, while our state's WorkSource Centers provide quality services overall, they are not yet positioned to provide adequate services to the farmworker community.

Traditionally, farmworkers in our state have been reluctant to go to official/bureaucratic settings in order to receive services. This holds true for our WorkSource Centers, most of which are housed in what were formerly Washington State Employment Security Department Job Service Centers, and which continue to be managed by this agency. Most WorkSource Centers maintain traditional business hours, Monday through Friday from 8:00 a.m. to 5:00 p.m. Moreover, service delivery is designed around a self-service methodology and makes extensive use of computer-based systems. As a result migrant and seasonal farmworkers are prevented from accessing services due to hours of operation. Also, people with low levels of literacy and/or limited/non-existent computer skills such as our customers cannot make effective use of available resources.

A compounding problem is the lack of resources needed to adequately serve customers with substantial barriers to employment. Our state is currently working to develop its biennium budget, which currently has a \$2.1 billion shortfall. Major cutbacks are targeted for most all state agencies, including the Employment Security Department which operates the WorkSource centers.

For years, our WorkSource Centers have struggled to maintain adequate staffing due to budgetary constraints. With our state's current budget crisis, this problem will only worsen. Our NFJP program has helped to alleviate this problem by out-stationing staff on a regularly scheduled basis in the eight WorkSource Centers and affiliate sites. Our bilingual-bicultural staff provides direct services to customers and collaborating with our other WorkSource partners in serving the universal access needs of our customers in general, and farmworkers and agricultural employers in particular.

The National Farmworker Jobs Program has been a success both nationally and within the state of Washington. To our knowledge, there are no resources at the federal or state level to fill the void that will occur if its funding is reduced or eliminated. Thus, the vital services now provided through the NFJP to Washington State's migrant and seasonal farmworkers, as well as to our state's WorkSource system, will not be replaced.

#### OIC NFJP SUCCESS STORIES

The following illustrates both the value provided through the National Farmworker Jobs Program, and the perseverance and dedication of those whom we are entrusted to serve.

Mrs. P came to Washington State with her family, not knowing anyone here or having any family members. Over most of her 17 years of married life, Mrs. P had never worked outside the home, while her husband provided for their five children (ages range from 3 years to 16 years) and her. Things changed dramatically when her husband suffered a severe emotional trauma resulting from his involvement in a fatal accident, together with other negative incidents. He has since been unable to work and is on long-term disability.

Without a high school education, no driver's license or work experience, Mrs. P was only able to work in agriculture. She found her way to our office through the referral of a previous participant. Following assessment, an Individual Employment Plan was developed with Mrs. P to help her move out of the fields and into a good job that paid a livable wage. Mrs. P began work experience training in our Mount Vernon office as an Office Assistant and attended GED classes in the evenings. Later that fall she received training in our Office Technology course, a class developed specifically for our participants to teach them keyboarding, Microsoft office professional programs and prepare them for an office occupation (classes are held in

the evening to accommodate participant such as Mrs. P who have to work during the day to support families). Mrs. P was also provided with job search/resume assistance that lead to an OJT with Housing Authority of Skagit County as a full time General Office Clerk earning \$9.28 an hour. Mrs. P also worked hard to get her Washington State Driver's License and after three attempts she finally realized this goal. Through her diligence, and the opportunities provided through our program, Mrs. P is now working as a Section 8 Specialist earning \$11.15 an hour with Housing Authority of Skagit County.

Prior to coming to our program, Ms. A. was, in her words, "On the road to nowhere." Abused as a child, she attempted suicide at 11 and ran away from home at the age of 13. When she found her way to our Wenatchee office, she was unemployed and without any funds to support her 16 year old son and herself. Her only meaningful employment was 20 years spent working in the orchards since she was 13. As might be expected, she never attended high school, and her prospects for full-time employment were bleak.

Staff met with Ms. A to perform an assessment to address her immediate needs; identify her skills, interests, and goals; and put together a plan to meet those goals. Ms. A focused on two goals that had always eluded her: to earn her GED and obtain a permanent job through which she could support her son.

Staff immediately provided Ms. A with emergency services for food and shelter to stabilize her situation. They then enrolled her into an evening High School Equivalency program to provide the instruction and tutoring she needed to work towards her GED. Also, a work experience placement was developed to help her develop essential job-related skills, while also providing income to her household. Staff also provided Ms. A with ongoing counseling and support to help her attain success.

Through her hard work, Ms. A felt the pride of having her son watch as she received her GED in a graduation ceremony with 22 other farmworkers. She also realized her employment goal when she became a full-time receptionist and assistant to the housing director for the Wenatchee Women's Resource Center. In all, staff worked with Ms. A for approximately one year to assist her in moving back onto a "road to somewhere."

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#### PREPARED STATEMENT OF THE NATIONAL JOB CORPS ASSOCIATION, INC.

On behalf of the National Job Corps Association (NJCA) we want to thank the Labor, Health and Human Services and Education Appropriations Subcommittee for its dedication to Job Corps and our country's most vulnerable youth. For 40 years, Job Corps has consistently demonstrated its relevance and positive results for employers and youth. The program's supporters represent a bipartisan and broad coalition of congressional leaders; employers and community organizations; and other key decision-makers. They all agree that Job Corps has adapted to America's economic changes by listening to local and national businesses. In turn, Job Corps has partnered with high demand, high growth businesses to develop innovative solutions to meet their workforce needs and find life-long careers for America's most economically disadvantaged youth.

We appreciate the Committee's strong support for the Job Corps program and urge you to provide Job Corps with \$1.6 billion in the fiscal year 2006 appropriations process. The NJCA is deeply concerned that President's budget request does not go far enough to efficiently maintain the effective job training and educational services and the requisite infrastructure necessary to serve Job Corps' estimated 68,000 students entering the 21st century workforce. While we encourage spending restraint by the United States Government, we also believe it is imperative to provide adequate funding to programs with proven positive results. We believe the work that Job Corps accomplishes on a daily basis goes hand-in-hand with the economic prosperity and security of our local communities and our nation.

#### JOB CORPS SUCCESSES

Job Corps is known as "America's first choice for a second chance" for a good reason. Job Corps works. Over the past 40 years, Job Corps has instilled in more than 2 million youth the skills and attitudes they need to become productive, contributing participants of the nation's workforce. For a moment, consider some of Job Corps' most shining examples and see for yourself why Job Corps is considered one of the most successful job training programs in the country.

Judge Sergio Gutierrez attended the Wolf Creek Job Corps Center (Oregon) in 1970 after he decided to drop out of high school to provide additional money for his family which was barely making ends meet at the time. The self proclaimed introvert proudly recalls how Job Corps enabled him to come into his own as a leader

of a carpentry crew. After graduating from Job Corps, Judge Gutierrez enrolled at Boise State University where he received his B.A. in Elementary Education. After teaching fifth grade and English as a Second Language for a few years, Judge Gutierrez went back to school to earn his Juris Doctor degree from the University of California. In 1993, Judge Gutierrez was selected to serve as the district judge for the 3rd Judicial District of Idaho. In 2002, he earned a higher judicial appointment, this time as a member of the Idaho Court of Appeals. Today, Judge Gutierrez takes his children to visit Job Corps centers. Judge Gutierrez said, "I wanted them to see where my success began."

Jasmine Small, a Licensed Practical Nursing (LPN) graduate from the Keystone Job Corps Center (Pennsylvania) graduated from the program and went on to pass the Pennsylvania State Board of Nursing Exam. The Tobyhanna, Pennsylvania native completed her clinical rotation at the Kingston HCR Manor Care facility, and in August 2004 accepted a job on-site. Small aspires to be a Registered Nurse (RN) one-day. "Job Corps helped me grow strong and determined to get things done," Small said. Thanks to employer partners like HCR Manor Care, Small will continue to advance her career within the health care field.

#### NJCA FISCAL YEAR 2006 REQUEST

The NJCA requests a total of \$1.6 billion for Job Corps in the fiscal year 2006 budget: \$1.486 billion for Job Corps' Operational account and \$115 million in the Construction, Rehabilitation and Acquisitions (CRA) account. The NJCA believes that Job Corps merits a \$54 million increase over the fiscal year 2005 appropriations. This increase would provide a modest cost-of-living increase over the fiscal year 2005 enacted levels that unfortunately have not been addressed over the last two fiscal cycles. The increase would allow Job Corps to maintain its existing student services and allotted slots with a full inflationary adjustment for the 122 centers, address infrastructure rehabilitation needs, continue to eliminate the \$350 million backlog of repairs, and provide second year funding for incremental expansion of Job Corps.

#### *Operational Funds*

As the nation's largest residential education and job training program, Job Corps is designed to serve our nation's at-risk youth who might otherwise "fall between the cracks." Job Corps succeeds by providing a safe place to learn the literacy, vocational, and employability skills youth need to become productive, taxpaying members of their community.

Job Corps' 24-hour-a-day, 7-day-a-week program of individualized attention, discipline, and support has produced long-term results that save taxpayer dollars. As a residential program, Job Corps operations are particularly vulnerable to fixed cost increases, including wholesale food, transportation, utilities/energy, and health care. As you are aware, the price of gasoline has spiked to all-time highs in the last three years; food and beverage costs have increased by 24 percent over the last ten years; and medical costs and health insurance premiums have risen at double-digit rates. These increases are costs Job Corps cannot control. While Job Corps has been implementing strategies to decrease costs—particularly energy costs—money has to be invested in the short-term to save money in the future. We all know that investing in our homes increases the property value. Investing in Job Corps increases the value of our local economies through an increased number of youth—32 percent of Job Corps youth come from families on public assistance—becoming well-positioned taxpaying members of their communities.

Job Corps continues to maintain a high placement rate. In fact, more than 90 percent of all Job Corps graduates get jobs, enlist in the military, or enroll in higher education, making Job Corps America's most effective job training programs for economically disadvantaged youth.

In fiscal year 2006 the NJCA requests the Committee provide \$1.486 billion for Job Corps' Operational account. This would allow Job Corps to:

- Maintain existing student services and allotted slots with a full cost-of-living increase for the 122 Job Corps centers across the country;
- Continue Job Corps' rigorous 24-hour-a-day, comprehensive residential services for approximately 68,000 economically disadvantaged youth per year;
- Provide funding necessary to cover the escalating costs of staff salaries, wholesale food, utilities/energy, transportation, medical, mental and dental services, and workers compensation insurance; and
- Develop Job Corps pilot and demonstration projects to strengthen academic and vocational offerings in high-growth and emerging occupations, including but not limited to health care, homeland security, and the military.

*Construction, Rehabilitation and Acquisition (CRA) Funds*

With respect to Job Corps' capital account, the NJCA requests \$115 million in fiscal year 2006. These funds would be targeted to: repair dorms, classrooms, and other student facilities on existing Job Corps centers; replace deteriorated structures, especially those that threaten safety and health or violate minimum building codes, including mechanical systems; continue to address the estimated \$350 million backlog in construction and/or repair needs; and provide second year funding for incremental Job Corps expansion.

As you know, Job Corps gives young people the opportunity to focus and learn in a safe, stable, and supportive environment. However, the average building on a Job Corps center is 46 years-old—20 years older than the industry standard. While the program is trying valiantly to address the backlog of construction and repair improvements, it needs more funding to allow students to learn in an auspicious setting. Over the past several years, the Committee has taken a proactive approach to provide the program with the funds necessary to maintain Job Corps' physical plant. We thank the Committee for its strong support and urge Members to continue that support in fiscal year 2006.

*Incremental Expansion*

Within Job Corps' CRA account, the NJCA strongly supports \$15 million for second year funding for the Congressional supported incremental expansion of Job Corps. As part of the NJCA's 10-year initiative—Job Corps: For the Nation and the Next Generation—to strengthen and improve Job Corps, the NJCA supports the Committee's past effort to designate centers as "High-Growth Centers," designed specifically to address the country's most vital workforce needs. The NJCA envisions these "High-Growth Centers" providing academic and vocational training in the following high growth, high demand industries such as: automotive, construction, financial services, health professions, hospitality, information technology, homeland security, and transportation. In Job Corps' most recent expansion process, more than 50 communities across the nation applied for new centers in their communities. Since that time, many other communities have expressed interest, including Las Vegas; Nevada, Ottumwa, Iowa; and the states of New Hampshire and Wyoming, the only states lacking a Job Corps center. The NJCA looks forward to working with the Committee to continue the incremental expansion of Job Corps.

*Preparing the Workforce for the 21st Century Job Corps: For the Nation and the Next Generation*

Increasingly, private and public employers have turned to the Job Corps program for qualified entry-level recruits. While they are enthusiastic about the employees they hire from the program, they commonly express one limitation: the number of trained and employment-ready graduates in these fields is too small. Although Job Corps is the nation's largest national residential training and education program, it currently can accommodate only about 68,000 students per year. Hospitals, pharmacies, nursing homes, the U.S. Army and Navy, civilian military support contractors, security firms, local police departments, and ambulance companies all say that they can hire as many qualified applicants as Job Corps can produce. Job Corps has beds, however, for only one percent of youth eligible to attend the program.

To address these demands, the NJCA has developed a decade-long initiative, Job Corps: For the Nation and Next Generation, to strengthen and expand Job Corps to help meet our nation's needs for trained, entry level workers in three areas: health care, homeland security, and military preparedness. This Initiative would leverage the contributions of private and public sector partners with federal appropriations to expand Job Corps' capacity to train entry-level employees in these three crucial areas of shortage. The Initiative would produce quantifiable results over 10 years: 60,000 graduates in health care occupations, 50,000 graduates defending homeland security, and 50,000 military personnel. To support this Initiative, the NJCA requests dedicated funds beyond the NJCA's \$1.6 billion request in the following federal programs and/or Departments:

*Addressing the Nation's Health Care Workforce Shortage*

The NJCA requests dedicated funding—\$5 million—for the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions to address the shortage of health care professionals and provide access to health care vocational opportunities for many disadvantaged young people enrolled in Job Corps. The NJCA strongly believes that Job Corps centers are uniquely qualified to utilize HRSA grant programs to train students to pursue health careers while generating more health care professionals to serve economically disadvantaged communities. The NJCA urges that HRSA funds be dedicated to Job Corps in two key grant pro-



grams: Pathways to Health Professions Demonstration Program and Health Careers Adopt-a-School Demonstration Program.

*Ensuring Safer Communities for the Nation*

Within the Department of Homeland Security (DHS) and building upon language in the fiscal year 2005 Omnibus Appropriations legislation, the NJCA requests funds—\$2 million—for a pilot demonstration program to establish local relationships between the Transportation Security Administration (TSA) at three designated Job Corps centers. The pilot program would study the needs of airports and attrition rates of airport security personnel and the feasibility of utilizing local Job Corps centers with security training programs as suppliers of qualified, eager-to-work homeland security and airport screener employees.

The NJCA also requests funds—\$3 million—from DHS in fiscal year 2006 budget to develop fully recognized Federal Emergency Management Agency (FEMA) training sites at three designated Job Corps centers. The partnership between FEMA and Job Corps would include Homeland Security and Fire Safety certifications that are currently incorporated into existing Safety/Security vocational programs on Job Corps campuses across the country.

*Enhancing America's Security and Readiness*

Building upon the mutually beneficial relationships that Job Corps has established with the U.S. Army, U.S. Navy, U.S. Coast Guard, and U.S. Army and Air National Guard, the NJCA requests \$5 million from the Department of Defense (DOD) to develop military-endorsed curriculum in order to establish six military preparation programs that would increase the number of Tier I high quality accessions recruits joining the military. These military preparation programs would be incorporated within a student's academic and vocational training. By providing these funds, Job Corps can significantly supplement the military's efforts to address unmet recruiting and retention needs through a 40-year successful residential education and training program for disadvantaged youth. Curricula would include the critical components valued by the military in grooming and advancing recruits to become high quality accession enlistments. Preference would be given to Job Corps centers located near military installations.

*President's Community College Initiative*

The NJCA requests that a minimum of \$10 million of President Bush's proposed \$250 million fiscal year 2006 Community College Initiative (also called the President's Community-Based Job Training Grants) be dedicated to community colleges partnerships with Job Corps centers. The NJCA requests this modest portion within the U.S. Department of Labor's Employment and Training Administration proposed budget be designated to: (1) develop strategic partnerships with community colleges, business and industry leaders, and Job Corps centers to train students in high, growth, high demand industries; and (2) design "dual enrollment" programs based on reciprocal agreements between Job Corps and adjacent community colleges.

The NJCA strongly believes it is fitting and proper for community colleges to work with Job Corps because both parties share the same basic goals of providing access and opportunity to disadvantaged Americans. Job Corps and community colleges also have the ability to partner with employers looking for higher-skilled workers. Numerous Job Corps centers have already established working relationships and participated with local community colleges to provide advanced career training, increased opportunity to pursue occupations in high-growth industries, and greater access to industry-recognized certification programs.

CONCLUSION

As Job Corps looks to the future, we hope you agree that it remains a federal program that is worthy of America's support. The NJCA looks forward to working with members of this Committee to define, expand and advance this decade-long effort to tie Job Corps' training more closely to our nation's most critical labor needs. Even in these tough budgetary times when no federal program can be above scrutiny, Job Corps shines through with versatility of purpose and a record of success that can help America address its most serious challenges. Job Corps remains a beacon of hope for many young Americans and an excellent example of our government's role in helping all sectors of our society. Thank you for your strong support.

The NJCA is a professional trade association comprised of business, labor, volunteer, advocacy, academic, and community organizations. All are joined in supporting the Association's mission "to unite the Job Corps community through activities and services that strengthen the program for the benefit of students, staff and employers."

## PREPARED STATEMENT OF RURAL OPPORTUNITIES, INC.

On behalf of the Migrant and Seasonal Farmworkers in Pennsylvania, Rural Opportunities, Inc. (ROI) extends a sincere thank you to the Sub-Committee for the opportunity to share our success as the statewide grantee funded by the United States Department of Labor under the Workforce Investment Act, Section 167—The National Farmworker Jobs Program (NFJP).

In providing services to migrant and seasonal farmworkers, ROI's 27 years of experience in Pennsylvania has clearly demonstrated that farmworkers are a "special population" that have unique needs that require not only basic skills, English-as-a-Second Language, and job training; but, access to services via outreach in rural communities at non-traditional hours of service provision where and when One-Stop services are virtually non-existent. Further, should these services be required, the language requirements to ensure access are often unavailable unless a ROI staff person is on site in the One-Stop.

In painting a personal picture, examples may be that if a farmworker were accessing services in Philadelphia County, they may speak Khmer. If a farmworker were accessing services in Franklin County or Chester County, he/she may speak Creole and Spanish respectively. ROI has continuously hired bilingual staff that is culturally sensitive and skilled at working with the predominant farmworker population in the specific service-provision area; thus, ensuring access.

With this said ROI has taken its responsibility seriously for the stewardship of the federal funds it is awarded by ensuring access to effective employment and training programs that not only ensure the transferability of skills, but future upward-mobility both within agriculture and out. ROI places a high priority on measuring and improving the efficiency and effectiveness of our program by collecting detailed data on our farmworker program participants through our Management Information System, by monitoring program results as they pertain to performance standards, and evaluating our net impact.

ROI has always been a strong training provider. Thus, again, having the NFJP Program "zeroed out" for funding, when we are a premiere program that truly provides training to the hardest-to-serve, is unconscionable. Perhaps, one can better understand the impact of the NFJP Program through the words of a program graduate. Alfonso Lua, of Dunmoyer Trucking, Inc., states, "When I came to the program several years ago, I had nothing. Rural Opportunities helped me get my Commercial Driver's License (CDL) and I became a truck driver. Now I own 13 rental properties. I am going to make almost \$70,000 this year. The program is like a ladder you can use to better yourself. If you want to have success, you have to educate yourself and learn something new. That's why the program is there to help with this. It is an alternative to staying where you are".

Alfonso Lua was a program participant who had been a farmworker for many years; yet, had always dreamed of becoming a truck driver. In the typical One-Stop setting, Alfonso may not have been able to access CDL Training because of his, then, language limitations. ROI worked hand-in-hand with Alfonso translating the parts of the truck from Spanish to English to ensure Alfonso clearly understood the translation. Further, ROI Staff provided on-site tutoring, ensuring a positive outcome. Another program participant, Madelyn Morales, a Department Manager at Wal-Mart, Inc. states, "Thank you to Rural Opportunities, Inc. who believed in me and opened possibilities for me to become someone in life". When program participants confront barriers in accessing employment that requires specialized training, ROI has the expertise to tailor a curriculum to an individual's needs. This is extremely important in working with the farmworker population.

ROI also has taken the initiative, as a NFJP Grantee, to work hand-in-hand with agricultural employers who often are overlooked in the One-Stop System. ROI has developed cross-training for agricultural upgrade taking harvesters into a variety of demand occupations. Without the services provided by ROI under the auspices of the NFJP program, these particular training services would be inaccessible. The significance of this can not be underestimated as an agricultural employer representative, Maria C. Serrano, Human Resource & Benefits Specialist of Giorgi Mushroom Company, states, "We at Giorgi Mushroom Company have the practice of employee development and we provide advancement opportunities to motivate employees. In our harvesting department it is often hard to promote within, since they lack the skills for advancement. That is where Rural Opportunities, Inc. comes in. They help tremendously, companies like ours to help and motivate employees to pursue a different position within the company. Their NFJP Program allows our employees the opportunity to advance by providing the necessary resources to develop new skills, where there is no economic drain to the company. Quite the contrary, it helps our company. We have enjoyed a very good relationship with ROI in allowing us the op-

portunity so that we can pass this program on to our employees. Their programs have helped not only our employees become a better people and gain a new position, but also our company as a whole. ROI offers remarkable programs that work for both the company and employees by giving them the chance. Without these programs, no one wins. We strongly agree that ROI Programs benefit both parties involved; and we deeply support their efforts.”

In closing, ROI believes our success speak volumes about the NFJP Program’s success. We are just one of the NFJP Grantees that the Department of Labor’s own assessment stipulates do excellent work every day. Let us not forget that Migrant and Seasonal Farmworkers already bring multiple barriers to the table. Let us not place another barrier in their path by eliminating the NFJP Program. We request the Sub-Committee recognize the enormous potential of this program by maintaining the NFJP Program in the Appropriations for the Department of Labor for 2006; thus, ensuring that the services this population so desperately needs is funded.

Thank you for this opportunity to present testimony today.

## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### PREPARED STATEMENT OF THE ACADEMIC FAMILY MEDICINE ADVOCACY ALLIANCE

Mr. Chairman, the Society of Teachers of Family Medicine, the Association of Departments of Family Medicine, the Association of Family Medicine Residency Directors, and the North American Primary Care Research Group, thank you for the opportunity to provide this statement for the record on behalf of funding for family medicine training, and the Agency for Health Care Research and Quality (AHRQ).

#### HEALTH PROFESSIONS: THE PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

Mr. Chairman, the Academic Family Medicine Advocacy Alliance would like to thank you and this committee for your commitment to these programs. We very much appreciate the funding included in the fiscal year 2005 appropriations funding bill, especially in light of fiscal constraints. Family medicine training programs are funded under Section 747, the Primary Care Medicine and Dentistry cluster, of Title VII of the Public Health Service Act. We ask that you continue your support for family medicine training, and restore the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, to fiscal year 2003 levels of \$92 million, a small increase of about \$3 million.

This statement is designed to show the committee how its investment is paying off. This statement will discuss the success of these programs and include recommendations about what still needs to be done. As you look at all the opportunities you have to fund domestic health programs you need to be able to make judgments about the value and utility of these programs. We have been asked in various venues to show proof that these funds actually do what they are designed to do. We must show that this money makes a difference. In this statement we intend to do just that. In addition, we believe Congress also needs to understand the unmet needs that exist in our nation—needs health professions programs can successfully help address.

#### *President’s Budget Request for Fiscal Year 2006 Once Again Zeros Out Primary Care Funding*

The President’s budget zeroes out funding for the Primary Care Medicine and Dentistry cluster. In addition, the proposal includes only \$11 million for all Title VII Health Professions programs, a sharp cut from current level funding of \$308 million.

#### *Family Medicine Training Programs Are A Success*

First, let’s take a look at health professions training—specifically family medicine training. These programs are producing the outcomes that Congress has requested. A recent study (Family Medicine, June 2002), by the Robert Graham Center For Policy Studies showed that federal funding through Title VII of family medicine departments, predoctoral programs, and faculty development hps made a difference. The study measured the differences in career choices made by students exposed to Section 747 funds compared to those who were not, both within the same school and in different schools. This research found that section 747 funding is associated with:

- 54 percent increase in students going into family practice
- 25 percent more into primary care
- 34 percent more into rural underserved counties

The increased number of family physicians associated with Title VII funding between 1978–1993 was found to be about 7,000. If the same continued for the next

decade, there would be 12,000 additional family physicians attributable to Section 747 funding in 2003. We must conclude from this data that this funding means that thousands of physicians are making different career choices, choices that positively affect millions of patients in underserved areas and in primary care. Moreover, if this money were to “go away” fewer students would be making these career choices.

*Funding primary care training programs improves the health of America*

A greater supply of primary care physicians is associated with positive health outcomes due to early detection and an increased integration of care and oversight. With the associated rise in primary care physicians cited above, we can extrapolate from other sources that this increase could mean:

- 4,600 cases of colon cancer prevented and 1,400 deaths from colon cancer prevented.
- 7,400 cases of cervical cancer prevented and 3,200 deaths from cervical cancer prevented.
- 24,000 individuals quit smoking.
- 7,700 additional physicians serving in rural areas and 970 additional physicians serving in HPSAs.
- 1.2 million deaths prevented.

*Primary care is cost effective*

A study in Health Affairs (April 2004) demonstrates that the associated measures in primary care physicians resulting from Title VII, section 747 leads to an estimated \$320 billion in saved health care expenses and 1.2 million lives saved over 26 years. For example, a study in the New England Journal of Medicine (Feb. 1996) looked at outcomes and costs of people who came to a primary care physician, a chiropractor, or an orthopedic surgeon for their back pain. It was determined that the patients all had the same outcome regardless of who provided care, but the primary care physicians’ care cost \$194 per person less. According to a study in the Journal of Family Practice (May 1998) because back pain is so common, a primary care physician can expect to see 82 cases per year; therefore, Title VII funds can be thought to have had an estimated overall health care cost savings of \$2.4 billion from back pain alone.

*Loss of funding for family medicine training would cause tremendous impact on service to the underserved*

A study by the Robert Graham Center looked at counties designated as HPSAs to determine the degree to which the United States relies on family physicians in comparison to more other specialty. Of the more than three thousand counties in the United States, 784 are designated HPSAs. In a hypothetical exercise, the study removed all family physicians from the U.S. counties. Without family physicians, there would be 1,184 HPSAs—a 43 percent increase.

*Family Physicians Staff the Nation’s Community Health Centers (CHCs)*

The President’s fiscal year 2006 budget would provide approximately \$2 billion to CHCs in fiscal year 2006, an increase of \$304 million. Since nearly one-half of the physicians who staff the nation’s CHCs are family physicians, support for Section 747 would mean more trained doctors for those centers.

*Family Physicians Have an Economic Impact on States*

On average, the income that comes into a community due to the presence of one family physician, and the additional jobs that result from his or her practice, amounts to approximately:

- \$1.2million in rural areas, and,
  - \$0.9 million in urban areas.
- (Oklahoma Physician Manpower Training Commission, October 2003.)

*What Is The Unmet Need? Why Must We Continue To Fund And Grow These Programs?*

According to a study by Politzer, et al (The Journal of Rural Health, Winter,1999) Title VII funding is key to ending HPSAs. This funding has led to the time needed for HPSA elimination to decrease to 15 years. Doubling the funding for these programs would decrease the time for HPSA elimination to as little as 6 years.

According to the study, without this funding, not only would HPSAs not be eliminated, but the number of shortage areas would continue to grow. Moreover, success has been attained by an allocation of funds more favorable to family medicine than the other two primary care specialties.

Title VII funding has indeed accomplished many of the objectives for which it was designed:

- Funding of innovative projects
- Providing “seed money” for the start-up of new projects
- The creation and maintenance of departments of family medicine in the nation’s medical schools
- The development of 3rd year clerkships in family medicine
- The increase in students selecting primary care residencies from those schools with funded family medicine departments and 3rd year clerkships
- The increased rate of graduates from Title VII funded projects entering practice in medically underserved areas (MUAs), with a resultant reduction in the time required for Health Professions Shortage Area (HPSA) elimination

*Section 747 Advisory Committee Recommends Higher Funding*

In 1998, Congress established an Advisory Committee to review and make recommendations on Section 747. The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recently released its recommendations to Congress and the Secretary of the Department of Health and Human Services. The first recommendation urges greatly expanding federal support for Section 747 to \$198 million. The Committee notes the growing need for primary care providers, as well as the success of Title VII funded programs.

The training enterprise that does not value primary care either financially or otherwise is a key part of the problem. Title VII funds that support the infrastructure and stability of family medicine departments in medical schools have to be sustained in order to keep producing the current levels of primary care physicians and, more specifically, those who will practice in rural and other underserved areas. Clearly, the programs of Title VII are on the right track toward meeting the health care challenges of the 21st century. So, while we believe that current funding must be maintained, more needs to be done.

*Proposed Performance Measures need to be redefined*

The current proposed performance measures are neither measurable nor appropriate. Consequently, assessments of effectiveness of the programs based on these measures are highly flawed.

For example, the target set for the proportion of underrepresented minorities (URMs) and disadvantaged students in health professions funded programs is set at 50 percent for 2005, even though only 12.5 percent of current medical school graduates are URMs, and data on disadvantaged backgrounds is not routinely, or accurately collected. The concept of disadvantaged background varies based on income related to family size, or is based on a vague—non-quantifiable—notion of persons growing up in environments that don’t prepare them to enter health professions schools.

In 2000 approximately 12.5 percent of the medical degrees awarded in the United States went to underrepresented minorities. For all of health professions minority representation has risen from 8.3 percent in 1985 to 11.7 percent in 2000. Given this data, it’s simply unrealistic to expect any program to increase its minority representation in one year from 12.5 percent to 25 or 50 percent.

*Primary Care Training Programs React Quickly to Emerging Health Challenges*

Title VII dollars have created an infrastructure that allows educational programs to respond to contemporary health care issues. Specifically, the ACTPCMD report states that:

“Investment in education to provide primary care has effects that touch the largest number of people in the country. No other group of health care providers can exert such a broad influence on the kind and quality of health care in the United States. Primary care training programs are ideally positioned to react quickly to meet ever-changing health care needs and issues, whether they are related to HIV/AIDS, growing numbers of elderly with chronic illnesses, implications of the modern genetics revolution, the threat of bioterrorism, or other issues that will continue to emerge and demand rapid educational intervention. Thus, this infrastructure is uniquely able to play a pivotal role in bringing emerging issues in health care to the population at large.”

Mr. Chairman, we know that this committee has to weigh the value of funding various programs against each other. We hope that the evidence we have presented here will bring the committee to the conclusion that funding spent on these programs would bring value for the money and would be money exceptionally well spent.

## FUNDING FOR THE AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

Mr. Chairman, once again, we thank you and this committee for funding this important agency. It is apparent that the key federal agency available to fund primary care research is the Agency for Healthcare Research and Quality (AHRQ). In its recent reauthorization, Congress established within the Agency a Center for Primary Care Research to “serve as the principal source of funding for primary care practice research in the Department of Health and Human Services.” The statute defined primary care research as research that “focuses on the first contact when illness or health concerns arise, the diagnosis, treatment or referral to specialty care, preventive care, and the relationship between the clinician and the patient in the context of the family and community.”

*Funding Request For AHRQ*

We recommend appropriations of \$440 million for the Agency for Healthcare Research and Quality (AHRQ) in fiscal year 2005. AHRQ conducts primary care and health services research geared to physician practices, health plans and policy-makers that helps the American population as a whole.

*President’s Budget Request for fiscal year 2006 AHRQ Funding*

The President’s budget includes \$316 million for AHRQ, which is the same as actual funding for fiscal year 2005. This figure does not recognize the \$53 million in authorization that Congress provided AHRQ in the Medicare Modernization Act to study “clinical effectiveness and appropriateness of specific health services and treatments.”

*What Does AHRQ Do?*

AHRQ’s three goals are to (1) improve physician practice and Americans’ health outcomes, (2) improve the quality of health care (e.g., patient safety), and (3) improve the health care system (e.g., increase access and reduce costs). In brief, AHRQ “helps to improve the health and health care of the American people . . .” (AHRQ report, March, 2001).

*How Does AHRQ Meet Its Goals?*

AHRQ translates research findings from basic science entities like the National Institutes of Health into information that doctors can use every day in their practice with their patients. Another key function of the agency is to support research on the conditions that affect most Americans.

*AHRQ Translates Research into Everyday Practice*

Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. AHRQ takes this basic science and produces information that physicians can use every day in their practices. AHRQ also distributes this information throughout the health care system. In short, AHRQ is the link between research and the patient care that Americans receive. An example of this link is basic science research showing that beta blockers reduce mortality. AHRQ supported research to help physicians determine which patients with heart attacks would benefit from this medication.

*AHRQ Supports Research on Conditions Affecting Most Americans*

Most Americans get their medical care in doctors’ offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. AHRQ looks at the problems that bring people to their doctors every day—the problems that send them to the hospital. For example, AHRQ supported research that found older antidepressant drugs are as effective as new antidepressant medications in treating depression, a condition that affects millions of Americans.

*Institute of Medicine Recommends \$1 Billion for AHRQ*

The Institute of Medicine’s report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001), recommended \$1 billion a year for AHRQ to “develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years.” The report looked at redesigning health care delivery in the United States. AHRQ is a linchpin in retooling the American health care system.

## RECOMMENDATIONS FOR FAMILY MEDICINE TRAINING AND RESEARCH

The Academic Family Medicine Advocacy Alliance have two main recommendations for the fiscal year 2006 Labor/HHS Appropriations bill. They are as follows:

- We ask that you continue your support for family medicine training, and bring the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, up to fiscal year 2003 levels of \$92 million, a small increase of approximately \$3 million.
- In order to support critical practice-oriented primary care research, and to ensure that existing grants and contracts will not be cut, we are asking that the Agency for Healthcare Research and Quality be funded at \$440 million.

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PREPARED STATEMENT OF AIDS ACTION

I am pleased to submit this testimony to the members of this committee on the importance of adequate funding for the fiscal year 2006 HIV/AIDS portfolio. The federal government's commitment to funding research, prevention, and care and treatment for those living with HIV is critical. We would not be where we are today in responding to this epidemic without the federal government's 24-year commitment to funding HIV programs here at home. AIDS Action is dedicated to working with the federal government to make sure it sustains this commitment.

Since 1984, AIDS Action's goals have been clear: to ensure effective, evidence-based HIV care, treatment, and prevention services; to encourage the continuing pursuit of a cure and a vaccine for HIV infection; and to support the development of a public health system which ensures that its services are available to all those in need. Furthermore, our commitment to working toward these goals is constant: AIDS Action is here Until It's Over.

For over 20 years AIDS Action Council, through its member organizations and the greater public health community, has worked to enhance HIV prevention programs, research protocols, and care and treatment services. An important part of this collaborative effort has been working to secure comprehensive federal resources to address community needs.

It is therefore on behalf of AIDS Action Council's diverse membership, comprising community-based AIDS service organizations, public health departments, and other organizations concerned with HIV research, education, and advocacy, that I bring your attention to some of the issues impacting the funding picture for fiscal year 2006.

Despite the good news of improved treatments, which have made it possible for people with HIV disease to lead longer and healthier lives, stark realities remain:

- There is neither a cure nor a vaccine for HIV.
- Current treatments do not work for everyone, and some have debilitating side-effects.
- There are nearly 1 million people living with HIV in the United States.
- Access to health care is unequal.
- Half a million HIV positive Americans are not receiving regular medical care.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which is administered by the Health Resources and Services Administration (HRSA) and is funded by this subcommittee, provides services to more than 533,000 people living with and affected by HIV throughout the United States and its territories. It is the single largest source of federal funding solely focused on the delivery of HIV services; it provides the framework for our national response to the HIV epidemic. As such, CARE Act programs have been critical to reducing the impact of the domestic HIV epidemic. Yet, providers of HIV services are working from a deficit. In recent years, CARE Act funding has been decreased through across-the-board rescissions. The .80 percent rescission that was executed on all non-defense and non-homeland security discretionary spending during the final negotiations for the fiscal year 2005 bill had a devastating impact on the HIV/AIDS portfolio in general, and on the Ryan White CARE Act in particular. Moreover, President Bush's budget for fiscal year 2006 requests just one increase to the CARE Act—an additional \$10 million for the AIDS Drug Assistance Program (ADAP).

Now in its fifteenth year, the Ryan White CARE Act is scheduled for reauthorization in this session of the 109th Congress, a fact President Bush made known to all Americans in his State of the Union address, when he voiced his strong support for reauthorization. He stated, "Because HIV/AIDS brings suffering and fear into so many lives, I ask you to reauthorize the Ryan White Act to encourage prevention, and provide care and treatment to the victims of that disease. And as we update this important law, we must focus our efforts on fellow citizens with the highest rates of new cases, African American men and women."

In June 2004, while discussing the global HIV epidemic, our President stated with confidence, "There's no doubt we can bring hope in all parts of the world, not only

in Africa, but in neighborhoods in our own country where people wonder what the American Dream means.”

On this point, AIDS Action Council concurs with President Bush: hope can be brought to all parts of the world. However, we respectfully disagree with the President on what will be needed to ensure hope here at home. The delivery of hope relies on the delivery of health care to all neighborhoods in this great nation—an effort that will not be sufficiently supported by the funding levels the President has requested for the HIV/AIDS portfolio in his fiscal year 2006 budget request.

Clearly, it will take more than a \$10 million increase for ADAP, a single program within the Ryan White CARE Act, to ensure HIV positive Americans receive the care and services necessary to remain healthy and productive. It is my hope that the Congress, through the good work of this subcommittee, will recognize and address the true funding needs of the care programs within the domestic HIV/AIDS portfolio.

Last year, there was an overall increase of 14.5 percent in the estimated number of living AIDS cases among the fifty-one hardest hit eligible metropolitan areas (EMAs) in the United States, with increases as high as 22.6 percent in some areas. Yet fiscal year 2004 funding allocations for Title I of the Ryan White CARE Act, which is designed to provide services to these areas, were reduced. Forty of the fifty-one jurisdictions experienced a decrease in funding, with some decreases as high as 15 percent. Similar reductions continued in fiscal year 2005 when thirty-three of the EMAs experienced a funding decrease, the highest being 14 percent.

Some of the services provided under Title I include physician visits, laboratory services, case management, home-based and hospice care, nutrition services, and substance abuse and mental health services. According to the most recent data available from the Health Resources and Services Administration (HRSA), more than half (51.8 percent) of Title I funds are allocated to core health care services, and more than one-third (35.0 percent) are allocated to services closely associated with medical care (including medically-based housing and care coordination and referral). These services are critical to ensuring patients have access to, and can effectively utilize, life-saving therapies.

Title II of the CARE Act ensures a foundation for HIV related health care services in each state and territory, including the critically important AIDS Drug Assistance Program (ADAP) and Emerging Communities Program. Title II base grants (excluding ADAP and Emerging Communities) decreased from \$292,279,000 in fiscal year 2004 to \$282,597,700 in fiscal year 2005 for a total decrease of over \$9 million (\$9,681,300).

Funding for Emerging Communities remained stable at \$10 million, but it was divided among an increased number of communities. The \$5 million “tier one” award was divided among four cities in fiscal year 2004 and among five cities this fiscal year, which resulted in funding reductions. Funding cuts for the original four cities ranged from \$200,000 to \$264,000 so that a fifth could receive \$836,000. This type of funding variability is not conducive to providing consistent HIV care in emerging communities.

We applaud the President’s recommended increase of \$10 million for ADAP in his fiscal year 2006 budget. ADAP provides medications for the treatment of individuals with HIV who do not have access to Medicaid or other health insurance. According to the National ADAP Monitoring Project, approximately 85,825 clients received medications through ADAP in June 2003.

A single drug in the multiple-drug regimen of highly active anti-retroviral therapy (HAART), the standard of care for HIV disease, may cost as much as \$15,000 annually. Drugs to treat other infections may bring the annual cost for a single HIV patient to \$40,000 a year. With the increasing number of people living with AIDS, the number of newly diagnosed infections fixed at 40,000 per year, and cuts in funding to state Medicaid programs, pressures on ADAP are increasing. Over the years, ADAP has proven to be a remarkable program, allowing people to receive the care and treatment they need. Consequently, AIDS Action urges Congress both to fully fund ADAP and to consider restructuring ADAP to ensure universal access to all needed drugs, regardless of state of residence. Moreover, many of the medicines supplied through ADAP reach maximum efficacy only in conjunction with proper nutrition. Therefore, we urge Congress to continue funding for Ryan White CARE Act nutrition programs, funded predominantly through Titles I and II.

Funding for Title III of the Ryan White CARE Act is awarded under the Early Intervention Services program. Title III grant recipients include community-based clinics and medical centers, hospitals, public health departments, and universities in 22 states and the District of Columbia. The grants are targeted toward new and emerging sub-populations impacted by the HIV epidemic. The Title III funds are particularly needed in rural areas where the availability of HIV care and treatment



is still relatively new. Urban areas also continue to need Title III funds to ensure that emerging populations within these areas are not shortchanged as grantees struggle to meet the needs of previously identified HIV positive populations.

The Title IV portion of the Ryan White CARE Act is awarded under the Comprehensive Family Services Program to provide comprehensive care for HIV positive women, infants, children, and youth, as well as their affected families. These grants fund the planning of services that provide comprehensive HIV care and treatment and the strengthening of the safety net for HIV positive individuals and their families.

If we are to comprehensively address the HIV care and treatment crisis in the United States, we must never forget the smaller—but nonetheless significant—programs in the CARE Act: AIDS Education and Training Centers (AETC), dental reimbursement, and special projects of national significance (SPNS). Like nearly every other CARE Act program, AETC and SPNS have been affected by diminishing federal funding.

Given that the President continues to support increases in funding to, and a greater reliance on, community health centers nationwide to provide care to the uninsured and under insured, we now find ourselves simultaneously faced with a pool of community providers who need to be educated about proper HIV care. The role of the AETCs is invaluable in ensuring that such education is available to physicians who are being asked to treat the increasing numbers of HIV positive patients who depend on them for care. Dental care is another crucial part of the spectrum of services needed by people living with HIV disease. Oral health is one of the first aspects of health care to be neglected by those who cannot afford, or do not have access to, proper medical care. Furthermore, oral health problems are often one of the first manifestations of HIV disease. Reimbursement offered by this CARE Act program allows dental education institutions to offer their much needed services to people living with HIV.

As this testimony suggests, rising infections and strapped care systems necessitate the research and development of innovative models of care. The SPNS program is designed for this very purpose and must therefore receive sufficient funding.

AIDS Action believes the entire Ryan White CARE Act portfolio needs \$3.2 billion for fiscal year 2006 to address the true needs of the approximately 1 million people that the Centers for Disease Control and Prevention (CDC) estimates are living with HIV in the United States. President Bush has requested just over \$2 billion (\$2,083,342,088).

The Housing Opportunities for People with AIDS (HOPWA) program, administered by the U.S. Department of Housing and Urban Development (HUD), is another integral program in the HIV care system. Stable housing is absolutely critical to the ability of people living with HIV to access and adhere to an effective HIV treatment plan. Without housing, one cannot appropriately store medicine or food and often cannot consistently access clean water or clean bathrooms. Furthermore, when one has no housing, the need for shelter often rises above the need to take care of one's HIV infection, which places the individual at higher risk of becoming ill and infecting others.

AIDS Housing of Washington has estimated that approximately one-third to one-half of people living with HIV are homeless, cannot afford their current housing, or are at risk of becoming homeless. HOPWA is the only program that specifically addresses the housing needs of people living with HIV. Despite the importance of the program, HOPWA's funding has been dramatically cut. In fiscal year 2005, HOPWA was funded at \$281.7 million (\$281,728,000), down from \$294.8 million (\$294,800,000) in fiscal year 2004—a cut of more than \$13 million. In his fiscal year 2006 budget proposal, the President proposes an additional cut to the program of almost \$14 million, to \$268 million (\$268,000,000) total. AIDS Action believes that \$385 million should be appropriated to the HOPWA program for fiscal year 2006 to address the needs of HIV positive people requiring housing assistance.

HIV continues to be an ongoing public health crisis. Despite treatment advances, there was a 2 percent increase in progression from HIV to an AIDS diagnosis between 2001 and 2002—the first such increase in several years. AIDS-defining illnesses are the leading cause of death among African-American women between the ages of 25 and 34 and they are the third leading cause of death among all African Americans in this age group. They are the sixth leading cause of death for Latinos and whites in this age group.

According to CDC estimates contained in the agency's December 2003 HIV/AIDS Surveillance Report, 929,985 cumulative cases of AIDS have been diagnosed in the United States, with a total of 524,059 deaths since the beginning of the epidemic. The CDC also estimates that between 850,000 and 950,000 people are living with HIV/AIDS in the United States, and approximately one-quarter of them, or 180,000—

280,000 people, are unaware of their status and could unknowingly transmit the virus to another person.

For several years, estimates of new infections have remained at 40,000 per year, compared to an estimated 180,000 new infections in the mid 1980s: an extraordinary achievement in efforts against HIV.

To further reduce new infections, the CDC implemented a new initiative in April of 2003 called Advancing HIV Prevention: New Strategies for a Changing Epidemic (AHP), consisting of four key strategies:

- Make HIV testing a routine part of medical care.
- Implement new models for diagnosing HIV infection outside medical settings.
- Prevent new infections by working with persons diagnosed with HIV and their partners.
- Decrease mother-to-child transmission of HIV.

The Urban Coalition for HIV/AIDS Prevention (UCHAPS), which represents the six cities that are directly funded by the CDC for HIV prevention and is an AIDS Action member, has responded positively to the AHP Initiative. UCHAPS members are working with the CDC to implement the Initiative effectively in their respective communities.

This Initiative, however, does not supersede the HIV Prevention Strategic Plan that was published by the CDC in 2001, which stated a goal of reducing by half the number of new HIV infections by 2005. These strategies, though innovative, require additional funding for implementation. AIDS Action Council estimates that the CDC HIV/AIDS, STD, and TB prevention programs will need \$2.33 billion in fiscal year 2006 to address the true unmet needs of prevention in HIV/AIDS, STDs, and TB. AIDS Action Council therefore is concerned that the President limited his fiscal year 2006 request for the CDC HIV/AIDS, sexually transmitted disease (STD), and tuberculosis (TB) prevention programs to \$956,283,000—a request that is \$4,428,000 less than what the CDC received in fiscal year 2005.

How will we keep pace of the epidemic and meet—albeit belatedly—the goal of limiting new infections to 20,000 annually without an immediate infusion of new resources, new partnerships, and new funding? Without such an infusion, this country will continue to face significant challenges in providing urgent care and treatment to HIV positive people.

Research on the domestic HIV epidemic is vital to the control of the disease. Research that includes biomedical, behavioral, and social services is the cornerstone of HIV prevention research. The research agenda for HIV prevention science at the Office of AIDS Research (OAR), part of the National Institutes of Health (NIH), targets interventions to at-risk individuals, both infected and uninfected, to reduce HIV transmission. It is essential that OAR continue its groundbreaking research to secure a vaccine that will keep HIV negative people negative. It is equally important that this office continue to research promising treatment vaccines that may help HIV positive people maintain optimal health. The research on microbicides for vaginal and anal sexual intercourse is critical as well. The use of microbicides by the receptive partner will give them power over their personal health when they cannot negotiate condom use with their partner to protect themselves from HIV transmission.

The research at NIH on new medications for drug resistant strains of HIV is also critical. The current success of treatment for people living with HIV and AIDS is due in large part to early research investments in new drugs that now have improved the health of people living with HIV. The United States must continue to take the lead in the research and development of new medicines to treat current and future strains of HIV. Primary prevention of new HIV infections must remain a high priority in the field of research.

Behavioral research to help individuals delay the initiation of sexual relations, limit the number of sexual partners, limit the consumption of alcohol and drugs prior to sexual relations, and move from drug use to drug treatment are all critically important in finding a solution to the spread of HIV in the United States. NIH's Office of AIDS Research is critical in supporting all of these research arenas. Increased funding is necessary to ensure that the resources needed to address all the research concerns are available both now and in the future. Commitment in research will ultimately decrease the care and treatment dollars needed if HIV continues to spread at the current rate.

AIDS Action is concerned that President Bush has only requested \$2,932,992,000 for the AIDS portfolio at NIH. AIDS Action believes the National Institutes of Health AIDS portfolio must be funded at \$3.327 billion for fiscal year 2006.

On behalf of all HIV positive Americans, and those affected by the disease, AIDS Action Council asks that you carefully consider the ramifications of the President's

suggested cuts to the domestic HIV/AIDS portfolio. Help us save lives by allocating sufficient funds to address this nation's epidemic.

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PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 94,000-member American Academy of Family Physicians submits this statement for the record to the Senate Appropriations Subcommittee on Labor/Health and Human Services, Education and Related Agencies. Our statement is made in support of the Section 747 Primary Care Medicine and Dentistry Cluster. The Academy also supports the Agency for Healthcare Research and Quality (AHRQ) and rural health programs.

SECTION 747 PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

*Family Medicine Training*

Section 747 is the only federal program that funds family physician training. The law requires the program to meet two goals: (1) increase the number of primary care physicians (family physicians, general internists and general pediatricians) and (2) boost the number of people to provide care to the underserved. Regarding family medicine specifically, Section 747 offers competitive grants for training programs in medical school and in residency programs.

The fiscal year 2005 spending bill provided \$89 million to Section 747, a figure that was \$3 million below the fiscal year 2003 levels, which is the highest figure the program has received in the last several years. Unfortunately, the President's fiscal year 2006 budget provided zero dollars for the program. In contrast, the congressionally established Advisory Committee on Training in Primary Care Medicine and Dentistry, which was set up solely to evaluate these programs, recommended significantly more funding: \$198 million.

Family physicians are the specialists trained to provide comprehensive, coordinated and continuing care to patients of both genders and all ages and ethnicities, regardless of medical condition. These residency-trained, primary care physicians treat babies with ear infections, adolescents who are obese, adults with depression and seniors with multiple, chronic illnesses. And because they focus on prevention, primary care, and integrating care for patients, they are able to treat illnesses early and cost-effectively and when necessary, they help patients navigate our complex health system and find the right subspecialists.

*Section 747 and Rural and Underserved Areas*

In the last few years, there has been a great deal of interest in whether Section 747 actually meets its statutory goals, and specifically whether or not more physicians are practicing in rural and underserved areas as a result of the program. Due to this concern, the Robert Graham Center for Policy Studies studied medical schools receiving Section 747 family medicine funds and concluded that these programs met the law's requirements. According to this research, the trainees exposed to Section 747 funding while in these schools were more likely to:

- Practice in family medicine or primary care;
- Practice in a rural area; or
- Practice in a whole county Primary Care Health Professions Shortage Area (HPSA) (i.e., a county with inadequate numbers of family physicians, general pediatricians, general internists or obstetrician/gynecologists).

More specifically, according to this research, students with any exposure to Section 747 were 25 percent more likely to go into a primary care HPSA and 34 percent more likely to go to a rural county to practice. Moreover, the exposure of students to Section 747 funding between 1978–1993 was associated with nearly 4,000 additional primary care physicians in rural areas and 500 additional physicians in HPSAs than would have otherwise occurred. This research showed that Section 747, was, in fact, meeting the goals of the law.

*Preventing HPSAs*

Along a similar vein, another study by the Robert Graham Center looked at counties designated as HPSAs. The research showed that the United States relies on family physicians more than any other medical specialty. For example, of the more than three thousand counties in the United States, 784 are designated HPSAs. In a hypothetical exercise, the study removed all family physicians from the U.S. counties and found that without these specialists, there would be 1,184 HPSAs—a 43 percent increase. Section 747 grants contribute to bringing health care to underserved areas.

*Family Physicians for Community Health Centers and NHSC*

Family physicians also play a major role in staffing the nation's Community Health Centers (CHCs) and National Health Service Corps (NHSC). The Academy strongly supports the Administration's commitment to funding increases for these programs. However, we believe that increasing funding for CHCs and the NHSC is only a partial solution. Without support for family physician training, there will be fewer physicians who work in these centers or practice in underserved areas. Thousands of family physicians will be needed if the necessary number of CHCs sites and NHSC staff is to be realized.

In fact, in 2003, Community Centers depended on primary care physicians for 95 percent of their physician staffing, over half of whom were family or general practice physicians. And, since 1971, the National Health Service Corps has placed more than 18,000 health care providers in underserved areas: almost half of the NHSC doctors were family physicians. Support for CHCs and the NHSC must go in tandem with funding for Section 747.

*Lower Health Care Costs and Improved Quality*

As the only federal program aimed at producing more generalists, Section 747 plays a role in lowering our nation's health care costs and increasing the quality of U.S. health care. For example, an article in *Health Affairs* (April 2004) demonstrated that states that spent more on Medicare had lower quality of care. There were two reasons for this result: states' expensive health care did not improve patient satisfaction, or, outcomes (e.g., people who were admitted to intensive care in the last 6 months of their life.)

The second reason was also important: the authors found the makeup of the health care workforce made a difference. In fact, more primary care doctors in a state meant higher quality care and lower cost. In contrast, more specialists and fewer generalists led to lower quality and higher costs. And, just a small increase in the number of generalists in a state was associated with a large boost in that state's quality ranking.

An article in a more recent edition of *Health Affairs* (March 2005), "The Effects of Specialist Supply on Populations' Health: Assessing the Evidence" went even further. This piece stated that there is a "negative relationship between the supply of primary care physicians and death from stroke, infant mortality and low-birth-weight, and all-cause mortality." The article went on to say that just one more primary care physician per 10,000 people was associated with a decrease of 34.6 deaths per 100,000 population.

The article also cited breast cancer research for the state of Florida, which indicated that "each tenth-percentile increase in primary care physician supply is associated with a statistically significant 4 percent increase in odd of early-stage breast cancer." Statistics were similar for other types of cancers: there was a relationship between early identification and the supply of primary care physicians. Numerous other research was included in the *Health Affairs* article indicating that a higher ratio of primary care physicians to populations led to better health outcomes. These data support the need for additional funding for Section 747, the only federal program that produces primary care physicians.

*Economic Impact*

In 2003, the Oklahoma Physician Manpower Training Commission studied the amount of income that comes into a community due to the presence of one family physician, and the additional jobs that result from his or her practice. Their research showed that the figure was approximately \$1.2 million in rural areas and \$0.9 million in urban areas.

*The Overspecialized U.S. Physician Workforce*

Unlike all other developed countries, the United States does not have a primary care-based health care system. While other developed countries have about equal numbers of primary care doctors and subspecialists, less than one-third of the U.S. physician workforce is primary care doctors (including family physicians). As a result, about two-thirds of the U.S. physician workforce is made up of subspecialists.

In addition, compared to those in other developed countries, the United States spends the most per capita on healthcare—but has the worst healthcare outcomes. More than 20 years of evidence have shown that a health system based on primary care produces greater health and economic benefits. Boosting support for Section 747, which funds training for family physicians and for other primary care disciplines, could improve the health of patients in the United States to enjoy those benefits.

## AGENCY FOR HEALTHCARE, RESEARCH AND QUALITY

The Academy recommends \$440 million for the Agency for Healthcare, Research and Quality (AHRQ). A major purpose of AHRQ is to conduct primary care and health services research geared to physician practices, health plans and policy-makers. What this means is that the agency translates research findings from basic science entities like the National Institutes of Health (NIH) into information that doctors can use every day in their practices. Another key function of the agency is to support research on the conditions that affect most Americans.

More recently, AHRQ has become the lead federal agency for research on comparative clinical effectiveness; information technology; and patient safety. For example, the Medicare Modernization Act asked AHRQ to study the "clinical effectiveness and appropriateness of specified health services and treatments," and to use this information to improve the quality and effectiveness of the costly Medicare, Medicaid and SCHIP programs. In fiscal year 2005, \$15 million was appropriated by Congress for this purpose, and the agency now has determined the top 10 conditions for initial research. This type of study on "what works" in clinical therapies is crucial in an era of skyrocketing health care costs and limited federal dollars.

Historically, however, AHRQ has been the lead agency to translate research into information for physicians and patients. Over the years, Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. However, AHRQ's role has been to take this basic science and produce understandable, practical materials for the entire healthcare system. In short, AHRQ is the link between research and the patient care that Americans receive.

In addition, AHRQ has long-supported research on conditions that affect most people. Most Americans get their medical care in doctors' offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. In brief, AHRQ looks at the problems that bring people to their doctors every day—not the problems that send them to the hospital.

## RURAL HEALTH PROGRAMS

Continued funding for rural programs is vital to provide adequate health care services to America's rural citizens. We support the Federal Office of Rural Health Policy; Area Health Education Centers; the Community and Migrant Health Center Program; and the NHSC. State rural health offices, funded through the National Health Services Corps budget, help states implement these programs so that rural residents benefit as much as urban patients.

## CONCLUSION

The Academy urges Congress to increase funding for Section 747 family medicine training, at a minimum, to the fiscal year 2003 level of \$92 million; provide \$440 million for AHRQ and support rural health programs. Federal funding for these initiatives is vital to sustain and improve America's health care system.

## PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

This statement is submitted on behalf of the American Academy of Pediatrics (AAP) and the endorsing organizations, the Society for Adolescent Medicine (SAM) and the Ambulatory Pediatric Association (APA).

There have been numerous and significant successes in improving the health of America's children and adolescents. The number of 2-year-olds who have received the recommended series of immunizations is at an all-time high. Child death rates have fallen steadily over the past several years. And teen pregnancy rates continue to decline. However, despite these significant improvements, more than 9 million children and adolescents through age 18 remain uninsured. Moreover, racial and ethnic health disparities for many children and adolescents continue to exist, while the percent of children living in poverty continues to climb. Clearly there remains much work to do. As clinicians we must not only diagnose and treat our patients but also promote strong preventive interventions to improve the overall health and well-being of all infants, children, adolescents and young adults. Likewise, as policy-makers, you have an integral role to play in improving the health of the next generation through adequate and sustained funding of vital federal programs.

The AAP, SAM and APA has identified three key priorities within this Committee's jurisdiction key priorities that are at the heart of improving the health and

well-being of America's children and adolescents: access to health care, quality of health care, and immunizations.

#### ACCESS

We believe that all children and adolescents should have full access to health care. From the ability to receive primary care from a pediatrician trained in the unique needs of children and adolescents, to timely access to pediatric medical subspecialists and pediatric surgical specialists, America's children and adolescents deserve access to quality pediatric care.

*Maternal and Child Health Block Grant.*—The Maternal and Child Health (MCH) Block Grant Program at the Health Resources and Services Administration (HRSA) is the only federal program exclusively dedicated to improving the health of all mothers and children. Nationwide, the MCH Block Grant Program provides preventive and primary care services to over 28 million women, infants, children, adolescents and children with special health care needs. In addition, the MCH Block Grant Program supports community programs around the country in their efforts to reduce infant mortality, prevent injury and violence, expand access to oral health care, and address racial and ethnic health disparities. Moreover, the MCH Block Grant Program includes efforts dedicated to addressing interdisciplinary adolescent training and services and research for adolescents' physical and mental health care needs. HRSA also supports adolescent health programs for vulnerable populations, including health care initiatives for incarcerated and minority group adolescents, and violence and suicide prevention. It also plays an important role in the implementation of the State Children's Health Insurance Program (SCHIP), which is critically important at a time when states are continuing to suffer from ongoing deficits and shifting costs. One of the many successful MCH Block Grant programs is the Healthy Tomorrows Partnership for Children Program, a public/private collaboration between the MCH Bureau and the American Academy of Pediatrics. Established in 1989, Healthy Tomorrows has supported over 140 family-centered, community-based initiatives in over 40 states, including Ohio, Wisconsin, Texas, California, Kentucky, and Maryland. These initiatives have addressed issues such as access to oral and mental health care, abstinence, injury prevention, and enhanced clinical services for chronic conditions such as asthma. To continue to foster these and other community-based solutions for local health problems, in fiscal year 2006 we strongly support an increase in funding for the MCH Block Grant Program to \$755 million.

*Family Planning Services.*—The family planning program, Title X of the Public Health Services Act, ensures that all teens have confidential access to valuable family planning resources. The consequence of adolescent pregnancy, sexually transmitted infections (STIs), and HIV/AIDS demands that adolescents be able to make informed, responsible sexual decisions. Title X—which does not provide funding for abortion services—supports teens in making those decisions. According to a January 2005 report from the Henry J. Kaiser Family Foundation, the percentage of high school students who report ever having had sexual intercourse has declined over the past decade, while the rate of contraceptive use among those teens has increased. Nevertheless, teen pregnancy rates continue to vary widely over racial and ethnic groups, over 4 million teens still contract a sexually transmitted infection each year, and nearly half (48 percent) of all teens say that they want more information from—and increased access to—sexual health care services. Responsible sexual decision-making, beginning with abstinence, is the surest way to protect against sexually transmitted diseases and pregnancy. However, for adolescent patients who are already sexually active, confidential contraceptive services, screening and prevention strategies should be available. We therefore support a funding level in fiscal year 2006 of \$350 million for Title X of the Public Health Service Act.

*Mental Health.*—It is estimated that one in five children and adolescents has a mental health problem such as depression, ADHD, or an eating disorder, and for as many as six million this problem may be significant enough to disturb school attendance, interrupt social interactions, and impact quality of family life. Despite these startling statistics, the National Institute of Mental Health (NIMH) estimates that fewer than one in five of these children receives treatment, due in part to stigma and the lack of affordability of care and availability of specialists. One key point of access for helping these children receive the mental health care they need is the inclusion of mental health services—provided by qualified counselors, psychologists, and social workers—in the nation's schools. Grants through the Children's Mental Health Services program have been instrumental in achieving decreased utilization of inpatient services, improvement in school attendance and lower law enforcement contact for children and adolescents. To ensure the continued and growing success of this and other programs focusing on children and adolescents with mental health

problems, the AAP and the endorsing organizations recommend that \$114.7 million be allocated in fiscal year 2006 for the Mental Health Services for Children program.

*Health Professions Education and Training.*—Critical to building a pediatric workforce to care for tomorrow's children and adolescents are the Training Grants in Primary Care Medicine and Dentistry, found in Title VII of the Public Health Service Act. These grants are the only federal support targeted to the training of primary care professionals. They provide funding for innovative pediatric residency training, faculty development and post-doctoral programs throughout the country. For example, at the Cincinnati Children's Hospital, Title VII health professions programs have funded critically important programs in pediatric medical education. The Residency Training in Primary Care grant is designed to train physicians for a career in primary care pediatrics, and features a strong emphasis on behavioral and developmental pediatrics, pediatrics in a community setting, and care for under-represented minorities and medically underserved populations. The community settings in which the primary care training takes place—and, often, ultimately where the physicians chose to practice—are federally-designated HPSAs with diverse populations. This program is now an integral part of the Cincinnati Children's pediatric residency training program, and widely sought after by physicians entering training at Children's.

Through the enduring support of this subcommittee and Congress, the Title VII program has continued to finance critically important educational opportunities in a variety of settings that educate and train tomorrow's generalist pediatricians to be culturally competent and to meet the special health care needs of their communities. We recommend fiscal year 2006 funding of at least \$40 million for General Internal Medicine/General Pediatrics. We also join with the Health Professions and Nursing Education Coalition in supporting an appropriation of at least \$550 million in total funding for Titles VII and VIII. We further recommend and support the Administration's increase in funds in fiscal year 2006 for the National Health Service Corps, a key component to ensuring an adequate distribution of health care providers across the country, but emphasize the need for continued support of the training and education opportunities through Title VII for health care professionals who will work in these areas including community health centers.

*Independent Children's Teaching Hospitals.*—Equally important to the future of pediatric education and research is the dilemma faced by independent children's teaching hospitals. Children's hospitals across the country are critical to the care of the nation's children and play a significant role in research and training tomorrow's pediatricians and pediatric subspecialists. This is especially important at a time when pediatric neurologists, gastroenterologists, and many other specialists for children are in short supply nationally. The children's hospitals have the critical mass of patients, physicians, and services needed to train these specialists, and their ability to sustain their teaching programs contributes to their ability to maintain these services. However, these hospitals qualify for very limited Medicare support, the primary source of funding for graduate medical education in other inpatient environments. As a bipartisan Congress has recognized in the past several years, equitable funding for Children's Hospitals Graduate Medical Education is needed to continue the education and research programs in these child- and adolescent-centered settings. We therefore reject the Administration's reduction in funding for this vital program and join with the National Association of Children's Hospitals to request total funding of \$309 million for the CHGME program in fiscal year 2006 reflecting an adjustment for the cost of inflation. The support for independent children's hospitals should not come, however, at the expense of valuable Title VII and VIII programs, including grant support for primary care training.

#### QUALITY

Access to health care is only the first step in protecting the health of all children and adolescents. We must ensure that the care provided is of the highest quality. Robust federal support for the wide array of quality improvement initiatives is needed if this goal is to be achieved.

*Emergency Services for Children.*—One program that assists local communities in providing quality care to children is the Emergency Medical Services for Children (EMSC) grant program. There are 31 million child and adolescent visits to the nation's emergency departments every year. Children under the age of 3 years account for most of these visits. Up to 20 percent of children needing emergency care have underlying medical conditions such as asthma, diabetes, sickle-cell disease, low birthweight, and bronchopulmonary dysplasia. Providers must be educated and trained to manage these special health care needs in emergency situations, and

emergency systems must be equipped with the resources needed to care for this especially vulnerable population. In order to assist local communities in providing the best emergency care to children, we urge that the EMSC program be maintained and funded at \$20 million in fiscal year 2006.

*Agency for Healthcare Research and Quality.*—Quality of care rests on quality research—for new detection methods, new treatments, new technology and new applications of science. As the lead federal agency on quality of care research, the Agency for Healthcare Research and Quality (AHRQ) provides the scientific basis to improve the quality of care, supports emerging critical issues in health care delivery and addresses the particular needs of priority populations, such as children. Substantial gaps still remain in what we know about health care needs for children and adolescents and how we can best address those needs. Children are often excluded from research that could address these issues. The AAP and endorsing organizations strongly support AHRQ's objective to encourage researchers to include children and adolescents as part of their research populations. We also support increasing AHRQ's efforts to build pediatric health services research capacity through career and faculty development awards and strong practice-based research networks. Additionally, AHRQ is focusing on initiatives in community and rural hospitals to reduce medical errors and to improve patient safety through innovative use of information technology—an initiative that we hope would include children's hospitals as well. Through its research and quality agenda, AHRQ continues to provide policymakers, health care providers, and patients with critical information needed to improve health care; therefore, we join with the Friends of AHRQ to recommend funding of \$440 million for AHRQ in fiscal year 2006.

*National Institutes of Health.*—Since its inception, the National Institutes of Health (NIH) is an integral part of the public health continuum. NIH has served as a vital component in improving the nation's health through research, both on and off the NIH campus, and in the training of research investigators, including pediatric investigators. Over the years, NIH has made dramatic strides that directly impact the quality of life for infants, children and adolescents through biomedical and behavioral research. For example, NIH research has led to successfully decreasing infant death rates, increasing the survival rates from respiratory distress syndrome, and the transmission of HIV from infected mother to fetus and infant has dropped from 25 percent to just 1.5 percent. NIH is engaged in a comprehensive research initiative to address and explain the reasons for a major public health dilemma—the increasing number of obese and overweight adults and children in this country. Today U.S. teenagers are more overweight than young people in many other developed countries. There is also a need for ongoing and increased biomedical research and funding support to study pre-term delivery, etiology, prevention and treatment regimens. In 2002, more than 480,000 babies were born prematurely and the causes of nearly half pre-term births are unknown. The pediatric community applauds the prior commitment of Congress to maintain adequate funding for the NIH and we urge you to sustain this momentum of scientific discovery. We support the recommendation of the Ad Hoc Group for Medical Research Funding for a funding level in fiscal year 2006 of \$30 billion. In addition, to ensure ongoing and adequate child and adolescent focused research, such as the National Children's Study conducted at the National Institute for Child Health and Human Development (NICHD), we join with the Friends of NICHD Coalition in requesting \$1.35 billion in fiscal year 2006.

We commend this committee's ongoing efforts to make pediatric research a priority at the highest level of the NIH. We urge continued federal support of NIH efforts to increase pediatric biomedical and behavioral research, including such proven programs as targeted training and education opportunities and loan repayment. We recommend continued interest in and support for the Pediatric Research Initiative in the Office of the NIH Director and sufficient funding to continue the pediatric training grant and pediatric loan repayment programs enacted in the Children's Health Act of 2000. This would ensure that we have adequately trained pediatric researchers in multiple disciplines that will not come at the expense of other important programs.

Finally, as clinicians, we know first-hand the considerable benefits for children and society in securing properly studied and dosed medications. The benefits of pediatric drug testing are undisputed. Proper pediatric safety and dosing information reduces medical errors and adverse events, ultimately improving children's health and reducing health care costs. In a very conservative estimate, the FDA projected savings from pediatric testing of over \$228 million a year in reduced hospitalization expenses for just five diseases affecting children. But until now there has been little incentive for drug companies to study off-patent drugs—older drugs that are critically needed therapies for children. The Research Fund for the Study of Drugs, cre-



ated as part of the Best Pharmaceuticals for Children Act of 2002, provides support for these critical pediatric testing needs, but unfortunately is currently funded at an amount sufficient to test only a fraction of the NIH and FDA-designated “priority” drugs. Therefore, we urge you to provide the NIH with sufficient funding to fund the study of generic (off-patent) and selected on-patent drugs for pediatric use.

We believe that these requests represent the best and most reliable estimates of the level of funding needed to sustain the high standard of scientific achievement embodied by the NIH. However, we encourage Congress to explore all possible options to identify additional sources of funding needed to support these increases if we are to reach these funding goals while not weakening any other valuable component of the Public Health Service.

#### IMMUNIZATIONS

Immunization remains one of the greatest public health achievements of the 20th century and has saved millions of lives. Since the widespread use of vaccines, millions of children have avoided terrible diseases that can cause great suffering and, in some cases, death. For example before immunization, polio paralyzed 10,000–25,000 children and adults, rubella (German measles) caused birth defects and mental retardation in as many as 20,000 newborns, and measles infected millions of children, killing 400–500 and leaving thousands with serious brain damage. Immunizations have reduced by more than 95 to 99 percent the cases of vaccine-preventable infectious diseases in this country. And some, like rubella, are virtually eliminated from North America, thanks to successful immunization programs.

Pediatricians, working alongside public health professionals and other partners, have brought the United States its highest immunization coverage levels in history. As a result, disease levels are at, or near, record low levels. We attribute this, in part, to the Vaccines for Children (VFC) Program and encourage Congress to maintain its commitment to ensuring the program’s viability. The VFC program combines the efforts of public health and private pediatricians and other health care professionals to accomplish and sustain vaccine coverage goals for both today’s and tomorrow’s vaccines. It removes vaccine cost as a barrier to immunization for some and reinforces the concept of vaccine delivery in a “medical home.” However, we are concerned that once again the Administration’s fiscal year 2006 proposal to reduce funding for the Section 317 program to expand VFC is shortsighted. Additional section 317 funding is necessary to provide the pneumococcal conjugate vaccine (PCV-7), a vaccine that prevents an infection of the brain covering, blood infections and approximately 7 million ear infections a year, to those remaining states that currently do not provide it. Increased funding also is needed to purchase the influenza vaccine. It is now recommended that young children between the ages of 6 months and 23 months of age receive an annual influenza vaccine. This age cohort is increasingly susceptible to serious infection and the risk of hospitalization. And an increase in funding is needed to purchase the recently recommended meningococcal conjugate vaccine (MCV). Meningococcal disease is a serious illness, caused by bacteria, with 10–15 percent of cases fatal and another 10–15 percent of cases resulting in permanent hearing loss, mental retardation, or loss of limbs.

The public health infrastructure that now supports our national immunization efforts must not be jeopardized with insufficient funding. One of the conclusions of the 2000 Institute of Medicine report, *Calling the Shots*, was that unstable funding for state immunization programs threatens coverage levels for specific populations and age groups and vaccine safety. This continues to be true today. A strong and sufficient infrastructure is essential. For example, adolescents continue to be adversely affected by vaccine-preventable diseases (e.g., chicken pox, hepatitis B, measles and rubella). Comprehensive adolescent immunization activities at the national, state and local levels are needed to achieve national disease elimination goals. States and communities continue to be financially strapped and therefore, many continue to divert funds and health professionals from immunization clinics in order to accommodate anti-bioterrorism initiatives. Moreover, continued investment in the CDC’s immunization activities must be made to avoid the reoccurrence of childhood vaccine shortages by providing and adequately funding a national 6 month stockpile for all routine childhood vaccines—stockpiles of sufficient size to insure that significant and unexpected interruptions in manufacturing do not result in shortages for children.

While the ultimate goal of immunizations clearly is eradication of disease, the immediate goal must be prevention of disease in individuals or groups. To this end, we strongly believe that CDC’s efforts must be sustained. In fiscal year 2006, we recommend an overall increase in funding of \$232 million to ensure that the CDC’s National Immunization Program has the funding necessary to accommodate vaccine

price increases, new disease preventable vaccines coming on the market, global immunization initiatives—including funds for polio eradication and the elimination of measles and rubella—and to continue to implement the recommendations developed by the IOM.

#### CONCLUSION

We appreciate the opportunity to provide our recommendations for the coming fiscal year. As this Subcommittee is once again faced with difficult choices and multiple priorities we know that as in the past years, you will not forget America's children and adolescents.

#### OTHER RECOMMENDATIONS FOR FISCAL YEAR 2006

##### DEPARTMENT OF HEALTH AND HUMAN SERVICES

Agency	Amount
Centers for Disease Control and Prevention (total) .....	\$8,065,000,000
Global Immunization (including polio eradication) .....	153,000,000
Birth Defects, Disability and Health .....	135,000,000
Newborn Hearing Screening Technical Assistance .....	9,000,000
National Violent Death Reporting System .....	10,000,000
Folic Acid Education Campaign .....	4,000,000
Health Resources and Services Administration (total) .....	7,500,000,000
Newborn Screening (Title XXVI) .....	25,000,000
Newborn Hearing Screening Grants to States .....	10,000,000
Consolidated Community Health Centers .....	2,038,000,000
Substance Abuse and Mental Health Services Administration (total) .....	3,531,000,000

#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 55,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 2006 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

A member of the Health Professions and Nursing Education Coalition (HPNEC), the Academy supports the HPNEC recommendation to provide at least \$550 million to support the Titles VII and VIII programs in fiscal year 2006, including \$18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

The Academy believes that the recommended increase in funding for the Title VII health professions programs is well justified. The programs are essential to the development and training of primary health care professionals and contribute to the nation's overall efforts to increase access to care by promoting health care delivery in medically underserved communities.

The Academy is very concerned with the Administration's proposal to eliminate funding for most Title VII programs, including zero funding for training in primary care medicine and dentistry. As Members of the Subcommittee are aware, these programs are designed to help meet the health care delivery needs of the nation's Health Professional Shortage Areas (HPSAs). By definition, the nation's more than 3,800 HPSAs experience shortages in the primary care workforce that the market alone can't address. We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support for these important programs in fiscal year 2006.

#### OVERVIEW OF PHYSICIAN ASSISTANT EDUCATION

Physician assistant programs provide students with a primary care education that prepares them to practice medicine with physician supervision. PA programs are located at schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are intensive education programs that are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 111 weeks of instruction. The first phase of the program consists of intensive classroom and laboratory study, providing students with an in-depth understanding of the medical sciences. More than 400 hours

in classroom and laboratory instruction are devoted to the basic sciences, with over 70 hours in pharmacology, more than 149 hours in behavioral sciences, and more than 535 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours or 50–55 weeks to clinical education, divided between primary care medicine and various specialties, including family medicine, internal medicine, pediatrics, obstetrics and gynecology, surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

Physician assistant education is competency based. After graduation from an accredited PA program, the physician assistant must pass a national certifying examination jointly developed by the National Board of Medical Examiners and the independent National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education credits over a two-year cycle and reregister every two years. Also to maintain certification, PAs must take a recertification exam every six years.

#### PHYSICIAN ASSISTANT PRACTICE

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are within the physician's scope of practice and the PA's training and experience, and are allowed by law. Forty-eight states, the District of Columbia, and Guam authorize physicians to delegate prescriptive privileges to the PAs they supervise.

PAs are located in almost all health care settings and in every medical and surgical specialty. Nineteen percent of all PAs practice in non-metropolitan areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 41 percent of PAs work in urban and inner city areas. Approximately 44 percent of PAs are in primary care. Nearly one-quarter practice in surgical specialties. Roughly 80 percent of PAs practice in outpatient settings. In 2004, an estimated 206 million patient visits were made to PAs and approximately 250 million medications were prescribed or recommended by PAs.

#### CRITICAL ROLE OF THE TITLE VII, PUBLIC HEALTH SERVICE ACT, PROGRAMS

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 nearly 45 million today. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to more than 3,800 today.

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 generate a supply of providers who are willing to work in the nation's medically underserved communities. 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.

Furthermore, now that there is compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations, increasing the diversity of health care professionals is essential. Title VII programs are unique in that they seek to recruit providers from a variety of back-

grounds. This is particularly important, as studies have found that those from disadvantaged regions of the country are three to five times more likely to return to those underserved areas to provide care versus other areas.

#### 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 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 1990-2003 reveals that students graduating from PA programs supported by Title VII are 65 percent more likely to be from underrepresented minority backgrounds and 29 percent more likely to practice in underserved settings, than students graduating from PA programs that were not supported by Title VII.

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, a PA educational program in Iowa uses Title VII funds to target recruitment efforts to disadvantaged students, providing shadowing and mentoring opportunities for prospective students, increasing training in cultural competency, and identifying new family medicine preceptors in underserved areas. PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. One Texas program uses Title VII funds for the development of web based and distant learning technology and methodologies so students can remain at clinical practice sites. A PA program in New York, where over 90 percent of the students are ethnic minorities, uses Title VII funding to focus on primary care training for underserved urban populations by linking with community health centers, which expands the pool of qualified minority role models that engage in clinical teaching, mentoring, and preceptorship for PA students. Several other PA programs have been able to use Title VII grants to leverage additional resources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training.

Without Title VII funding, many of these special PA training initiatives 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. 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. Currently 36 percent of PAs met their first clinical employer through their clinical rotations.

Changes in the health care marketplace reflect a growing reliance on PAs as part of the health care team. Currently, 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 med-

ical market demand and the estimated workforce requirements for PAs would exceed supply. Additionally, the Bureau of Labor Statistics projects that the number of available PA jobs will increase 49 percent between 2002 and 2012. Title VII funding has provided, and continues to provide, a crucial pipeline of trained PAs to underserved areas. One way to assure an adequate supply of physician assistants, especially PAs likely to practice in underserved areas, is to continue offering financial incentives, such as funding preferences, to PA programs that emphasize recruitment and placement of people interested in primary health care in medically underserved communities.

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. Nor has the Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budgets from 1984 through 2003 indicates an average annual increase of seven percent, a total increase of 245 percent over the past 19 years, yet federal support has remained relatively static.

#### RECOMMENDATIONS ON FISCAL YEAR 2006 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 2006. 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 or bioterrorist attack, 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.

Furthermore, while the Academy applauds the Administration’s proposal to strengthen national security by increasing support for health emergency preparedness initiatives, it should not do so at the expense of Title VII programs. Training is the key to preparedness, and Title VII, section 747, is an ideal mechanism for educating primary care providers in public health competencies, facilitating population based and community-based skills and training, and increasing the alliance between public health and primary care providers. This is particularly important for our Nation’s most disadvantaged and underserved populations, because they are the most vulnerable during medical emergencies because of a lack of resources and access to care.

The Academy respectfully requests that the Title VII and VIII health professions programs receive \$550 million in funding for fiscal year 2006, including \$18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

Thank you for the opportunity to present the American Academy of Physician Assistants’ views on fiscal year 2006 appropriations.

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS (AANA)

#### FISCAL YEAR 2006 APPROPRIATIONS REQUEST SUMMARY

	Fiscal year 2005 actual	Fiscal year 2006 budget	AANA request
HHS /HRSA /BHP Title VIII Advanced Education Nursing, Nurse Anesthetist Education Reserve.	Awaiting grant allocations \$3.5 MM fiscal year 2004.	Grant allocations not specified.	\$3,000,000
Title VIII HRSA BHP Nursing Education Programs.	\$150,674,000 .....	\$150,471,000 .....	210,000,000

Chairman Specter, Ranking Member Harkin, and members of the Subcommittee: The AANA is the professional association for more than 30,000 Certified Registered Nurse Anesthetists (CRNAs) and student nurse anesthetists representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs are directly involved in approximately 65 percent of all anesthetics given to patients each year in the United States. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, as well as providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and are the sole anesthesia providers in almost 70 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Having provided anesthesia since the Civil War, masters' educated nurse anesthetists today have set for ourselves the most rigorous continuing education and recertification requirements in the field. We are humbled and honored that the Institute of Medicine reported in 1999 that anesthesia is 50 times safer than 20 years ago. And a recent study by Dr. Michael Pine of over 400,000 cases in 22 states involving CRNAs, anesthesiologists, or both together finds "the type of anesthesia provider does not affect inpatient surgical mortality." In addition, a recent AANA workforce study's data showed that CRNAs and anesthesiologists are substitutes in the production of surgeries. Through continual improvements in research, education, continuing education and practice, nurse anesthetists are vigilant to continue improving patient safety.

And CRNAs provide the lion's share of the anesthesia care required by our U.S. Armed Forces through active duty and the reserves, from here at home to the leading edge of the field of battle. In May 2003, at the beginning of "Operation Iraqi Freedom" 364 CRNAs had been deployed to the Middle East to ensure military medical readiness capabilities. For decades CRNAs have staffed ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support.

#### IMPORTANCE OF TITLE VIII NURSE ANESTHESIA EDUCATION FUNDING

Our chief request before the Subcommittee today, for at least \$3 million to be reserved for nurse anesthesia education from Title VIII, is based on two facts. First, there is a 12 percent vacancy rate of nurse anesthetists in the United States impacting people's healthcare. And second, the Title VIII program supported strongly by members of this Subcommittee in the past is an effective means to help address the nurse anesthesia workforce demand. This demand for CRNAs is something we as a profession are addressing every day with success, and with the critical assistance of federal funding through HHS' Title VIII appropriation.

In 2003 the AANA conducted a nurse anesthesia workforce study, which concluded a 12 percent vacancy rate in hospitals for CRNAs, and a lower vacancy rate in ambulatory surgical centers for 2002. The supply has increased in recent years, stimulated by increases in the number of CRNAs trained. However, these increases had not been enough to offset the number of retiring CRNAs. This trend, as of 2003, will require raising the number of nurse anesthesia graduates to fill the growing vacancy rate. This is compounded by rising number of Medicare-eligible Americans, from about 34 million today, to more than 40 million in 2010, who will require the care that CRNAs provide.

The problem is not that our 94 accredited schools of nurse anesthesia are failing to attract qualified applicants. These CRNA schools are located all across the country including ten in Pennsylvania, five each in Ohio and Florida and Texas, four each in Illinois and New York, three each in California and Connecticut and Maryland, two in Rhode Island, and one in Wisconsin. It is that they are full. Each CRNA school continues to turn away qualified applicants—bachelor's educated nurses who had spent at least one year serving in a critical care environment. Recognizing the importance of nurse anesthetists to quality healthcare, the AANA has been working with its 94 accredited schools of nurse anesthesia to increase the number of qualified graduates, and to expand the number of CRNA schools. The Council on Accreditation of Nurse Anesthesia Educational Programs (COA) reports that in 1999, our schools produced 948 new graduates. By 2005, that number had increased to 1,628, a 72 percent increase in just five years. The growth is expected to continue. The COA projects CRNA schools to produce 1,800 graduates in 2005. But to meet the challenge, we simply must continue expanding the capacity and number of CRNA schools. With the help of competitively awarded Title VIII funding, we are

making significant progress, expanding both the number of clinical practice sites and the number of graduates.

We are pleased to report that this progress is extremely cost-effective from the standpoint of federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. And we know what the Pine study confirms, "the type of anesthesia provider does not affect inpatient surgical mortality." Yet, for what it costs to train just one anesthesiologist, eleven CRNAs may be educated for the same task at the same superlative level of safety. This represents an eleven to one educational cost/benefit for supporting CRNA educational programs with federal dollars vs. supporting other anesthesia providers' education. This also contributes to a three or four to one anesthesia delivery cost/benefit. These ratios represent a cost/benefit unprecedented in any other healthcare specialty.

So is this \$3 million Title VIII investment in nurse anesthesia education effective? In February 2003, AANA surveyed its CRNA school program directors, to gauge the impact of the Title VIII funding. Of those that had reported receiving competitive Title VIII Nurse Education and Practice Grants funding, and there were eleven such schools from 1998 to 2003, they said they on average had increased their number of graduating CRNAs by more than 15 each per year. They reported on average more than doubling their number of CRNA graduates per school, who provide care to patients during and following their education. Moreover, they reported producing additional CRNAs that went to serve in rural or medically underserved areas. Under both of these circumstances, an increased number of student nurse anesthetists and CRNAs are providing healthcare to the people of medically underserved America.

We believe it is important for the Subcommittee to allocate \$3 million for nurse anesthesia education for several reasons. First, as we have shown, the funding is cost-effective and well-needed. Second, the Title VIII authorization previously providing such a reserve expired in September 2002. The amount we request is consistent with what Title VIII provided in fiscal year 2001. Third, this particular funding is important because nurse anesthesia for rural and medically underserved America is not affected by increases in the budget for the National Health Service Corps and community health centers, since those initiatives are for delivering primary and not surgical healthcare. And, last, this funding meets an overall objective to increase access to quality healthcare in medically underserved America.

#### TITLE VIII FUNDING FOR STRENGTHENING THE NURSING WORKFORCE

Mr. Chairman, the AANA joins a growing coalition of nursing organizations and others in support of the Subcommittee providing a total of \$210 million in fiscal year 2006 for nursing shortage relief through Title VIII. This amount is approximately \$60 million over the fiscal year 2005 level, and over the President's fiscal year 2006 budget. Every district in America is familiar with the importance of nursing.

I understand that this request is a significant increase over the President's request. Thanks to your leadership and that of the Subcommittee, Congress increased nurse education funding \$5 million over the President's request in fiscal year 2005 for which we are grateful, though we are concerned the Division of Nursing "expert panel" report that motivated requests to reduce Advanced Education Nursing is itself fraught with shortfalls, pitfalls and problems.

Another perspective is that America spends more than \$1.7 trillion on healthcare this year, paid by private and public sources. About \$298 billion of that is estimated to be Medicare outlays in 2005. About \$8.7 billion of that Medicare funds direct and indirect GME, with some 99 percent of that funding helping to educate physicians and allied health professionals, and about 1 percent to help educate nurses. \$301 million of the fiscal year 2005 appropriations bill supports a GME-type program for pediatricians through children's hospitals. These are all worthy things. But for every present and future healthcare patient, Congress must put some focus on nurses and nurse anesthesia care.

From each dollar America spends in healthcare our request is that the federal government should allocate at least 15 thousandths of a cent to ensure we have enough nurses, and at least two ten-thousandths of a cent to ensure we have the safe anesthesia care we need when we need it. This action will improve patients' healthcare, and strengthen seniors' Medicare, all at once.

Thank you.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF OBSTETRICIANS AND  
GYNECOLOGISTS

The American College of Obstetricians and Gynecologists (ACOG), on behalf of its 46,000 partners in women's health care, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Specter, Ranking Member Harkin, and the entire subcommittee for their leadership to continually address maternal and child health care services.

The Nation has made important strides to improve women and children's health over the past several years, and ACOG is grateful to this Committee for its commitment to research. We look forward to working with the Members of this Committee to ensure that vital research continues to eliminate disease and to ensure valuable new treatment discoveries are implemented. The NIH has examined and determined many disease pathways, while the Health Resources and Services Administration has been successful in translating research findings into valuable public health policy solutions. This dedicated commitment to elevate, promote and implement medical research faces an uncertain future at a time when scientists are on the cusp of new cures.

It is vital that the Committee provide strong support for current studies, and for future advances, as well. We urge the Committee to support a 6 percent increase for the National Institutes of Health (NIH) in fiscal year 2006, and a 6 percent increase for the National Institute of Child Health and Human Development (NICHD). We also continue to support efforts to secure adequate funds for important public health programs such as the Health Resources and Services Administration (HRSA). Continued appropriations to these agencies will ensure ongoing and new research initiatives continue to yield positive results for women and children's health.

NATIONAL INSTITUTES OF HEALTH—RESEARCH LEADING THE WAY

*Ob-Gyn Representation on the NICHD Advisory Council*

ACOG is most concerned that research conducted through the National Institute on Child Health and Human Development (NICHD) receives adequate funding, that the Institute can attract new ob-gyn researchers, and that individuals who have expertise and knowledge about its work guide NICHD.

NICHD has overseen tremendous advancements for women including improving pregnancy and childbirth outcomes, and identifying cures for diseases and conditions affecting women of all ages and at all stages in life. NICHD is, in fact, the Institute where the vast majority of ob-gyn related research takes place and the only Institute where ob-gyns have a prominent role. It's critical, then, to require that the NICHD Advisory Council include an adequate number of individuals who have distinguished themselves in ob-gyn clinical practice and research.

Currently, this important Council, which guides the Institute's research funding decisions, is composed of 17 appointed members, including pediatricians, ob-gyns, sociologists, biologists, media consultants, and nurses. The ob-gyns on the Council bring years of expertise and knowledge of women's health care needs, research priorities, and the impact of research discoveries on women's lives. In November 2004, the number of ob-gyns on the Council was reduced from 3 to 2.

ACOG worked actively with the NICHD to advocate the appointment of another ob-gyn to this position, and we are deeply troubled that NICHD filled this position with an attorney, rather than with another ob-gyn. Research conducted at NICHD helps shape the future of women's health care. Women across America and the world suffer from issues of maternal morbidity, uterine fibroids, vulvodynia and numerous other health care issues that are far from being understood and cured. The world faces global challenges, too, of the spread of sexually transmitted diseases, which have barely been acknowledged, much less challenged and defeated.

The NICHD Advisory Council must include an adequate number of ob-gyns who are experts in these clinical and research areas. We object strongly to any attempt to reduce the ability of our specialty to contribute to the research direction of this Institute which is obviously so critical to the area that we know better than any other group or medical specialty—women's health.

We look to Congress to amend the NICHD statute to require that its Advisory Council include no fewer than three experts in the field of ob-gyn. This action is necessary to ensure that decisions that will affect the future of women's health care are made by individuals with expertise and a deep level of commitment to the field. We hope to work actively with this Committee and the Congress to restructure the Council representation requirements.



*Research at the NICHD*

The NICHD conducts research that holds great promise to improve maternal and fetal health and safety. With the support of Congress, the Institute has initiated research addressing the causes of cerebral palsy, gestational diabetes and pre-term birth. However, much more needs to be done to reduce the rates of maternal mortality and morbidity in the United States. More research is needed on such pregnancy-related issues as the impact of chronic conditions during pregnancy, racial and ethnic disparities in maternal mortality and morbidity, and drug safety with respect to pregnancy.

A commitment to research in maternal health sheds light on a breadth of issues that save women's lives. Important research examining the following issues must continue:

*Reducing High Risk Pregnancies*

NICHD's Maternal Fetal Medicine Unit Network, working at 14 sites across the United States (University of Alabama, University of Texas-Houston, University of Texas-Southwestern, Wake Forest University, University of North Carolina, Brown University-Women and Infant's Hospital, Columbia University, Drexel University, University of Pittsburgh-Magee Women's Hospital, University of Utah, Northwestern University, Wayne State University, Case Western University, and Ohio State University), will help reduce the risks of cerebral palsy, caesarean deliveries, and gestational diabetes. This Network discovered that progesterone reduces preterm birth by one-third.

*Reducing the Risk of Perinatal HIV Transmission*

In the last 10 years, NICHD research has helped decrease the rate of perinatal HIV transmission from 27 percent to 1.2 percent. This advancement signals the near end to mother-to-child transmission of this deadly disease.

*Reducing the Effects of Pelvic Floor Disorders*

The Institute has made recent advancements in the area of pelvic floor disorders. The NICHD is investigating whether women that have undergone cesarean sections have fewer incidences of pelvic floor disorder than women who have delivered vaginally.

*Reducing the Prevalence of Premature Births*

NICHD is helping our Nation understand how adverse conditions and health disparities increase the risks of premature birth in high-risk racial groups.

*Drug Safety During Pregnancy*

The NICHD recently created the Obstetric and Pediatric Pharmacology Branch to measure drug metabolism during pregnancy.

*The Challenge of the Future: Attracting New Researchers*

Despite the NICHD's critical advancements, reduced funding has made it difficult for this research to continue, largely due to the lack of new investigators. Congressional programs such as the loan repayment program, the NIH Mentored Research Scientist Development Program for reproductive health, and a small grant program, all attract new researchers, but low pay lines make it difficult for the NICHD to maintain these researchers. Due to the structure of the peer review system, previous grant recipients have an advantage because their grants require fewer funds. This makes it more difficult for new investigators to get into the system, jeopardizing the future of women's health research. We urge the Committee to significantly increase funding at the NICHD to maintain a high level of research innovation and excellence, in turn reducing the incidence of maternal morbidity and mortality and discovering cures for other chronic conditions.

HEALTH RESOURCES AND SERVICES ADMINISTRATION: TURNING RESEARCH INTO SOLUTIONS

It is critical that we rapidly transform women's health research findings into public health solutions. The Health Resources and Services Administration (HRSA) has created women and children's health outreach programs based on research conducted on prematurity, high risk pregnancies, gestational diabetes, and a variety of other health issues. The National Fetal Infant Mortality Review and the Provider's Partnership are two examples of the successful programs under the Healthy Start Initiative.

For example, research shows tobacco abuse and health disparities are risk factors for infant mortality. Healthy Start offers programs for states, which fund provider and community education programs that improve maternal health through tobacco

cessation programs, and finds ways to decrease the infant mortality rate by investigating cultural and institutional health disparities.

#### NATIONAL FETAL INFANT MORTALITY REVIEW

The Fetal and Infant Mortality Review (FIMR) is a cooperative federal agreement between ACOG and the Maternal Child Health Bureau at HRSA. FIMR uses the expertise of ob-gyns and local health departments to find solutions to problems related to infant mortality. In light of the recent increase in the infant mortality rate for 2002, the FIMR program is vital to develop community-specific, culturally appropriate interventions. Today 220+ local programs in 42 states are implementing FIMR and finding it is a powerful tool to bring communities together to address the underlying problems that negatively affect the infant mortality rate.

In order to meet the demand of the increasing number of FIMR programs, NFIMR must be able to continue its activities at an adequate funding level. A rigorous national evaluation of FIMR conducted by Johns Hopkins University has concluded that the FIMR methodology is an effective perinatal initiative. Based on that new research, FIMR can now be called an evidence based MCH intervention. All Healthy Start programs and every locality with disparities in infant outcomes should be actively encouraged to implement this FIMR process.

We urge this Committee to recognize the many positive contributions of the FIMR program and ensure it remains a fully funded program within HRSA.

#### PROVIDER'S PARTNERSHIP

Through May 2003, HRSA funded the Provider's Partnership, a cooperative agreement between the Federal Maternal and Child Health Bureau and ACOG. This Partnership includes a series of state-level projects initiated to address key women's health issues, while simultaneously building partnerships between ACOG Members and public health leadership.

The Partnership works specifically with psychosocial issues that greatly impact the health and well being of women. The morbidity and mortality attributed to issues such as a woman's depression, tobacco use, substance abuse and domestic violence are becoming increasingly apparent as they weigh on both the woman and her entire family. Without treatment, these psychosocial issues place a heavy financial burden on state and federal resources. Obstetrician-gynecologists play a critical role in addressing these problems within their current practice, however because of the complexity and the importance of promptly linking at-risk women with appropriate services, responsibility for full psychosocial assessment and treatment cannot fall solely on obstetrician-gynecologists. Partnerships between women's health care physicians and state and community programs are needed that allow for integration of medical care with psychosocial services. Partnerships increase coordination thereby minimizing demands on both the behavioral health care system and individual providers. Provider's Partnership enables stakeholders to improve prevention interventions, so that later complications can be avoided.

There are currently 30 state-level Partnership teams focused on depression in women, tobacco use, perinatal HIV transmission and oral health. These teams have been successful at surveying obstetric providers on their screening; counseling and referral practices for perinatal depression and tobacco use, the results of which have been the basis for the development of statewide legislative and practice policy guidelines; establishing pilot screening and intervention initiatives for depression in women; and instituting provider training and technical assistance for depression and tobacco use screening and intervention. Despite their successes, these teams still struggle for funds to offset administrative and program costs. Representatives from additional states have expressed an interest in developing an ACOG Provider's Partnership, however, any new efforts are being postponed until additional funding can be identified.

Interagency cooperation to address the multiple factors that affect maternal and child health will help us increase our Nation's overall health. By continuing to translate research done at the NICHD on high-risk pregnancies, drug metabolism, and preterm births, into positive outreach programs such as NFIMR and the Provider's Partnership, we can further improve maternal health and reduce infant mortality.

Again, we would like to thank the Committee for its continued support of maternal and child health research and programs. We strongly urge this Committee to support increased funding for the National Institute of Child Health and Human Development (NICHD), and renewed appropriations for the National Fetal Mortality Review (NFIMR) and the Provider's Partnership programs. This funding would significantly increase the number of women and families who benefit from smoking

cessation programs, depression screening, and community specific solutions to infant mortality. Through joint community and government efforts we can decrease the harmful consequences these issues have on the Nation's health.

We further urge the Committee and the Congress to pass a requirement that the NICHD Advisory Council include no fewer than three experts in the field of ob-gyn, to ensure a bright future for advancements in women's health.

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PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Heart disease, stroke and other cardiovascular diseases kill more Americans each year than the next 5 leading causes of death combined, putting people of all ages at risk. Cardiovascular diseases remain our nation's No. 1 killer and a major cause of disability. We are concerned that our government is still not devoting sufficient resources for research and prevention to America's No. 1 killer—heart disease—and to our country's No. 3 killer—stroke.

STILL NO. 1—AN UNHAPPY DISTINCTION

Cardiovascular diseases represent a continuing crisis of pandemic proportions. More than 70 million Americans suffer from these diseases, and risk factors are on the rise. About 65 percent of American adults are overweight or obese and an estimated 9.2 million children and adolescents ages 6–19 are overweight or obese. Also, an estimated 65 million Americans have high blood pressure, nearly 38 million adults have high cholesterol, and nearly 14 million have diagnosed diabetes. Cardiovascular diseases cost Americans more than any other disease—an estimated \$394 billion in medical expenses and lost productivity in 2005. Heart defects are the most common birth defect and cause more infant deaths than any other birth defect.

HEART DISEASE AND STROKE. YOU'RE THE CURE

Now is the time to capitalize on our progress in understanding heart disease, stroke and other cardiovascular diseases. Promising, cost-effective breakthroughs in treatment and prevention are available, and new ones are on the horizon. A continued, sustained investment in the NIH and appropriate funding for NIH heart disease and stroke will support critically needed new initiatives, especially in the translation of that research into useful clinical and state programs. For fiscal year 2006, we urge you to:

*Appropriate \$30 billion for the National Institutes of Health (NIH)—to provide a continued, sustained investment in life-saving medical research*

NIH research provides new treatment and prevention strategies, creates jobs, and maintains America's status as the world leader in the biomedical and biotechnology industries.

*Provide \$2.3 billion for NIH heart research and \$341 million for NIH stroke research*

Researchers are on the brink of advances to enhance prevention and to provide new treatments so you and your loved ones can be spared the pain and suffering of heart disease and stroke. For example, the impact of co-morbidities on the progression of atherosclerosis and on its prevention and treatment needs further study. In terms of the well-recognized epidemic of obesity, research is needed on the science of weight regulation, on both the genetic and environmental bases of obesity, and on nutrition and exercise science. Inter-Institute communication and joint programs, which have been encouraged by the Director, should continue to grow, particularly in areas such as growth and development, atherosclerosis, obesity and diabetes among others.

*Allot \$55.6 million for Heart Disease and Stroke for the CDC to expand, intensify and coordinate prevention initiatives such as the State Heart Disease and Stroke Prevention Program and the Paul Coverdell National Acute Stroke Registry*

Science must be translated into state programs that hearten Americans to make healthy lifestyle choices to avert and control heart disease and stroke and track and improve stroke care delivery.

*Allocate \$15 million to continue to help rural and community areas treat cardiac arrest in time to save lives by initiating automated external defibrillator (AEDs) programs*

The Rural Access to Emergency Devices Act (part of Public Law 106–505) and the Community Access to Emergency Defibrillation Act (part of Public Law 107–188)

help rural and community areas purchase AEDs and train emergency and lay responders in their use.

#### HEART AND STROKE RESEARCH BENEFITS ALL AMERICANS

Thanks to advances in addressing risk factors and in treating cardiovascular diseases, more Americans are surviving these often deadly and disabling diseases. Heart disease and stroke research, prevention and treatment breakthroughs are saving and improving lives. Several examples follow.

*Automated External Defibrillator.*—Each year, 250,000 Americans die from cardiac arrest. Training volunteers to perform cardiopulmonary resuscitation and to use an AED—a briefcase-size device that shocks the heart into a normal rhythm—distributed in shopping malls, sports venues and other public places can double the survival rate of cardiac arrest victims.

*Implantable Cardioverter Defibrillator.*—An ICD, which provides an electrical impulse to correct an often fatal irregular heart beat, notably reduces deaths in heart failure patients. So, the government announced an expansion of the number of Medicare recipients eligible to receive ICDs. They estimate that about 25,000 Medicare beneficiaries will receive ICDs in the first year, possibly saving up to 2,500 lives. These patients are required to share information about their condition, so medical professionals can assess which individuals are helped the most by ICDs.

*Women and Low-Dose Aspirin.*—A study found that low-dose aspirin on alternative days did not prevent first heart attacks or death from cardiovascular diseases in women, but clot-based strokes were significantly reduced, with the greatest benefit in women age 65 and older.

*Ultrasound in Combination with tPA Enhances Drug's Effectiveness Against Stroke.*—Tissue plasminogen activator (tPA) effectively dissolves clots that are causing an acute clot-based stroke. But, using ultrasonography, a non-invasive technique that uses sound waves, in combination with tPA improves the drug's clot busting abilities, leading to improved chances for a better recovery from stroke.

We join other members of the research community in advocating for a fiscal year 2006 appropriation of \$30 billion for the NIH to provide a continued, sustained investment in life-saving medical research and support investigation into new therapies. The NIH budget for heart disease and stroke remains disproportionately under-funded compared to the enormous burden of these diseases and the numerous promising scientific opportunities that could advance the fight against these disorders. Heart disease, stroke and other cardiovascular diseases meet the NIH's criteria for priority setting (public health needs, scientific quality of research, scientific progress potential, portfolio diversification and adequate infrastructure support), but the NIH continues to invest only 7 percent of its budget on heart research and a mere 1 percent on stroke research. We have a particular interest in individual NIH components that relate directly to our mission. Our funding recommendations for these Institutes follow.

#### HEART RESEARCH CHALLENGES AND OPPORTUNITIES FOR NHLBI

Advances have been made by more than 50 years of American Heart Association-funded research and more than a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. While more people survive heart disease and stroke, they can cause permanent disability, requiring costly medical care and loss of productivity and quality of life.

We urge this Committee to appropriate funding for the NHLBI and for its heart disease and stroke-related efforts to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively advance the battle against heart disease and stroke. To accomplish this goal, we advocate an appropriation of \$3.1 billion for the NHLBI, including \$1.9 billion for heart disease and stroke. This added investment is needed to focus on heart disease and stroke challenges and opportunities. Several of these follow.

*Heart Failure Clinical Research Network.*—Despite advances in treatment, the number of new cases and the number of Americans suffering from heart failure continue to grow. And, the long-term prognosis for patients remains poor. A planned research network with the capability of implementing multiple concurrent clinical studies would conduct clinical studies of new approaches to improve outcomes and would provide an infrastructure to enable rapid translation of promising research findings into patient care.

*Novel Targets and Therapy Development for Clot-based Stroke.*—There is only one FDA-approved emergency treatment for clot-based stroke: t-PA. However, fewer than 5 percent of patients receive it, largely because it must be given within three hours from the onset of symptoms. To address an urgent need to develop new thera-

pies, the NHLBI and the National Institute of Neurological Disorders and Stroke (NINDS) have planned a collaborative effort to identify new molecular targets, explore promising agents, and develop innovative therapies to quickly restore blood flow to the brain and limit stroke damage.

*Technologies for Engineering Small Blood Vessels.*—A need exists to develop alternatives to natural blood vessels for patients who require heart artery bypass surgery and for children born with complex heart defects because the supply of native blood vessels to use as grafts does not meet the demand and prosthetic grafts fail at an unacceptable rate. Planned research would address the development of functional, small blood vessel substitutes.

*Specialized Centers of Clinically Oriented Research for Vascular Injury, Repair, and Remodeling.*—The NHLBI has planned a new SCCOR program to conduct interdependent clinical and multidisciplinary basic research projects on the molecular and cellular mechanisms of vascular (blood vessel) injury, repair, and remodeling. This program would promote patient-oriented research to improve prevention, detection, and treatment of vascular diseases, such as stroke. The SCCORs would provide resources to enable new clinical investigators to develop skills and research capabilities to conduct relevant research in this area.

#### STROKE RESEARCH CHALLENGES AND OPPORTUNITIES FOR NINDS

Stroke is the No. 3 killer of Americans and a major cause of permanent disability. Many of America's 5.4 million stroke survivors face debilitating physical and mental impairment, emotional distress and huge medical costs. About 1 in 4 stroke survivors is permanently disabled. An estimated 700,000 Americans will suffer a stroke this year, and nearly 163,000 will die. In addition to the elderly, stroke also strikes newborns, children and young adults.

We urge you to provide sufficient funding for the NINDS to support and expand current activities and to invest in promising and critically needed new initiatives to aggressively prevent stroke, protect the brain during stroke and enhance rehabilitation. To accomplish this goal, we advocate for an fiscal year 2006 appropriation of \$1.6 billion for the NINDS, including \$183 million for stroke. Some challenges and opportunities follow.

*Strategic Stroke Research Plan.*—As a result of congressional report language during the fiscal year 2001 appropriations process, the NINDS convened a Stroke Progress Review Group (SPRG). Their report serves as a guide for a long-range strategic planning for stroke and includes 5 research priorities and 7 resource priorities to be addressed in the coming years. Multiple scientific programs initiated since the SPRG report are making impressive progress. But, more funding is needed to continue to implement these activities and other components of the plan.

*Emerging Stroke Risk Factors.*—Although more Americans are controlling major stroke risk factors, such as high blood pressure and smoking, the number of stroke victims continues to rise. Scientists are defining new risk factors and re-examining the role of existing ones. Researchers are studying the role of inflammation in damaging arteries, heart valve disease, irregular heartbeats, and the long-term effects of high blood pressure. Increased funding for new approaches in these areas may lead to new ways to prevent stroke.

*Therapeutic Strategies for Stroke.*—Several major clinical trials have identified new methods for preventing and treating stroke in high-risk populations, including stroke survivors. But, as the number of strokes increases and disparities in treatment persist, funding for translational and clinical studies is vital to providing cutting-edge stroke treatment and prevention.

*Stroke Education.*—As a member of the Brain Attack Coalition, organizations devoted to fighting stroke, we work with the NINDS to increase public awareness of stroke symptoms and the need to call 9-1-1. Together, we initiated a public education campaign, Know Stroke: Know the Signs, Act in Time, and we are striving to develop systems to make tPA available to appropriate patients. In partnership with the CDC, the NINDS extended this campaign to launch a grassroots program called Know Stroke in the Community to enlist the aid of "Stroke Champions" who educate communities about stroke signs and symptoms. A pilot phase of the program in 5 cities has just been completed. When these measures are implemented, stroke treatment will shift from supportive care to early brain-saving intervention. But more funding is needed to educate the public and health providers about stroke.

#### RESEARCH IN OTHER NIH INSTITUTES BENEFIT HEART DISEASE AND STROKE

Research seeking to prevent and find better treatments for heart disease, stroke and other cardiovascular diseases is supported by other NIH entities like the National Institute on Aging, the National Institute of Diabetes and Digestive and Kid-

ney Diseases, the National Institute of Nursing Research, the National Institute of Child Health and Human Development and the National Center for Research Resources. It is important to provide sufficient additional resources for these entities to continue and expand their critical work.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The AHRQ is a critical partner with the public and private health care sectors. They help develop evidence-based information needed by consumers, providers, health plans and policymakers to improve health care decision making. We join with the Friends of AHRQ in advocating for an appropriation of \$440 million for the AHRQ to advance health care quality, cut medical errors and expand the availability of health outcomes information.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

Prevention is the best way to protect Americans' health and ease the financial and human burden of disease. Resources must be made available to bring the benefits of research to places where heart disease and stroke strike—our towns and neighborhoods. The CDC builds a bridge between what we learn in the lab, translating findings into programs in the communities where we live. We advocate a fiscal year 2006 appropriation of \$8.7 billion for the CDC, with a 10 percent increase over current funding for state-based chronic disease prevention and health promotion programs.

Within that figure, we support an appropriation of \$55.6 million for the CDC's Heart Disease and Stroke line—which would bring per capita spending for heart disease, stroke and other cardiovascular disease prevention from 10 cents to about 12 cents. This would allow the CDC to better expand, intensify and coordinate prevention activities against these diseases, such as enhancing the State Heart Disease and Stroke Prevention Program and the Paul Coverdell National Acute Stroke Registry. It would also allow the CDC to begin the development of a state-based cardiac arrest registry, augment current health communication projects on heart attack and stroke signs and symptoms, as well as public and health care provider education; and support critical standardization of lipid and other measurements.

We commend Congress for encouraging the CDC to create a Heart Disease and Stroke Division. With ample resources and capacity, a Division would further enable CDC's efforts in this area. Thanks to this Committee's support since fiscal year 1998, the CDC's State Heart Disease and Stroke Prevention Program covers 33 states, allowing them to design and/or implement state-tailored prevention programs. But only 12 states receive funding to actually implement programs to prevent and control heart disease and stroke. The other 21 states were only provided funds to support program planning; which is now largely complete. Since cardiovascular diseases remain the No. 1 killer in every state, each state needs funding for basic implementation of a State Heart Disease and Stroke Prevention Program. With fiscal year 2005 funding, the CDC can only elevate up to two states from planning to program implementation.

An appropriation of \$55.6 million would allow the CDC to add up to 4 new states to the State Heart Disease and Stroke Prevention Program, allowing them to conduct a state-tailored prevention plan, and would elevate 4 more states to from planning to program implementation. It would enhance the Paul Coverdell National Acute Stroke Registry, which tracks and improves delivery of acute stroke care that can mean the difference between a fairly normal life and long-term disability. After developing and conducting 8 registry prototypes (fiscal year 2001–2003), the CDC funded 4 state health departments to implement registries in fiscal year 2004.

We recommend the following fiscal year 2006 funding levels for the following CDC programs:

- \$132 million for the Preventive Health and Health Services Block Grant;
- \$70 million for the Obesity, Physical Activity and Nutrition Program;
- \$50 million for the Youth Media Campaign;
- \$82.4 million for the School Health Education Program; and
- \$145 million for the Office of Smoking and Health.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION.

About 95 percent of cardiac arrest victims die before reaching a hospital. AEDs are small, easy-to-use devices that can shock a heart back into normal rhythm and restore life. The Rural Access to Emergency Devices Act and the Community Access to Emergency Defibrillation Act authorize funds for state and local governments to start AED programs. States, cities and towns nationwide eagerly await funds from these vital public health service grant awards, with available funds far below re-

quests. An appropriation of \$15 million is required to support these authorized programs.

DEPARTMENT OF EDUCATION

Physical inactivity is a key risk factor for heart disease and stroke. Yet, our youth have fewer chances for physical education. Congress has been appropriating money for the Carol M. White Physical Education Program (PEP) to provide funding for school-based physical education initiatives that teach life-long physical activity habits and thus prevent diseases, like heart disease and stroke. We advocate for an appropriation of \$100 million for PEP.

ACTION NEEDED

Despite progress, heart disease, stroke and other cardiovascular diseases remain America's No. 1 killer. Cardiovascular diseases meet the NIH's criteria for priority setting, but NIH continues to invest only 7 percent of its budget on heart research and a mere 1 percent on stroke research. Increasing funding for promising research opportunities and for proven prevention and treatment programs will allow continued strides against these diseases. Our government's response to this challenge will help define the health and well being of Americans for decades.

PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF ALLIANCE

The ANSR Alliance (Americans for Nursing Shortage Relief) appreciates the opportunity to submit written comments for the record regarding funding for nursing workforce and research programs in fiscal year 2006. ANSR is a coalition of 48 nursing organizations representing a diverse cross section of healthcare and professional organizations, healthcare providers, and friends of nursing that have united to address the ever-growing nursing shortage.

To ensure that the nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century, ANSR and the nation's 2.7 million registered and advanced practice registered nurses (RNs and APRNs) advocate at least \$210 million for the nursing workforce programs within Title VIII of the Public Health Service Act at the Health Resources and Services Administration (HRSA) as well as \$160 million for the National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH) in fiscal year 2006. ANSR stands ready to work with policymakers at the federal level to advance policies and programs that will sustain and strengthen the nation's nursing workforce.

NURSING SHORTAGE BACKGROUND

Nursing is the nation's largest healthcare provider group with an estimated 2.7 million licensed nurses. Nurses play a critical role in the health care system because they represent approximately 54 percent of all health care workers and provide patient care in virtually all locations in which health care is delivered. Our ability, as a nation to meet these projected workforce needs is complicated by a number of factors.

- The total nursing workforce is aging. By 2010, the average age of RNs is forecasted to be 45.4 years, an increase of 3.5 years over the current age, with more than 40 percent of the RN workforce expected to be older than 50 years.
- Approximately half of the RN workforce is expected to reach retirement age within the next 10 to 15 years. The average age of new RN graduates is 31 years; RNs are entering the profession older and will have fewer years to work than nurses traditionally have had.
- For the first time, registered nurses top the U.S. Bureau of Labor Statistics list of occupations with the largest projected 10-year job growth. Nurses have been on the list for some time but never as number one. The Bureau's latest projections put the demand for registered nurses at 2.9 million in 2012, up from 2.3 million in 2002.
- The national nursing shortage also is affecting our nation's 7.6 million veterans who receive care through the 1,300 Veterans Administration (VA) health care facilities.
- Nearly 1,800 faculty members leave their positions and fewer than 400 potential faculty candidates receive doctoral degrees each year.
- For the 2003–2004 academic year, an estimated 125,000 qualified applicants were turned away from nursing programs at all levels due largely to a faculty shortage.

## ADEQUATE NURSING WORKFORCE: HOMELAND SECURITY

Homeland security efforts try to prevent harm to our country, and nurses play a critical role. These efforts involve the health system, and nurses represent the largest group of health care providers who will be called on to respond to an emergency, disaster, or mass-casualty event. The estimates for the nurse workforce demand in 2010 do not take into account the healthcare system's ability to meet the healthcare needs of a surge of patients that could be expected from a mass-casualty event, whether natural or man-made. Given the findings of the bipartisan 9–11 Commission, it seems particularly relevant now to ensure an adequate supply of all levels of nurses, who are often front-line, first-responders in the case of tragedy. Unless steps are taken now, the nation's ability to respond to a natural or intentional disaster will be impeded by the growing nationwide nursing shortage. An investment in the nurse workforce is a step in the right direction to re-build the public health infrastructure and increase our nation's healthcare readiness and emergency response capabilities.

## GROWING UNMET NEED

Fortunately—after years of failing to have enough interested individuals to pursue nursing—our nation is finally seeing a slight upturn in nursing school applications. Many Americans, who have lost their jobs due to the economy, and others interested in a second career, find nursing attractive because of the job security, sufficient pay, and the opportunity it affords to help others. However, nursing organizations are hearing from prospective nursing students that they face waiting periods of up to 3 years before they can matriculate because there is not enough teaching faculty available. In many cases, students who have been accepted into programs face long waits to matriculate in nursing school due to these challenges. For example, in 2004, U.S. nursing schools turned away more than 32,000 qualified applicants to entry-level baccalaureate and graduate nursing programs due to insufficient faculty, clinical sites, classroom space, clinical preceptors, and budget constraints, including almost 3,000 students who could potentially fill faculty roles. When nursing programs of all levels are considered, the number of qualified applicants turned away during the 2003–2004 academic year grows to more than 125,000. Without sufficient support for current nursing faculty and adequate incentives to encourage more nurses to become faculty—our nation will fail to have the teaching infrastructure necessary to educate and train the next generation of nurses we need so desperately to care for our family and friends, neighbors, colleagues, and ourselves.

Enacted in 2002, the Nurse Reinvestment Act included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in fiscal year 2003, HRSA received 8,321 applications for the Nurse Education Loan Repayment Program, but only had the funds to award 7 percent (602) of all applications. Also in fiscal year 2003, HRSA received 4,512 applications for the Nursing Scholarship Program, but only had funding to support a mere 2 percent (94) of all applications.

Therefore, the ANSR Alliance strongly urges Congress to provide HRSA with a minimum of \$210 million in fiscal year 2006 to ensure that the agency has the resources necessary to fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications as well as implement other essential endeavors to sustain and boost our nation's nursing workforce.

## SUSTAIN AND SEIZE NURSING RESEARCH OPPORTUNITIES

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses such as cancer. The ANSR Alliance supports a fiscal year 2006 appropriation level of \$160 million for the NINR at the National Institutes of Health.



## CONCLUSION

The ANSR Alliance stands ready to work with policymakers to advance policies and support programs that will sustain and strengthen our nation's nursing workforce. We thank you for this opportunity to discuss the funding levels necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow.

Programmatic area	Final fiscal year 2005	President's budget fiscal year 2006	ANSR's request
Nurse Workforce Development Programs .....	\$151,889,000	\$150,000,000	\$210,000,000
National Institute of Nursing Research .....	138,000,000	139,000,000	160,000,000

ANSR Alliance Organizations that endorse this testimony: American Association of Critical-Care Nurses; American Association of Occupational Health Nurses, Inc.; American Academy of Nurse Practitioners; American College of Nurse Practitioners; American Nephrology Nurses Association; American Society of PeriAnesthesia Nurses; Association of periOperative Registered Nurses; Association of State and Territorial Directors of Nursing; Association of Women's Health, Obstetric and Neonatal Nurses; Emergency Nurses Association; Infusion Nurses Society; National Association Nurse Massage Therapists; National Association of Orthopaedic Nurses; National Association of Pediatric Nurse Practitioners; National Association of School Nurses; National Council of State Boards of Nursing; National League for Nursing; National Nursing Centers Consortium; National Student Nurses' Association; Nurses Organization of Veterans Affairs; Oncology Nurses Society; Society of Trauma Nurses; and Society of Urologic Nurses and Associates.

## PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates this opportunity to comment on fiscal year 2006 appropriations for nursing education, workforce development, and research programs. Founded in 1886, ANA is the only full-service national association representing registered nurses. Through our 54 constituent member associations, we represent registered nurses (RNs) across the nation in all practice settings.

The ANA gratefully acknowledges this Subcommittee's history of support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of quality health care services. This testimony will give you an update on the status of the nursing shortage, its impact on the nation, and the outlook for the future.

## THE NURSING SHORTAGE TODAY

The nursing shortage is far from solved. Here are a few quick facts:

- On February 11, 2004, the Bureau of Labor Statistics reported that registered nursing will have the greatest job growth of all U.S. professions in the time period spanning 2002–2012. During this 10-year period, health care facilities will need to fill more than 1.1 million RN job openings.
- The Division of Nursing at the Health Resources and Services Administration projects that, absent aggressive intervention, the supply of nurses in America will fall 29 percent below requirements by the year 2020.
- The American College of Healthcare Executives reported in October, 2004 that 72 percent of hospitals were experiencing a nursing shortage at their facility.
- According to the National Council of State Boards of Nursing, the number of first-time, U.S. educated nursing school graduates who sat for the NCLEX-RN® (the national licensure examination for registered nurses) decreased by 20 percent from 1995–2003. A total of 19,820 fewer students in this category of test takers sat for the exam in 2003 as compared with 1995.

This growing nursing shortage is having a detrimental impact on the entire health care system. Numerous recent studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study based on a review of more than 6 million patients was published in the *New England Journal of Medicine* in May, 2002. The researchers found that hospitalized patients had better outcomes when the number of hours of RN care per day increased. Specifically, nursing shortages were found to correlate with longer lengths of stay, increased incidence of urinary tract infections and upper gastrointestinal bleeding, higher rates of pneumonia, shock and cardiac arrest. Increased hours of RN care resulted in fewer "failure-to-rescue" deaths from pneumonia, shock

or cardiac arrest, upper gastrointestinal bleeding, sepsis and deep venous thrombosis.

Research published in the October 23, 2002 Journal of the American Medical Association demonstrated that more nurses at the bedside could save thousands of patient lives each year. In reviewing more than 232,000 surgical patients at 168 hospitals, researchers from the University of Pennsylvania concluded that a patient's overall risk of death rose roughly 7 percent for each additional patient above four added to a nurse's workload.

A Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) study published in 2002 shows that nearly one-quarter of all unanticipated deaths or injuries result from a lack of adequate nursing care.

#### THE IMPACT ON PREPAREDNESS AND MILITARY HEALTH CARE

This growing nursing shortage has effects well beyond domestic health care. RNs are integral in everything from adequate terrorism preparedness, to veterans' health delivery, to disaster response. In the event of a terrorist attack, nurses will be needed to evaluate patients, administer vaccines and medications, perform disease surveillance, and to train non-licensed staff. The Agency for Healthcare Research and Quality has developed a model to determine the number of health staff needed for these activities. According to this model, a small-scale anthrax attack in New York City would require 18,981 trained staff working around the clock for four days to provide needed testing and antibiotics. A contained, small-scale smallpox attack in Columbus, OH would require 2,296 patient-care staff working around the clock for 4 days. The GAO reports that five out of 7 states have claimed that nursing shortages are hindering their bioterrorism preparedness efforts.

The nursing shortage is also stressing military health care delivery. Because the military holds the vast majority of its health care assets in the reserves, the reserve activation has been particularly hard on nursing. There are currently more than 19,000 RNs providing care through the military reserves. As these nurses are drawn out of the domestic labor pool, the shortage is exacerbated.

The Army, Navy, and Air Force are offering lucrative RN recruitment packages that include large sign-on bonuses, generous scholarships, and loan forgiveness packages. Yet, for the last 2 years the Army has not met its RN recruiting goals for either the active service or the reserves. The Air Force has not met its recruiting goals for the last 5 years. Therefore, this shortage impacts our very strength as a nation.

#### NURSING WORKFORCE DEVELOPMENT PROGRAMS

Federal support for the Nursing Workforce Development Programs contained in Title VIII of the Public Health Service Act is unduplicated and essential. In 2002, the 107th Congress recognized the detrimental impact of the developing nursing shortage and passed the Nurse Reinvestment Act (Public Law 107-205). This law improved the programs of Title VIII to meet the unique characteristics of today's shortage. This significant achievement holds the promise of recruiting new nurses into the profession, promoting career advancement within nursing and improving patient care delivery. This promise will not be met, however, without a significant investment.

In fiscal year 2004 this Subcommittee allocated \$142 million in funding for Title VIII, this supported 28,253 individual student nurses. In fiscal year 2005, the hard work of this Subcommittee resulted in \$151 million in funding for Title VIII programs. ANA strongly urges you to increase funding for Title VIII programs by at least \$24 million to a total of \$175 million in fiscal year 2006. The nursing shortage and its impact on the health care of the nation demand this continued investment.

In 1974, this Subcommittee invested \$153.6 million Title VIII. Inflated to today's dollars, this long-ago appropriation would equal \$592 million, approximately four times the current appropriation. Certainly, today's shortage is more dire and systemic than that of the 1970's; it deserves an equivalent response.

Title VIII includes the following program areas:

*Nursing Education Loan Repayment Program & Scholarships.*—This line item is comprised of the Nurse Education Loan Repayment Program (NELRP) and the Nursing Scholarship Program (NSP), the Secretary of HHS has the authority to allocate funds between the two areas. The NELRP repays nursing student loans in return for at least two years of practice in a facility with a critical nursing shortage. For the first two years of service, the NELRP will repay 60 percent of the RN's student loan balance. If the nurse elects to stay for another year, an additional 25 percent of the loan will be repaid. Within 3 years, a nurse can pay off 85 percent of his/her student loans.

The NELRP boasts a proven track record of delivering nurses to facilities hardest hit by the nursing shortage. HRSA has given NELRP funding preference to RNs who work in skilled nursing facilities, disproportionate share hospitals, and departments of public health. However, lack of funding has hindered the full implementation of this program. In fiscal year 2004, HRSA received more than 4,800 applications for the NELRP. Due to lack of funding, only 857 loan repayments were awarded. Therefore, 82 percent of the nurses willing to immediately begin practicing in facilities hardest hit by the shortage were turned away from this program.

The nursing scholarship program offers funds to nursing students who, upon graduation, agree to work for at least two years in a health care facility with a critical shortage of nurses. Preference is given to students with the greatest financial need. Like the loan repayment program, the nursing scholarship program has been stunted by a lack of funding. In fiscal year 2004, HRSA received more than 8,800 applications for the nursing scholarship. Due to lack of funding, a mere 126 scholarships were awarded. Therefore, 98 percent of the nursing students willing to work in facilities with a critical shortage of nurses were denied access to this program.

*Nurse Faculty Loan Program.*—This program establishes a loan repayment fund within schools of nursing to increase the number of qualified nurse faculty. Nurses may pursue a master's or doctoral degree. They must agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a 4-year period. Loans can cover the costs of tuition, fees, books, laboratory expenses, and other reasonable education expenses.

This program is vital given the critical shortage of nursing faculty. America's schools of nursing can not increase their capacity without an influx of new teaching staff. Last year, schools of nursing were forced to turn away tens of thousands of qualified applicants due largely to the lack of faculty. In fiscal year 2004, HRSA awarded 61 nurse faculty loan repayments.

*Nurse Education, Practice, and Retention Grants.*—This section contains grant areas designed to expand enrollments in baccalaureate nursing programs; develop internship and residency programs to enhance mentoring and specialty training, and; provide new technologies in education including distance learning. Practice grant areas are designed to expand practice arrangements in non-institutional settings to improve primary health care in medically underserved communities; provide care for underserved populations; provide skills necessary to practice in existing and emerging health systems, and; develop cultural competencies. Retention grant areas include career ladders and improved patient care delivery systems. The career ladders program supports education programs that assist individuals in obtaining the educational foundation required to enter the profession, and to promote career advancement within nursing.

Enhancing patient care delivery system grants are designed to improve the nursing work environment. It provides grants to facilities to enhance collaboration and communication among nurses and other health care professionals, and to promote nurse involvement in the organizational and clinical decision-making processes of a health care facility. These best practices for nurse administration have been identified by the American Nurse Credentialing Center's Magnet Recognition Program. These practices have been shown to double nurse retention rates, increase nurse satisfaction, and improve patient care.

*Nursing Workforce Diversity.*—This program provides funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities, as well as individuals who are economically disadvantaged. Racial and ethnic minorities currently comprise more than 25 percent of the nation's population and will comprise nearly 40 percent by the year 2020. Only 12 percent of the RNs in the United States come from diverse backgrounds. Increasing the number of RNs from diverse races helps to address the prevention, treatment, and rehabilitation needs of an increasingly diverse population. For fiscal year 2004, HRSA received 144 submissions for nursing workforce diversity grants. HRSA was only able to fund 20 (14 percent of applications).

*Advanced Nurse Education.*—Advanced practice registered nurses (APRNs) are RNs who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Most have practice experience as RNs prior to entering graduate school. Practice areas include, but are not limited to: anesthesiology, family medicine, gerontology, pediatrics, mental health, midwifery, neonatology, and women's & adult health. Title VIII grants have supported the development of virtually all initial state and regional outreach models using distance learning methodologies to provide advanced study opportunities for nurses in rural and remote areas.

These grants also provide traineeships for masters and doctoral students. Title VIII funds more than 60 percent of U.S. nurse practitioner education programs and assists 83 percent of nurse midwifery programs. Over 45 percent of advanced nursing graduates go on to practice in medically underserved communities, and in areas with large Medicaid populations. Many provide care to minority or disadvantaged patients. In fiscal year 2004, HRSA funded 82 advanced education nursing grants (78 percent of applications), 335 advanced education nursing traineeships (every application), and 73 nurse anesthetist traineeships (every application).

*Comprehensive Geriatric Education Grants.*—This authority awards grants to train and educate nurses in providing health care to the elderly. Funds are used to train individuals who provide direct care for the elderly, to develop and disseminate geriatric nursing curriculum, to train faculty members in geriatrics, and to provide continuing education to nurses who provide geriatric care. The growing number of elderly Americans and the impending health care needs of the baby boom generation make this program critically important. In fiscal year 2004, HRSA continued 17 previously awarded grants.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

ANA also urges the Subcommittee to increase funding for the NINR, one of the institutes at the National Institutes of Health (NIH). Nursing research is an integral part of the effectiveness of nursing care. 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. Research programs supported by 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.

Recent studies have revealed the difference in heart attack symptoms in women versus men, the most effective means to prevent infectious diseases in inner city households, the incidence and risk factors for uterine rupture in pregnancies following cesarean section, and the means to help family caregivers provide high-quality long, term care for loved ones with chronic health care needs. NINR is leading the NIH research on end-of-life and palliative care. NINR is the lowest funded institute at NIH. ANA recommends \$160 million in fiscal year 2006 funding for the NINR.

#### CONCLUSION

While we appreciate the continued support of this Subcommittee, ANA is concerned by the fact that Title VIII funding levels have not been sufficient to assist qualified students enter the nursing profession. The nursing shortage will continue to worsen if significant investments are not made in nursing workforce development programs. Recent efforts have shown that aggressive and innovative recruitment efforts can help avert the impending nursing shortage—if they are adequately funded.

ANA asks you to meet today's shortage with a relatively modest investment of \$175 million in Title VIII programs. Additionally, an investment of \$160 million in the NINR will help assure that these nurses are equipped with the information needed to provide the best care possible.

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#### PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION (APHA)

The American Public Health Association (APHA), the oldest organization of public health professionals, represents more than 50,000 members from over 50 public health occupations. We are pleased to submit our views on federal funding for public health activities in fiscal year 2006.

#### RECOMMENDATIONS FOR FUNDING THE PUBLIC HEALTH SERVICE

APHA's budget recommendation concurs with the estimate developed by the Coalition for Health Funding: we believe the Public Health Service needs an increase of \$3.5 billion in fiscal year 2006. This figure is based on the professional estimate of need and opportunity within each agency of the Public Health Service and would accommodate needed increases for the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institutes of Health (NIH), as well as agencies outside this subcommittee's jurisdiction—the Food and Drug Administration (FDA) and the Indian Health Service (IHS).

## CENTERS FOR DISEASE CONTROL AND PREVENTION

APHA supports a funding level for the Centers for Disease Control and Prevention that enables it to carry out its mission to protect and promote good health and to assure that research findings are translated into effective state and local programs. It is time to support CDC as an agency—not just the individual programs that it funds. In the best professional judgment of the American Public Health Association, in conjunction with the CDC Coalition—given the challenges of terrorism and disaster preparedness, new and re-emerging infectious diseases, the epidemic of obesity, particularly among children, and our many unmet public health needs and missed prevention opportunities—the agency will require funding of at least \$8.65 billion to support its mission for fiscal year 2006.

APHA is pleased with the support the Subcommittee has given to CDC programs over the years, including your recognition of the need to fund Severe Acute Respiratory Syndrome (SARS) response efforts, obesity prevention, chronic disease prevention, and solutions to the shortage of the flu vaccine. By translating research findings into effective intervention efforts in the field, the agency has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From anthrax to West Nile to smallpox to avian flu, the Centers for Disease Control and Prevention is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

In fiscal year 2002, Congress appropriated \$7.7 billion for CDC. In fiscal years 2003, 2004 and 2005, Congress appropriated \$7.1 billion, \$7.2 billion, and \$8.0 billion, respectively. Now the President's proposed budget for the agency in fiscal year 2006 is \$7.5 billion—a \$500 million cut from last year's funding, and \$200 million below the fiscal year 2002 funding level. We are moving in the wrong direction. Public health is being asked to do more, not less. As far as we can tell, in light of the current workload placed on the public health service—in addition to the threat of emerging diseases such as the avian flu—it simply does not make any sense to cut the budget for CDC at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability.

Furthermore, the President's budget proposes the elimination of two very important chronic disease prevention programs: the Preventive Health and Health Services Block Grant and the Childhood Obesity Prevention Program (COPP), also referred to as the VERB or CDC Youth Media campaign. As states use their Prevention Block Grant dollars to address high priority needs such as emerging and chronic diseases, child safety seat programs, suicide prevention, smoke detector distribution and fire safety programs, adult immunization, oral health, worksite wellness, infectious disease outbreaks, food safety, emergency medical services, safe drinking water, and surveillance needs—we can scarcely understand why the Prevention Block Grant should be eliminated. And the success of the COPP program shows that over 30 percent of the target audience, children ages 9 to 10 years, increased their physical activity as a direct result of the VERB media campaign. This type of success warrants continued funding of a program to empower our children to respond to the growing concerns of the obesity epidemic and improve the health of this nation. We encourage the Subcommittee to restore the cuts and fund the Prevention Block Grant at \$132 million and the COPP program at \$70 million.

Until we are committed to a strong public health system, every crisis will force trade offs. For instance, the Administration's recent reprogramming request to make up for the vaccine shortage with money originally appropriated by Congress for chronic disease prevention programs (COPP and the Preventive Health and Health Services Block Grant) and bioterror preparedness funds is the most recent concrete example of attention to one disease coming at the expense of another.

We also encourage the Subcommittee to provide \$10 million for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. As with the public health workforce, the environmental health workforce is declining. Furthermore, the agencies that carry out these services are fragmented and their resources are stretched. These services are the backbone of public health and are essential to protecting and ensur-

ing the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA programs assure that all Americans have access to our nation's best available health care services. HRSA provides a health safety net for medically underserved individuals and families, including 45 million Americans who lack health insurance; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 850,000 to 950,000 people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in erasing our nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where the need exists, in communities all over America. The agency's overriding goal is to achieve 100 percent access to healthcare, with zero disparities. In the best professional judgment of APHA, in conjunction with the Friends of HRSA Coalition, to respond to this challenge, the agency will require a funding level of at least \$7.5 billion for fiscal year 2005.

We are grateful to the Subcommittee for your consistent strong support for all of HRSA's programs, including the initiatives in terrorism preparedness and response in the past. Unfortunately, the president's budget overall recommends a massive \$838 million or over 12 percent cut to the agency for fiscal year 2006. We urge the members of the Subcommittee to restore the cuts and fund the agency at a level that allows HRSA to effectively implement these important programs.

APHA is pleased that the Administration has requested a significant 17.5 percent increase for Community Health Centers. More than 4,000 of these sites across the nation provide needed primary and preventive care to nearly 15 million poor and near-poor Americans. Health centers provide access to high-quality, family-oriented, culturally and linguistically competent primary care and preventive services, including mental and behavioral health, dental and support services. Nearly three-fourths of health center patients are uninsured or on Medicaid, approximately two-thirds are people of color, and more than 85 percent live below 200 percent of the poverty level.

However, we are once again very concerned that the HRSA health professions programs under Title VII and VIII have once again landed on the chopping block. 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. An adequate, diverse, well-distributed and culturally competent health workforce is indispensable to our national readiness efforts and to address critical health care needs. These programs help meet the health care delivery needs of the areas in this country with severe health professions shortages, at times serving as the only source of health care in many rural and disadvantaged communities. Therefore, the elimination of most funding for the Title VII health professions training programs and flat funding for Title VIII nurse training will only make certain that the needs of these medically underserved populations will not be met.

Furthermore, we believe the elimination of the Healthy Community Access Program, universal newborn hearing screening programs, and the Emergency Medical Services for Children Program, especially when coupled with the flat-funding of the Maternal and Child Health Block Grant, will further undermine the availability of health services for some that are most in need—especially children. The Healthy Community Access Program is an example in which communities build partnerships among health care providers to deliver a broader range of health services to their neediest residents. This program of coordinated service delivery is innovative, not duplicative of other available programs, and therefore its elimination is of grave concern. Also, the proposed zero funding of universal newborn hearing screening programs in the Administration's budget will likely cause many hearing impairments in infants to go undetected, which can negatively impact speech and language acquisition, academic achievement, and social and emotional development. The proposed elimination of the Emergency Medical Services for Children Program will hurt many children who are eligible for Medicaid and SCHIP, but not enrolled due to state enrollment limits and budgetary pressures, and therefore frequently use emergency health services.

We are very concerned that most programs under the Ryan White CARE Act, administered by HRSA's HIV/AIDS Bureau, would be flat-funded should the figures requested by the Administration be implemented. The CARE Act program is an important safety net program, providing an estimated 533,000 people access to services and treatments each year. At a time when HIV/AIDS is the fifth leading cause of death for people who are 25 to 44 years old in the United States, and the number

of new domestic HIV/AIDS cases is increasing, not decreasing, flat funding these critical Ryan White Act programs does not make much sense.

Through its many programs and new initiatives, HRSA helps countless individuals live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled change in the nation's health care delivery system. HRSA is well positioned to meet these new challenges as it continues to provide first-rate health care to the nation's most vulnerable citizens. We recommend growth in HRSA's budget to meet the needs of vulnerable populations served by the agency.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

We request a funding level of \$443 million for the Agency for Healthcare Research and Quality for fiscal year 2006, an increase of \$124 million over last year. This level of funding is needed for the agency to fully carry out its Congressional mandate to improve health care quality, including eliminating racial and ethnic disparities in health, reducing medical errors, and improving access and quality of care for children and persons with disabilities. The cuts proposed in the administration budget will severely hamper these efforts.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

APHA supports a funding level of \$3.5 billion for the Substance Abuse and Mental Health Services Administration for fiscal year 2006, an increase of \$262 million over last year. This funding level would provide support for substance abuse prevention and treatment programs, as well as continued efforts to address emerging substance abuse problems in adolescents, the nexus of substance abuse and mental health, and other serious threats to the mental health of Americans.

#### DEPARTMENT OF HEALTH AND HUMAN SERVICES

The budget of the Office of Minority Health has been decreased in the last several years. In fiscal year 2004, OMH received \$55 million; in fiscal year 2005, OMH received \$50 million; and the proposed budget in fiscal year 2006 is \$47 million. APHA is concerned that at a time when we have increasing evidence of disparities in health care delivery, access and health outcomes, the budget of OMH is getting cut. We support restoring OMH funding to the fiscal year 2004 level.

#### CONCLUSION

In closing, we emphasize that the public health system requires financial investments at every stage. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes, and other interventions that are effective and available for everyone. While we have said this before, in the post-September 11th era, we need to apply this to our spending growth in terrorism preparedness as well. We must think in a broad and balanced way, leveraging homeland security programs and funding whenever possible to provide public health benefits as a matter of routine, rather than emergency.

We thank the subcommittee for the opportunity to present our views on the fiscal year 2006 appropriations for public health service programs.

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#### PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

Mr. Chairman and members of the subcommittee, I am pleased to submit testimony on behalf of the Association of Maternal and Child Health Programs (AMCHP) regarding the critical need for funding of the Title V Maternal and Child Health Services Block Grant in fiscal year 2006. As AMCHP's President and the director of Iowa's Child Health Specialty Clinics program, which uses MCH block grant funds to serve Iowa's children and their families, I know these funds make a difference. Because of the MCH Block Grant, states are able to fund a variety of activities to improve the health of your constituents. I urge you to provide \$755 million for the MCH Block Grant this year.

AMCHP is a national non-profit organization representing the leaders of state public health programs for maternal and child health, and children with special health care needs in all 50 states, the District of Columbia, and eight additional jurisdictions. Every state health department receives Title V Maternal and Child Health Services Block Grant funds to improve the health of all mothers and children.

This modest increase to \$755 million (3 percent) is necessary to help states maintain current levels of service. Between 1999 and 2003, the number of women and children served by this program increased by almost 4 million (16 percent). Federal funding has declined since 2003. The President's request of \$723.9 million for fiscal year 2006 would be the fourth straight year of level or reduced funding. States are being called to do more with less and state MCH programs have done their best to make sure that the women and children we served are not adversely affected. However, maternal and child health programs in every state have reached a breaking point, with many states experiencing reductions in both state and federal funding; without additional funds, more severe cuts may have to be made.

I also urge you to reject the Administration's proposal to eliminate funding for HRSA's Emergency Medical Services for Children program, Universal Newborn Hearing Screening program, trauma program and CDC's preventive health and health services block grant. The budget request argues that states will be able to use their MCH Block Grant funds to support some of these activities. States already work with these programs to avoid duplication and to ensure that each federal dollar, whether obtained through the block grant or not, goes further. The reality is that states have less federal and state funds available for maternal and child health programs and would not be able to support the current activities without cutting funds for other health priorities. Eliminating Newborn Hearing Screening grants will force states to cut other worthy MCH programs in order to continue hearing screening or to scale back or not conduct newborn hearing screening activities. According to a recent report, thanks to the HRSA funding, over 86 percent of infants born in hospitals nationwide are screened for hearing loss, up from 25 percent in 1999. Additionally, continued funding (\$5 million) within the Special Projects of Regional and National Significance (SPRANS) set-aside for MCH oral health activities is critical. Most state dental programs for children are part of the state's maternal and child health program and are supported through the Maternal and Child Health block grant and support ongoing leadership to states to address long-term oral health problems.

The Title V Maternal and Child Health Block Grant is one of the nation's oldest health programs and plays a pivotal part in states' current maternal and child health policy. The authorization of funding for the Maternal and Child Health Block Grant goes back to the Social Security Act of 1935. The legislation represented one of the very first state "grant-in-aid" programs, allocating federal revenues to states that agreed to meet the program's basic conditions of participation, which revolved around two main goals. The first was to help states lessen the negative social and public health impact of the Great Depression through promotion of maternal and child health services and the development of a basic preventive and primary health care infrastructure for women and children. The second, and one directly tied to the terrible epidemic of polio, was to assist states through grants to develop services for "crippled children."

Today, Maternal and child health programs have expanded their roles and lead state efforts to increase immunization and newborn screening rates, reduce infant mortality, prevent childhood accidents and injuries, and reduce adolescent pregnancy. Each year, more than 27 million women, infants, children and adolescents, including those with special health care needs, are served by MCH Block Grant funds. Half of the 4 million women who give birth annually receive health services made possible by the MCH Block Grant.

While the block grant now represents a much smaller funding stream for states, it still remains one of the few resources that gives states' the ability to provide numerous services to meet needs identified by the states, to millions of women, children, and their families annually. And in every state, the MCH Block Grant still provides a health safety net for low-income women and children, by being a payor of last resort for needed medical services when other sources of payment (either public or private) are not available.

#### WHO DO WE SERVE? WHAT DOES THE TYPICAL TITLE V CLIENT LOOK LIKE?

Every year, over 4 million babies are born in this country. Many of them are healthy and families leave the hospital confident of a better future. I can discuss the many ways that MCH Block Grant dollars and state programs help in producing those healthy outcomes. However, I want to focus on the case of those families with children who may have special health care needs present at birth or shortly afterwards. Like the parent from Massachusetts with a son who was eventually diagnosed with congenital heart disease, abnormal heart rhythms, and is now pacemaker dependent. Immediately after birth, the parent made countless visits to the pediatrician sensing that something seemed wrong with her son, but she didn't



know what. He was jaundiced for weeks after he was born and didn't gain weight, as he should. Even on formula, her son still did not gain weight. In a span of two calendar years, her son was hospitalized for 134 consecutive days. For all the "I feel for you" visits she had from hospital social workers, no one ever told her son was eligible for SSI after the first 30 consecutive calendar days as an inpatient, or that her family could apply for Massachusetts Medicaid buy-in option to offset their exorbitant out-of-pocket costs for the healthcare services her son was receiving. This parent, like many others, continued to have great difficulty in coordinating health care services. She had to make thousands of phone calls to state agencies and search the Internet, plead with her insurance company to pay for things, call state agencies, surf the Internet late into the night looking for support services, for other parents, or for anything that would help.

Another family in Pennsylvania juggle 11 doctors who treat their son with special health care needs and who constantly struggle to navigate the health care system for as many options that are available to improve the quality of life for their son. These are just a few examples of what is unfortunately a very common occurrence throughout the country.

MCH Block Grant funds help assure that every state has the ability to connect families like the one described above to services and when those services are not otherwise available, to pay for that care. In Missouri, a child was born with an infection similar to a form of meningitis and was in the NICU for the first 8 weeks of his life. Within a day after mother and child went home, a nurse from the Bureau of Special Health Care Needs contacted the family. The support from the state's children with special health care needs program did not stop but continued and even now 16 years later, is available when the family needs it. Anything from adaptive equipment, to personal care attendant services have been provided when necessary.

State Maternal and Child Health Programs play a primary role in assuring health care for children with special health care needs and their families. The services that each state provides may vary but by law, 30 percent of each state's Maternal and Child Health Block Grant allocation must be used to provide services for these kids. Why? Because the experiences for families that I outlined above have occurred too often. Since 1935, Congress has provided funding to states to make sure that we put an end to stories like these. A recent national survey by the Maternal and Child Health Programs estimated 13 percent of children in the United States have a special health care need. Maternal and Child Health Block Grant funded programs are reaching slightly over 1 million but more can be done with increased funding for this important program.

In Iowa, Child Health Specialty Clinics is the designated Title V Children with Special Health Care Needs program. We operate a statewide program that works with families, service providers and communities to provide subspecialty health care and support to children, from birth through age 21, who have a chronic condition (physical, developmental, behavioral or emotional) or who have an increased risk of a chronic condition and need special services. Like similar programs in all states, the program is primarily funded through the Maternal and Child Health Block Grant. Each specialty clinic center can offer from one to four evaluation and planning clinics per month. These clinics are staffed by community pediatricians, nurses, and nutritionists and serve mostly children with behavioral and developmental problems. Clinics serve children with chronic health problems like heart disease, diabetes, sickle cell disease, and bone and joint disease. Fees for the clinics are based on a sliding scale that accounts for family size and income.

Besides the clinics, Iowa uses MCH block grant funds to provide other services for children and their families including making sure family support is available and organizing care plans for children. Through a statewide parent-to-parent network, we provide one-on-one emotional support, problem-solving assistance and help with understanding health insurance to families. The network connects parents new to the program with parents who have already been through many of the same experiences. When one child can have as many as 11 doctors, the burden on families to navigate the health care maze can be crushing. Another way we help is helping families navigate the health care system. Some children with complicated health problems require different services from varied agencies and we help coordinate needed care with local agencies within the family's community. These are provided as free services to families.

Child Health Specialty Clinics serve approximately 9,000 children yearly, including 800 infants and 1,500 preschoolers, including making phone, mail and face-to-face contacts with families and health care providers. A few years ago I had 14 of these centers throughout Iowa. Today, we have 13 centers and in most other locations are now open only four days a week. Funding reductions at the state and fed-

eral level mean less clinics, families have to travel farther, and no ability to address emerging needs such as care for children with special emotional and behavioral health needs, one of the largest needs that we are currently seeing in the state.

#### STATE BUDGET CUTS

More MCH Block Grant funds are needed. Below are specific examples of reductions in services that states have made due to declining federal and state funding for maternal and child health.

#### IOWA

Because of decreased state and federal funding along with increases in personnel costs (inflation), Iowa closed pediatric mobile clinics, eliminated nutrition services for children, closed the Waterloo center and reduced services at other centers. Without increased funding, we are looking at:

- Closing centers in Burlington, Council Bluffs, Sioux City
- Consolidating the Dubuque and Davenport with other centers
- Increased waiting time up to 12 months for families and their kids to get the services they need
- Ending behavioral pilot programs, a medical home project and other activities to make sure these children and their families get the right services when they need them.

#### OHIO

Ohio received one of the steepest cuts in federal MCH block grant funding, losing \$1.5 million (or 6 percent) between fiscal year 2003 and fiscal year 2004. Combined with a \$7.5 million decline in the state funds available to support MCH, the ability for the program to maintain services to the 266,000 women, infants, and children who received services in 2002 has been severely compromised. Ohio's Children with Special Health Care Needs (CSHCN) program, because of both state cuts and cuts in the Ohio MCH Block Grant, has had to decrease the number of diagnoses covered by the CSHCN Treatment Program and to change the eligibility rules to reduce the services provided. Three diagnosed conditions were eliminated from coverage, affecting almost 600 children.

Other changes may affect up to 5,000 children who rely on the program. Co-payments are increased for families. Raising co-payments can significantly impact the financial and physical health of these families and their children if they are unable to pay them. These families turn to Title V when insurance (either private or public) cannot provide the services. The Ohio Specialty Field Clinic Program received a 20 percent decrease in MCH block grant and other funding support. The Specialty Clinic Program provides access to pediatric specialists for children in Ohio. The number of clinics will be cut, all in rural Ohio where the greatest need for services exists. This will affect the access to care for 300 children in Ohio's rural areas. Cardiac Specialty Clinics will be closed as of July 1, 2004. Funding reductions also slow the ability to respond to emerging issues, such as an increase in Ohio's infant mortality rate, which rose from 7.5 per 1,000 births in 2000 to 7.9 in 2002.

#### TEXAS

Texas received a reduction of \$753,000 (3 percent) in federal MCH funds. That reduction along with a reduction in state funds for MCH in 2004–2005 will drastically increase the unmet needs of the MCH population in Texas. Currently, the MCH program addresses less than 10 percent of the MCH population-in-need. For example, Title V MCH fiscal year 2004 contracts for services (i.e., initiatives directed toward teen pregnancy, childhood obesity, immunization, etc) decreased by 33 percent and by 13 percent for direct services (prenatal care, child well-check visits, dental, family planning, etc.). In 2001, the Texas Children with Special Health Care Needs program instituted a waiting list that has grown to 1,200 families and is expected to continue to increase.

#### CONCLUSION

Since its creation, the Title V Maternal and Child Health Block Grant has grown from a \$2.7 million program in fiscal year 1936 to a \$723.9 million program in fiscal year 2005, and despite its relatively modest size, it has been revisited by Congress repeatedly over the years as new maternal and child health related concerns become evident. Even with the enactment of Medicaid in 1965, the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program in 1967 (which simultaneously amended Medicaid and Title V to increase support for primary care) and

SCHIP in 1997, Title V continues as a source of flexible funding that allows states to invest in the child health “infrastructure” for both basic and specialty care. Increased funding is crucial to helping state MCH programs navigate the changing maternal and child health world. Please provide \$755 million for the Maternal and Child Health Block Grant in fiscal year 2006. Again, thank you for this opportunity to testify.

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PREPARED STATEMENT OF THE ASSOCIATION OF WOMEN’S HEALTH, OBSTETRIC AND NEONATAL NURSES

The Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to comment on the fiscal year 2006 appropriations for nursing education, research, and workforce programs as well as programs designed to improve maternal and child health. AWHONN is a membership organization of 22,000 nurses whose mission is to promote the health of women and newborns. AWHONN members are registered nurses, nurse practitioners, certified nurse-midwives, and clinical nurse specialists who work in hospitals, physicians’ offices, universities, and community clinics across North America as well as in the Armed Forces around the world.

AWHONN appreciates the support that this Subcommittee has provided for nursing education, research and workforce programs as well as maternal and child health programs in the past. We realize that there are many competing priorities for the Subcommittee members, and we appreciate your consistent support.

GROWING NURSING SHORTAGE

AWHONN supports the advancement of quality care through an adequate nurse workforce. Data from the Bureau of Health Professions, Division of Nursing’s National Sample Survey of Registered Nurses—February 2002, confirm that of the approximately 2.7 million registered nurses in the nation, only about 82 percent of these nurses were working full-time or part-time in nursing. In addition to the shrinking pipeline of nurses coming into the program, the dominant factor in this shortage is the impending retirement of up to 40 percent of the workforce by 2010 or soon thereafter. This will occur at the same time that the needs of the aging baby boomer population will markedly increase demand for health care services and the services of registered nurses.

This critical demand is reinforced by the fact that in February 2004, the U.S. Bureau of Labor released statistics detailing how registered nurses have the largest projected 10-year job growth in the United States, with about 1 million new job openings by 2010. In addition to the care provider shortage, nursing faculties are also decreasing in number, requiring universities to decline acceptance to qualified nursing school applicants. The Southern Regional Education Board states that with faculty vacancies and newly budgeted positions, there has been a 12 percent shortfall in the number of nurse educators needed to train nursing applicants. The entire nursing workforce needs strengthening. As a result, it will take long-term planning and innovative initiatives at the local, state and federal level to assure an adequate supply of a qualified nurse workforce for the nation.

NURSE WORKFORCE DEVELOPMENT PROGRAMS

*AWHONN recommends a total of \$210 million for fiscal year 2006 to fund the Nurse Workforce Development programs in Title VIII*

The Nurse Education Act (Public Health Service Act, Title VIII), enacted in 1964, represents the only comprehensive federal legislation to provide funds for nursing education. The programs authorized in this portion of Public Law 105–392 help schools of nursing and nursing students prepare to meet patient needs in a changing health care delivery system, favoring programs in institutions that train nurses for practice in medically underserved communities and Health Professional Shortage Areas.

Reauthorized as the Nursing Workforce Development section in 1998, the new NEA gives the Department of Health and Human Services more discretion over the focus of federal spending. In 2002, Congress enacted the Nurse Reinvestment Act, which provides funding for new and expanded programs. These programs include scholarships, career ladders, internships and residencies, retention programs, and faculty loans designed to encourage students to consider nursing, keep nurses in the field, and ensure that nurse educators are plentiful enough to educate future nurses that we desperately need. The new programs received an initial appropriation of \$20 million in fiscal year 2003, which was in addition to \$93 million in funding provided

for existing Title VIII programming. Unfortunately, due to limited funding in the first 2 years of the new authorization, the loan and scholarship programs have not been successful in providing support to students in nursing schools. In the first year, only 574 loan repayment contracts were made nationally, averaging roughly 11 loan repayment agreements per state, and less than 2 percent of all scholarship applicants were funded.

The shortage of registered nurses and the effect of the shortage on nurse staffing and patient safety demand a significant increase in funding for these programs. Nursing is the largest health profession with over 2.7 million nurses, yet only one-fifth of 1 percent of federal health funding is directed to nursing education. A significant increase in funding for these programs would lay the groundwork to expand the nursing workforce, through education and clinical training and retention programs, in order to address some of the serious shortage issues.

The nursing shortage is not confined solely to care providers; there is also a growing, significant shortage of nurse faculty. The American Association of Colleges of Nursing (AACN) reports that the average age of nursing professors is 52, and for associate professors the average age is 55. The impending retirement of these seasoned educators will impact the ability of our schools and universities to meet the educational health care needs of the nation. According to AACN, U.S. nursing schools turned away almost 16,000 qualified applicants to baccalaureate nursing programs in 2003 due to insufficient faculty, clinical sites, classroom space, and budget constraints. Additionally, 125,000 qualified applicants were turned away from nursing programs at all levels across the United States in 2004 according to the National League for Nursing.

While the capacity to implement faculty development is currently available through Section 811 and Section 831, adequate funding and direction is needed to ensure that these programs are fully operational. Options to provide support for full-time doctoral study are essential to rapidly prepare the nurse educators of the future. AWHONN recommends that a portion of the funds be allocated for faculty development and mentoring.

Further, AWHONN recognizes the importance of appropriate investments in advanced practice nursing programs. As in other professions the advanced degree has become a necessary achievement for career advancement, and registered nurses who pursue the MSN degree are a part of the cadre of nurses who go on to become faculty. Our nation needs more nurses with basic training to enter the field, but focusing only on these nurses addresses just half of the problem. The nursing shortage encompasses nursing faculty; both advanced practice nursing and basic nursing must receive additional funding but not one at the expense of the other.

#### MATERNAL AND CHILD HEALTH BUREAU

*AWHONN recommends \$850 million in funding in fiscal year 2006 for the Maternal and Child Health Bureau*

This program provides comprehensive, preventive care for mothers and young children, as well as an array of coordinated services for children with special needs. In fact, the Maternal Child Health Block Grant (MCH) serves over 80 percent of all infants in the United States, half of all pregnant women, and 20 percent of all children.

MCH programs are facing increased demands for services due to continued growth in the Children's Health Insurance Program, which in turn identifies more children who are eligible for other MCH Services. Title V complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and enhanced access to care in underserved areas. Additional funding would give states the resources they need to expand prenatal and infancy home visitation programs, an approach that has been shown, in NINR research, to improve the prenatal health-related behavior of women and reduce rates of child abuse and neglect as well as maternal welfare dependence.

#### INDIAN HEALTH SERVICE

*AWHONN recommends an fiscal year 2006 appropriation of \$5.54 billion for IHS*

The Indian Health Service (IHS) is the principal federal health care provider and health advocate for Indian people with the goal of "ensur[ing] that comprehensive, culturally acceptable personal and public health services are available and accessible to all American Indian and Alaska Native people." IHS is tasked with an enormous responsibility in providing care to over half of the American Indian population.

The American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. Lower life expectancy and the

disproportionate disease burden exist perhaps because of inadequate education, poverty, discrimination in the delivery of health services, and cultural differences. These are broad quality of life issues rooted in economic adversity and poor social conditions.

A recent study of federal health care spending per capita found that the United States spends \$3,803 per year per federal prisoner, while spending about half that amount for a Native American: \$1,914. Per capita health care spending for the U.S. general population is \$5,065 per year. A significant increase in funding over fiscal year 2005 spending levels is necessary for the federal government to fulfill its responsibility to Indian Country and achieve its stated goals.

While the nursing shortage continues nationwide, IHS has been disproportionately affected by the lack of RNs. IHS nurses are older, with an average age of 48, and nearly 80 percent of RNs are over the age of 40. Further, the average vacancy rate for RNs is 14 percent. IHS administers three interrelated scholarship programs designed to meet the health professional staffing needs of IHS and other health programs serving Indian people. These programs are severely under-funded. Targeted resources need to be invested in the IHS health professions programs in order to recruit and retain registered nurses in Indian Country.

Additionally, Section 112 of the Indian Health Care Improvement Act, Public Law 94-437, authorizes grants to public or private schools of nursing, tribally-controlled community colleges and tribally-controlled post secondary vocational institutions for the purpose of recruiting, training and increasing the number of professional nurses who deliver health care services to Indian people. On average, Section 112 programs provide five undergraduate scholarships per year and two master's program scholarships. This important program should be expanded to provide many more scholarships, both at the undergraduate and graduate levels, in an effort to offer meaningful relief to the nursing shortage for IHS healthcare providers and the patients they serve.

#### NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

*AWHONN recommends an increase of \$22 million over fiscal year 2005 funding levels for the NINR, resulting in an fiscal year 2006 appropriation of \$160 million*

NINR engages in significant research affecting areas such as health disparities in ethnic groups, training opportunities for management of patient care and recovery, and telehealth interventions in rural/underserved populations. This research allows us to refine the practice and provide quality patient care in its current challenging environment.

NINR research contributes to or results in improved health outcomes for women. Recent public awareness campaigns target differences in the manifestation of cardiovascular disease between men and women. The differing symptoms are the source of many missed diagnostic opportunities among women suffering from the disease, which is the primary killer of American women. In a study funded by NINR, researchers were able to qualitatively analyze the intensity of pain and limitation of activity experienced by women suffering from angina, both of which were found to be of greater intensity than that experienced by men. The study concluded that the gender variation could significantly impact diagnosis and treatment of female patients suffering from related cardiovascular problems.

Because of the emphasis on biomedical research in this country, there are few sources of funds for high-quality behavioral research for nursing other than NINR. It is critical that we increase funding in this area in an effort to optimize patient outcomes and decrease the need for extended hospitalization.

#### NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

*AWHONN supports an increase in funding for NICHD for fiscal year 2006, bringing the appropriation to \$1.35 billion*

NICHD seeks to ensure that every baby is born healthy, that women suffer no adverse consequences from pregnancy, and that all children have the opportunity for a healthy and productive life unhampered by disease or disability. With increased funding, NICHD could expand its use of the NICHD Maternal-Fetal Medicine Network to study ways to reduce the incidence of low birth weight. Prematurity/low birthweight is the second leading cause of infant mortality in the United States and the leading cause of death among African American infants. AWHONN, like many organizations directly involved in programs to improve the health of women and newborns, looks to NICHD to provide national initiatives, such as the Maternal-Fetal Medicine Network that assists with the care of pregnant women and babies.

Recently NICHD released research indicating they may have found a test to predict preeclampsia in patients before the life-threatening complication, affecting five percent of all pregnancies, occurs. Abnormal levels of placental growth factor (PlGF) were found in the urine of pregnant women who later developed preeclampsia. Once NICHD screens for women who are high risk for developing preeclampsia, this group can be studied to prevent or cure this complication. This finding is a promising lead in the effort to prevent and cure preeclampsia.

NATIONAL INSTITUTES OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS)

*AWHONN supports an increase in funding for NIEHS for fiscal year 2006, bringing the appropriation to \$680 million*

Research conducted by the NIEHS plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Our expanded knowledge, as a result, allows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

One impressive collaborative research project spearheaded by the NIEHS is the recent partnering of public and private funding agencies that will examine how better community design encourages people to be more physically active in their daily lives. Researchers will identify how our built environment contributes to obesity and how environmental changes can combat a growing public health problem. The NIEHS will examine the program's impact on physical activity, obesity, and other health indicators.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

*AWHONN recommends an fiscal year 2006 appropriation of \$8.65 billion for the CDC*

For nearly 60 years, the Centers for Disease Control and Prevention (CDC) has evolved to assume responsibility for programs in infectious disease surveillance, control and prevention, injury control, health in the workplace, prevention of heart disease, cancer, stroke, obesity and other chronic diseases, improvements in nutrition and immunization, environmental effects on health, prevention of birth defects, laboratory analyses, outbreak investigation and epidemiology training, and data collection and analysis on a host of vital statistics and other health indicators. Now more than ever, CDC's role in protecting the nation's health through prevention has become evident as we address issues of terrorism, emergency preparedness and health system capacity and infrastructure. Increased funding for CDC is critical.

*Birth Defects*

For over 30 years, CDC has been deeply involved in the prevention of birth defects through programs like the Folic Acid Education Campaign and the new National Center on Birth Defects and Developmental Disabilities (NCBDDD). The public health impact of birth defects is tremendous. Of the four million babies born each year in the United States, approximately 120,000 are born with a serious birth defect. According to CDC, the lifetime costs of caring for infants born in 1992, with at least one birth defect<sup>1</sup> or cerebral palsy was about \$8 billion. The emotional and financial burden for the families with affected children is devastating. CDC funds several programs critical to reducing the number of children born with birth defects, including funding to states for birth defects tracking systems. Due to lack of funds, CDC is only able to fund 15 states in fiscal year 2005, which is down from 28 states in fiscal year 2004. Additional funding for these grants is needed to fund all of the states seeking CDC assistance for these critical surveillance programs.

*Cardiovascular Disease*

Cardiovascular disease is the leading cause of death in the United States, causing one death every 34 seconds and \$393.5 billion a year in direct and indirect healthcare costs, according to the American Heart Association. The CDC reports that almost one-fourth of the U.S. population has some form of cardiovascular dis-

<sup>1</sup> These birth defects include: Spina bifida, truncus arteriosus, single ventricle, transposition/double outlet right ventricle, Tetralogy of Fallot, tracheo-esophageal fistula, colorectal atresia, cleft lip or palate, atresia/stenosis of small intestine, renal agenesis, urinary obstruction, lower-limb reduction, upper-limb reduction, omphalocele, gastroschisis, Down syndrome, and diaphragmatic hernia.

ease. Additionally, 65 percent of American adults are overweight or obese and nearly 16 percent of children and adolescents are overweight. Obesity is considered a major public health problem because it serves as the gateway disease for many other illnesses including but not limited to: depression, type 2 diabetes, hypertension, stroke, and poor female reproductive health and pregnancy complications.

These are but two examples of illnesses with programmatic public health funding through CDC. Any cuts to these programs will potentially leave millions of Americans without primary prevention programs that ultimately save lives and money. AWHONN urges \$8.65 billion in funding for CDC chronic disease prevention and health promotion programs to ensure that these programs have the resources necessary to translate preventive health research into practice. This investment will save lives and billions in health care costs and productivity.

#### SUMMARY RECOMMENDATIONS

A summary of AWHONN formal funding recommendations for these and other federal health programs:

Programmatic area	Final fiscal year 2005 <sup>1</sup>	President's budget fiscal year 2006	AWHONN's request
Nurse Workforce Development Programs .....	\$151,889,000	\$150,000,000	\$210,000,000
Maternal & Child Health Block Grant .....	729,817,000	724,000,000	850,000,000
Indian Health Service .....	2,985,000,000	3,048,000,000	5,540,000,000
Title X—Family Planning .....	288,283,000	286,000,000	350,000,000
Newborn Hearing Screening .....	9,872,000	.....	13,000,000
AHRQ .....	319,000,000	319,000,000	440,000,000
NIH .....	28,649,000,000	28,845,000,000	30,368,000,000
NINR .....	138,000,000	139,000,000	160,000,000
NICHD .....	1,271,000,000	1,278,000,000	1,350,000,000
NIHES .....	645,000,000	648,000,000	680,000,000
CDC .....	4,572,000,000	4,017,000,000	8,650,000,000

<sup>1</sup> Fiscal year 2005 numbers taken from conference report on omnibus bill do not reflect a further .8% across-the-board rescission.

Thank you for the opportunity to submit testimony on these critical areas of funding.

#### PREPARED STATEMENT OF THE BLUE CROSS AND BLUE SHIELD ASSOCIATION

The Blue Cross and Blue Shield Association (BCBSA), which represents 40 independent, locally operated Blue Cross and Blue Shield Plans throughout the nation, is pleased to submit written testimony to the subcommittee on fiscal year 2006 funding for Medicare contractors.

Blue Cross and Blue Shield Plans play a leading role in administering the Medicare program. Many Plans contract with the federal government to run much of the daily work of paying Medicare claims accurately and timely. Blue Cross and Blue Shield Plans serve as Part A Fiscal Intermediaries (FIs) and/or Part B carriers and collectively process most Medicare claims.

This testimony focuses on three areas:

- Background, including a description of Medicare contractor functions;
- Current financial challenges facing Medicare contractors; and
- BCBSA recommendations for Medicare contractor fiscal year 2006 funding.

#### BACKGROUND

Blue Cross and Blue Shield Medicare contractors are proud of their role as Medicare administrators. While workloads have soared, operating costs—on a unit cost basis—have declined about two-thirds from 1975 to 2005. In fact, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Medicare contractors have four major areas of responsibility:

1. *Paying Claims.*—Medicare contractors process all the bills for the traditional Medicare fee-for-service program. In fiscal year 2006, it is estimated that contractors will process over 1.1 billion claims, nearly 4 million every working day.

2. *Providing Beneficiary and Provider Customer Services.*—Contractors are the main points of routine contact with Medicare for both beneficiaries and providers. Contractors educate beneficiaries and providers about Medicare and respond to over 50 million inquiries annually.

3. *Handling Hearings and Appeals.*—Beneficiaries and providers are entitled by law to appeal the initial payment determination made by carriers and FIs. These contractors handle nearly 8 million annual hearings and appeals.

4. *Special Initiatives to Fight Medicare Fraud, Waste, and Abuse.*—All contractors have separate fraud and abuse departments dedicated to assuring that Medicare payments are made properly. Few government expenditures produce the documented, tangible savings of taxpayers' dollars generated by Medicare anti-fraud and abuse activities. For every \$1 spent fighting fraud and abuse, Medicare contractors save the government \$14.

#### CURRENT FINANCIAL CHALLENGES

Of utmost importance to attaining outstanding performance is an adequate budget. Medicare contractors have been underfunded since the early 1990's, however, and the largest portion of the contractor budget—Medicare operations—faces particularly severe funding pressures. Medicare operations activities include claims processing, beneficiary and provider education and communications, hearings and appeals of claims initially denied, and systems maintenance and security.

The underfunding of CMS and its Medicare contractors has gotten even more acute since the passage of the Health Insurance Portability and Accountability Act (HIPAA), the Benefits Improvement and Protection Act (BIPA), and the Medicare Modernization Act (MMA), which places new responsibilities on contractors, without sufficient resources to perform those duties. For example, between 1992 and 2002, Medicare benefits outlays increased 97 percent; claims volume increased 50 percent; yet Medicare operations funding increased a mere 26 percent. Contractor staffing only increased by 6 percent during this time even though many new responsibilities were added and claims volume continued to rise. Clearly funding has not kept pace with additional work. In addition, the Medicare reform legislation includes significant changes that will require additional resources on an ongoing basis for contractors to implement.

Whenever possible, contractors respond to reduced funding by achieving significant efficiencies in claims processing, but it is not enough to keep pace with rising Medicare claims volume and diminishing funding levels. It should be noted that contractors are already extremely efficient. Currently, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Inadequate budgets for Medicare operations also impact Medicare's fight against fraud and abuse. While many think of Medicare operations activities as simply paying claims, these activities are Medicare's first line of defense against fraud and abuse and are critically linked to activities under the separately-funded Medicare Integrity Program (MIP). As an example, many of the front-end computer edits (e.g., preventing duplicate payments and detecting inaccurately coded claims or claims requiring additional screening) are funded through Medicare operations.

Inadequate funding impacts different functions at different times, but always disrupts the integration of all the functional components needed to "get things right the first time." It thus results in inefficiency and higher costs.

#### BCBSA FISCAL YEAR 2006 FUNDING RECOMMENDATIONS FOR MEDICARE CONTRACTORS

BCBSA is pleased that many Members of this subcommittee recognize the need for adequate administrative resources at CMS. We are concerned the Administration's fiscal year 2006 budget would significantly cut Medicare operations funding by nearly \$43 million. BCBSA urges Congress to take the following steps to allow Medicare contractors to meet increased workloads as well as beneficiary and provider needs:

##### A. *Increase Medicare Contractor Operations Funding to \$2,240 Million for fiscal year 2006*

Medicare contractors continue to face increases in Medicare claims volume. Further reductions in administrative costs, as proposed in the President's budget, would seriously jeopardize contractors' ability to administer Medicare. BCBSA recommends:

1. *Claims processing funding must be maintained at \$812 million (\$10 million more than President's budget).*—The President's budget would decrease claims processing funding by \$10 million under the assumption that beneficiary movement to Medicare Advantage plans will decrease contractor workloads, particularly in claims processing, appeals and inquiries. BCBSA disagrees with this assumption.

While BCBSA recognizes a slight reduction in claims, appeals, and inquiries could occur, the amount is highly uncertain. In fact, data suggests claims volume will increase by 4 percent in fiscal year 2006. Congress must ensure funding is available



should volume and costs be higher than anticipated. Otherwise, contractors will be faced with budget shortfalls that will result in reduced services for beneficiaries and providers.

2. *Appeals funding must be restored to \$109 million (\$12.5 million more than the President's budget).*—The President's budget would decrease appeals funding by \$25 million under the assumption that the new Qualified Independent Contractors (QICs) will take on certain appeals responsibilities, lessening the load for contractors. BCBSA disagrees with this assumption.

Appeals workloads and costs are on the rise for several reasons. First, implementation of the QICs is behind schedule, requiring contractors to continue some of this work. Second, contractor interfaces with QICs require funding to prepare the case and transfer information. Third, CMS recently announced it will eliminate provider phone appeals, which cost \$10 compared to \$19 for written appeals, and require separate written notification of favorable determinations.

3. *Inquires funding must be increased to \$232 million (\$27 million more than the President's budget).*—The President's budget would decrease inquiries funding by \$17 million under the assumption that CMS' 1-800-MEDICARE call volume will continue to increase, diminishing work at the contractor site. BCBSA disagrees with this assumption.

While Medicare contractor call volume may decrease, the complexity and length of the call is increasing significantly. CMS often refers complex beneficiary and provider inquiries to the Medicare contractor that originally processed the claim. Further, CMS implemented a new Provider Customer Service Program required by the Medicare Modernization Act, but did not account for its costs in the fiscal year 2006 budget.

*B. Increase Flexibility and Funding for the Medicare Integrity Program (MIP)*

Congress created MIP in 1996 to provide a permanent, stable funding authority for the portion of the Medicare contractor budget that is explicitly designated as fraud and abuse detection activities. Despite the continued rise in claims, MIP funding has been capped at \$720 million since fiscal year 2003. In fact, claims volume increased by more than 16 percent (158 million claims) since MIP was last increased. Clearly, benefit integrity activities cannot keep pace with rising claims volumes without additional funding. BCBSA recommends Congress:

- Authorize an automatic yearly increase in MIP consistent with the rate of inflation and increase in claims volume;
- Direct a portion (\$20 million) of the new Part D oversight funding toward MIP Part A and B activities; and
- Urge CMS to give contractors greater flexibility to manage their Medicare Integrity budgets.

The following chart highlights BCBSA's request compared to fiscal year 2005 and the President's fiscal year 2006 request.

[In millions of dollars]

Medicare contractor budget	Fiscal year 2005	President's fiscal year 2006 recommendation	BCBSA fiscal year 2006 recommendation
Medicare Operations .....	2,233	2,190	2,240
Medicare Integrity Program .....	720	720	740
<b>Total Contractor Budget .....</b>	<b>2,953</b>	<b>2,910</b>	<b>2,980</b>

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to provide this testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding fiscal year 2006 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The Governors appreciate the Subcommittee's consistent support for the LIHEAP program, and we recognize the difficult decisions facing the Subcommittee in this time of severe fiscal constraints. However, in light of sharply higher home energy prices, we request the Subcommittee provide \$3.4 billion in regular fiscal year 2006 LIHEAP funding as well as the authority to release emergency contingency funds for unforeseen circumstances, such as price spikes in home heating fuels, severe weather and other potential emergencies.

LIHEAP is a vital tool in making home energy more affordable for almost 5 million of the nation's very low-income households—the elderly and disabled on fixed incomes and families with young children. The percentage of income spent on total home energy by these low-income households can be four times higher than average households. For many of these households, annual income is simply not sufficient to pay high winter heating bills, even in periods of economic growth. Even after taking constructive actions to reduce their home energy use, too many low-income residents are forced to make dangerous choices between heating their homes, paying the full rent or mortgage, seeking medical attention, or purchasing food or vital medications.

The substantial rise in home heating fuel prices hits these vulnerable citizens especially hard. The Northeast is heavily dependent on deliverable home heating fuels such as home heating oil, kerosene, and propane. In addition, price volatility in these fuels adversely affects the low-income households who, without the disposable income to purchase fuels off-season, typically enter the market when both the demand for and price of fuels are high.

The Energy Information Administration predicts that the price of home heating oil, propane, and natural gas will continue to rise this year. Compared with 2001 to 2002, households can expect this winter to pay 55 percent more to heat a home with natural gas, 93 percent more for those heating with home heating oil, and 51 percent more for those heating with propane. However, within this same time period, the annual LIHEAP appropriation has increased modestly. In spite of the welcomed increase in LIHEAP funding, only a fraction—approximately 15 percent of eligible households—can be served at current LIHEAP funding. As a result, states across the country in recent years have seen significant increases in their regular LIHEAP caseloads, as well as in requests for emergency assistance from those households in imminent danger of a utility or fuel service cut-off. At current funding levels, states may be faced with the prospect of serving even fewer eligible households, reducing benefits, or curtailing the duration of the program. Clearly, the projected need far outweighs the available funding.

Higher energy prices diminish the purchasing power of available LIHEAP funding assistance. In addition, without funds to carryforward to the new heating season, state LIHEAP programs lack the capability to undertake the “pre-buy” programs that help stabilize heating fuel prices for low-income households and expand the reach of limited program funds. An increased federal appropriation would allow states to manage the program resources in a manner to better take advantage of market opportunities.

The current uncertainty of world energy markets underscores the importance of states being able to prepare for rising and potentially volatile energy prices. These preparedness activities, while critical, cannot fully shield our lowest-income citizens from the impacts of higher heating fuel prices. An increase in the regular LIHEAP appropriation to \$3.4 billion in fiscal year 2006 will enable states across the nation to reach more of those vulnerable citizens in need of assistance and more fully implement cost-effective measures to meet their continuing energy needs.

Your support for fiscal year 2006 LIHEAP appropriations at the \$3.4 billion level, as well as the authority to release emergency contingency funds for unforeseen circumstances, is urgently needed to enable our states to help mitigate the potential life-threatening emergencies and economic hardship that confront the nation's most vulnerable citizens.

We thank the Subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast.

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PREPARED STATEMENT OF THE COMMUNITY MEDICAL CENTERS

Mr. Chairman and Members of the Subcommittee: My name is Dr. Philip Hinton and I am the Chief Executive Officer of Community Medical Centers in Fresno, California. Community Medical Centers is a not-for-profit, locally owned health care corporation that is committed to improving the health of the community. I am pleased to provide the subcommittee with a request for assistance in securing federal monies for a critical project in the Central San Joaquin Valley that would improve access to health care to the uninsured in Fresno County.

The challenges and struggles facing our nation's public hospitals and health systems are ever-increasing. The nation's uninsured population continues to grow while there are significant reductions in state and federal government support. Hence, it is imperative for public hospitals to maximize their public funding sources while

being proactive and creative in its strategies to deliver care to those who need it most.

Community Medical Centers serves as the “safety net” provider for Fresno County. In its 1996 partnership with the County of Fresno, Community assumed the obligations of indigent care. In order to fulfill this obligation, last year Community provided over \$90 million in uncompensated care. However, as Community looks to the future, it has determined the need for a more bold and aggressive strategy to meet the tremendous need for health care services in Fresno County.

In its efforts to make health care available to the over 30 percent of the County’s residents who are uninsured, Community has planned an Outpatient Care Center on the campus of the Regional Medical Center in downtown Fresno. This proposed facility will provide primary and specialty care including a children’s clinic, a women’s clinic focusing on prenatal, obstetrical and gynecological needs, asthma treatment and education, diabetes education and treatment, and surgical follow-up. This facility addresses the need for primary care services to the underinsured and uninsured population while attempting to reduce the number of unnecessary visits to local emergency departments. Although the overcrowding of emergency departments by the uninsured is a national problem, the Fresno area is particularly impacted with a larger percentage of uninsured.

In addition to a high percentage of uninsured, the region boasts some equally sobering statistics:

- An unemployment rate hovering at 15 percent
- Over 25 percent of the residents living below the poverty line
- The third highest asthma mortality rate in the nation
- The highest rates of teen pregnancy in the state
- Late or no prenatal care for pregnant women

We believe that an Outpatient Care Center is critical to begin addressing these challenges, and we would like to ask for your assistance in securing \$1 million towards the construction of this facility. We at Community Medical Centers are working diligently to secure significant private foundation monies for this facility as well. We understand that this request would require a special earmark under the Health Resources Services Administration account in the Labor/Health and Human Services/Education appropriations bill. We know that funds are limited, but feel that this project merits funding. It is a project which will improve the quality of life in the Central San Joaquin Valley.

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PREPARED STATEMENT OF THE COUNCIL OF STATE AND TERRITORIAL  
EPIDEMIOLOGISTS

The Council of State and Territorial Epidemiologists (CSTE) is pleased to provide the Subcommittee with its fiscal year 2006 funding recommendations for nine priorities all of which are programs and activities administered by the Centers for Disease Control and Prevention.

CSTE is a professional association with over 850 public health epidemiologists working in all 50 states as well as local and territorial health agencies to detect, prevent and control conditions that impact the public’s health. CSTE members possess expertise in surveillance and epidemiology in a broad range of areas including communicable diseases, immunization, environmental health, chronic diseases, occupational health, injury control, maternal and child health and oral health.

PUBLIC HEALTH WORKFORCE: INCREASING STATE AND LOCAL EPIDEMIOLOGY AND  
LABORATORY CAPACITY

- \$4 million increase for CDC’s Office of Workforce and Career Development in fiscal year 2006 to support 65 CDC/Council of State and Territorial first year applied epidemiology fellows at a cost of \$60,000 per year;
- \$2 million in increased funding for CDC’s National Center for Infectious Diseases in fiscal year 2006 to support 35 CDC/Association of Public Health Laboratory applied research training fellows.

The disciplines of epidemiology and laboratory science are the pillars and backbone of public health practice. States and local communities have come to rely on well trained public health epidemiologists and laboratory scientists to investigate, monitor, and respond aggressively to public health threats. Every state’s residents have become familiar with the “disease detectives” who they know will be in the lead for communicating risks and recommending preventive action for outbreaks of SARS, flu, West Nile virus, Monkeypox and epidemics of obesity, diabetes, HIV/AIDS and a host of other serious threats the public has experienced during recent years. These are the “go to” professionals in every state. Yet, a new 2004 epidemi-

ology capacity survey shows the number and the level of training of epidemiologists is perceived as seriously deficient in most states. Federal funding has increased the number of epidemiologists engaged in bioterrorism preparedness since 2002, but has done so at the expense of state environmental health, injury and occupational health activities—shifting epidemiologists from these activities to federal bioterrorism preparedness priorities. Those engaged in chronic disease activities have increased since 2002, but are still viewed as too low in number and training and the number of epidemiologists engaged in infectious disease activities has stagnated.

Efforts under the leadership of CDC have been made to begin addressing these gaps at both the federal and state level. In addition to expanded CDC Epidemic Intelligence Service and Career Epidemiology Field Officers for state and local health departments, CDC is supporting training fellowship programs for epidemiologists and laboratory scientists who are expected to increase state capacity and provide future leadership in these professions. CSTE applauds these efforts and proposes aggressive expansion of existing state-focused programs to increase the number of epidemiologists and public health laboratory scientists at state and local health departments. The proposed fiscal year 2006 increase will provide CSTE and APHL with the resources to accelerate much needed expansion of the state and local workforce in these critical disciplines to approximately 75 epidemiologists and 75 laboratory scientists in training during fiscal year 2006.

The overall benefits to the states and localities will be additional well trained epidemiologists and laboratory scientists entering employment through training programs that include the following characteristics:

- national recruiting through a partnership between CSTE and the Association of Schools of Public Health
- orientation and training course with CDC and CSTE and APHL faculty
- a ready-made applicant pool for state and local positions with adequate time to evaluate job performance
- a structured, individualized training curriculum for each fellow
- technical and administrative support for fellows and state mentors

#### PUBLIC HEALTH INFRASTRUCTURE ENHANCEMENT AND TERRORISM PREPAREDNESS

CSTE supports \$927 million, at a minimum, for CDC's State and Local preparedness grants to enhance capacity to prepare for and respond to terrorist attacks. The President's fiscal year 2006 request for CDC's State and local terrorism preparedness grants cuts funding by \$130 million and appears to shift this funding to National Stockpile activities, including a new \$50 million Federal Mass Casualty Initiative. CSTE opposes this cut to on-going efforts to build strong state and local capacity which means, in many cases, eliminating personnel already hired. New federal initiatives, if they are deemed needed, should be funded from new resources.

After decades of neglect of governmental public health systems, documented in numerous Institute of Medicine (IOM) reports, and Reports to Congress (The Future of the Public's Health in the 21st Century, IOM, 2003; Emerging Microbial Threats to Health in the 21st Century, IOM, 2003; Report to Congress, Public Health's Infrastructure: a Status Report, CDC, 2001; Emerging Infectious Diseases: Consensus on Needed Laboratory Capacity could Strengthen Surveillance, GAO, 1999), Congress and the Administration began a substantial effort to repair the damage following the events of 9/11 and the ensuing anthrax attacks. This effort to restore and enhance the system to protect the public against terrorist attacks, as well as naturally occurring disease threats, such as SARS, pandemic influenza, and West Nile virus, is beginning to have positive effect, but progress can only continue with sustained support.

Reasons for maintaining funding levels in fiscal year 2006:

- No single State, and no community in any State, has reached a full level of national security preparedness to address the health consequences of a terrorist event.
- Few public health preparedness investments are one-time expenses. State and local health departments have been strongly urged to use preparedness funding to increase their personnel capacity in epidemiology, laboratory science, communications and logistics. Personnel are on-going expenses.
- State and local health departments are in the third year of expanded funding for terrorism preparedness. The effect of reducing the amount of available funding by 14 percent will seriously jeopardize their momentum in addressing critical capacity needs.
- The CDC cooperative agreement guidance listed several new eligibility areas for State spending, including mental health, chemical preparedness, and food security and newly expanded guidance is expected for fiscal year 2005. In addition,

States are being asked to help administer several new federal programs such as BioWatch, BioSense, ChemPack, additional smallpox vaccination program activities, and consequence management for postal facility Biohazard Detection Systems. This requires spreading funding over increased areas of responsibility.

Now is not the time to reduce our national commitment to State and local health departments. Building a strong public health infrastructure, particularly a trained public health workforce with sufficient epidemiologists and public health laboratory scientists, core public health professionals, will take a sustained commitment of resources over a long period of time, but will reap critical benefits in protected health.

#### CSTE SUPPORTS \$132 MILLION FOR THE PHHS BLOCK GRANT IN FISCAL YEAR 2006

The Preventive Health and Health Services Block Grant, currently funded at \$132 million, is proposed to be eliminated in the President's fiscal year 2006 budget. CSTE urges Congress not to cut this important prevention program for states, but maintain funding at the fiscal year 2005 level. When this proposed cut is considered alongside the \$130 million cut in the state and local Bioterrorism grant program, the net result is to seriously undermine support for developing state public health capacity and activities, a strong Congressional goal leading up to and following the attacks of 9/11.

The Block Grant was created to help states focus on achieving the health objectives identified in Healthy People 2010—a nationally conceived effort to set and achieve national health goals. To receive block grant funding, states must develop health plans, report to the federal government about their activities, and target public health interventions to populations in need. The flexibility of the grant allows each state to address their own unique challenges in exciting and innovative ways.

Examples of this include a program in Idaho to prevent falls for older adults. Falls are the leading cause of injury death for Idaho adults age 65 and older, with hip fractures alone costing the United States \$20 billion annually. The Idaho program funds a curriculum and provides training to individuals who lead senior fall prevention exercise programs throughout the state. Another example is in Alabama where the Community Waterborne Disease Program, funded solely with PHHS Block Grant dollars protects 340,000 Alabamians who reside in rural areas against waterborne disease outbreaks from contaminated wells and septic tanks. Other Block Grant funds are used to combat newly emerging public health threats, such as West Nile virus, distribute smoke detectors, counter the growing epidemic of obesity and ensuing chronic diseases, improve cancer screening, conduct disease surveillance and infectious disease outbreaks, such as Hepatitis A and E.coli O157:H7. While Block Grant funds sometimes complement existing categorical programs, they DO NOT DUPLICATE other CDC funded programs.

#### CSTE SUPPORTS \$250 MILLION FOR INFECTIOUS DISEASES CONTROL IN FISCAL YEAR 2006

Infectious diseases are the leading cause of death worldwide, and the number of deaths from infectious diseases had been increasing in the recent past and remains substantial in the United States today. New challenges in the growth of resistance to commonly used antibiotics, emerging disease threats such as avian flu, SARS, the rapid spread of West Nile virus across the United States, and the rising number of food borne disease outbreaks, including increased monitoring of mad cow disease, make increased resources for infectious diseases control essential to the nation's health and well-being.

CSTE's fiscal year 2006 recommendation for infectious diseases control is \$25 million more than the fiscal year 2005 appropriation level of \$225.5 million. CSTE urges that the additional \$25 million in funding target the following critical areas:

- Expand the Emerging Infections Program (EIP) from its current funding level of about \$20 million to allow more than the current 11 States (CA, CO, CT, GA, MD, MA, NM, NY, OR, TN, TX) to join this program that provides a population-based network of surveillance for infectious diseases, applied epidemiologic and laboratory research, as well as capacity for flexible public health response.
- Provide support for epidemiology fellowship programs to expand the number of trained public health epidemiologists, particularly at the State level, where shortages in these essential public health professionals are severe.
- Expand the Epidemiology and Laboratory Capacity (ELC) cooperative agreement program which provides the 50 States, plus six large local health departments (Chicago, Houston, Los Angeles, New York City, Philadelphia, Washington, D.C.) and Puerto Rico, with support to strengthen the collaboration between epidemiologic and laboratory science at the State and local level to meet the demands placed upon the country by emerging and re-emerging infectious disease threats.

- Ensure that funding for CDC's new initiative in global infectious diseases supports the International Emerging Infections Program, which is modeled on the U.S. EIP program.

CSTE SUPPORTS \$50 MILLION FOR CDC'S HEALTH TRACKING GRANT PROGRAM IN FISCAL YEAR 2006

Researchers have linked specific diseases with exposures to some environmental hazards, such as the link between exposure to asbestos and lung cancer. Other links remain unproven, such as the suspected link between exposure to disinfectant by-products and bladder cancer. As the Pew Environmental Health Commission's report, "America's Environmental Health Gap: Why the Country Needs A Nationwide Health Tracking Network" noted, there is currently no national surveillance system to investigate the possible links between these environmental exposures and a number of diseases and conditions. Most states have little environmental health capacity. The Environmental Public Health Tracking Program is designed to increase state and local environmental health capacity by providing resources to conduct surveillance of health effects, exposures and hazards and their possible linkages.

*Program Accomplishments*

Since fiscal year 2002, CDC has supported 20 state and local health departments to:

- Build environmental health capacity
- Increase collaboration between environmental and health agencies
- Identify and evaluate existing data systems
- Build partnerships with non-governmental organizations and communities
- Develop model systems that link data

Additional funding would be used to:

- Fund additional state health departments to increase their environmental health capacity
- Fund technical development activities to support a nationwide network
- Expand training and education activities
- Expand collaboration with national partners to coordinate technologic standards development efforts for the network

*Surveillance: Four Priorities—Behavioral Risk Factor Surveillance Survey (BRFSS).*—Among the many important chronic disease programs within CDC's Center for Chronic Disease Prevention, Health Promotion, and Genomics which CSTE supports, a priority is the Behavioral Risk Factor Surveillance Survey (BRFSS). CSTE urges continued progress toward achieving a funding level of \$18 million (+\$10 million)—the base amount needed to fully implement the survey. CSTE is very pleased that Congress increased funding for the survey from \$1.8 million where it had remained for many years, to \$6.9 million in fiscal year 2003 and to \$7.2 million in fiscal year 2004 and \$7.6 million in fiscal year 2005. The BRFSS is a primary source of information to guide intervention, policy decision, and budget direction at the local, state and federal level for a host of health problems, especially chronic diseases. It is the source of data for 24 of the 73 chronic disease indicators, six areas of the Healthy People 2010 leading health indicators and serves as the core source of surveillance for multiple public health programs across the CDC. The additional funding provided in fiscal year 2004 and fiscal year 2005 will significantly improve data collection infrastructure, timeliness, and analysis that will not only improve guidance for state-based public health activities, but allow state to state comparisons, state to national comparisons, and a more solid foundation for national resource and other decisions with regard to a range of public health activities.

*HIV/AIDS Surveillance.*—Within a total recommendation of \$1,049.2 million (+\$386.6 m) for CDC's HIV/AIDS prevention activities, CSTE urges an increase of \$35 million in fiscal year 2006 for HIV/AIDS surveillance cooperative agreements with state and local health departments to strengthen HIV case reporting. Surveillance activities are critical to the goal of preventing new HIV infections which can save an estimated \$195,000 in lifetime treatment costs per individual. Persistent, significant funding gaps between what state and local health departments have requested and what CDC can provide impede attainment of national prevention goals. CSTE recommends, at minimum, an additional \$35 million for HIV/AIDS core surveillance, enhanced perinatal surveillance, incidence surveillance, behavioral surveillance and morbidity monitoring.

*National Violent Death Reporting System.*—Within a total recommendation of \$168 million (+\$30 m) for CDC's National Center for Injury Prevention and Control, CSTE urges \$10 million in funding for fiscal year 2006 (+\$6.8 million) to continue building a fully implemented violent death reporting system in every state. Information from the reporting system can be used to target prevention and early

intervention efforts to prevent a significant number of the 50,000 annual deaths in the United States due to violence. Increased resources in fiscal year 2006 would be used to create uniform reporting systems in more states and build capacity to both collect and analyze data; ensure leadership and assistance; establish strong partnerships among federal, state, and non-governmental organizations; and research potential barriers to data collection. As of August, 2004, CDC is funding 17 states: AK, CA, CO, GA, KY, MA, MD, NC, NJ, NM, OK, OR, RI, SC, UT, VA, WI.

*State-Based Occupational Safety and Health Surveillance.*—Within a total recommendation of \$335 million (+\$49 m) for CDC's NIOSH activities, CSTE urges that \$10 million be provided in fiscal year 2006 to fully fund this program to prevent workplace injuries, diseases and death.. Both the CDC and CSTE believe that programs should be established within State Health departments as one of the most effective ways to build a nationwide system to prevent major causes of injuries and illnesses that are caused by hazardous conditions at work. The CDC and CSTE have established 13 occupational health indicators that every State should use to measure the burden of workplace injuries and illnesses, and then determine where they need to act to reduce preventable disease and disability in the population. In fiscal year 2005, NIOSH has funded the first 12 States to establish programs to use these indicators to count workplace injuries and illnesses, and make recommendations about how to prevent a few important health conditions (such as asthma, pesticide illness, silica lung diseases, and needlesticks). This program should be expanded to all 50 States to assure that every State has the capacity to track work-related health problems and take steps to prevent work-related injury, disease and death. Professional judgment assesses that \$10 million is needed to expand this program to all 50 States.

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PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES  
ADMINISTRATION (HRSA)

The Friends of HRSA is an advocacy coalition of more than 100 national organizations, collectively representing millions of public health and health care professionals, academicians and consumers. Our member organizations strongly support programs that assure Americans' access to health services.

HRSA programs assure that all Americans have access to our nation's best available health care services. Through its programs in thousands of communities across the country, HRSA provides a health safety net for medically underserved individuals and families, including 45 million Americans who lack health insurance; 49 million Americans who live in neighborhoods where primary health care services are scarce; African American infants, whose infant mortality rate is more than double that of whites; and the estimated 850,000 to 950,000 people living with HIV/AIDS. Programs to support the underserved place HRSA on the front lines in erasing our nation's racial/ethnic and rural/urban disparities in health status. HRSA funding goes where the need exists, in communities all over America. The Friends support a growing trend in HRSA programs to increase flexibility of service delivery at the local level, necessary to tailor programs to the unique needs of America's many varied communities. The agency's overriding goal is to achieve 100 percent access to health care, with zero disparities. In the best professional judgment of the members of the Friends of HRSA, to respond to this challenge, the agency will require a funding level of at least \$7.5 billion for fiscal year 2006.

Through its many programs and new initiatives, HRSA helps countless individuals live healthier, more productive lives. In the 21st century, rapid advances in research and technology promise unparalleled change in the nation's health care delivery system. HRSA is well positioned to meet these new challenges as it continues to provide first-rate health care to the nation's most vulnerable citizens. We are grateful to the Subcommittee for your consistent strong support for all of HRSA's programs, including the initiatives in terrorism preparedness and response in the past. Unfortunately, the president's budget overall recommends a massive \$838 million or over 12 percent cut to the agency for fiscal year 2006. We urge the members of the Subcommittee to restore the cuts and fund the agency at a level that allows HRSA to effectively implement these important programs.

Community-based health centers and National Health Service Corps-supported clinics form the backbone of the nation's safety net. More than 4,000 of these sites across the nation provide needed primary and preventive care to nearly 15 million poor and near-poor Americans. HRSA primary care centers include community health centers, migrant health centers, health care for the homeless programs, public housing primary care programs and school-based health centers. Health centers provide access to high-quality, family-oriented, culturally and linguistically com-

petent primary care and preventive services, including mental and behavioral health, dental and support services. Nearly three-fourths of health center patients are uninsured or on Medicaid, approximately two-thirds are people of color, and more than 85 percent live below 200 percent of the poverty level. Additional primary care is provided by 2,700 clinicians in the National Health Service Corps. Corps members work in communities with a shortage of health professionals in exchange for scholarships and loan repayments. The Friends of HRSA are pleased that the president has requested a significant 17.5 percent increase for Community Health Centers for a total of \$2.038 billion.

The Friends are concerned about a number of programs slated for deep cuts or elimination under the Administration's fiscal year 2006 budget proposal. An adequate, diverse, well-distributed and culturally competent health workforce is indispensable to our national readiness efforts. We are concerned with the president's proposed cut for hospital preparedness. In the post 9/11 era, all responders, providers and facilities must be ready to detect and respond to complex disasters, including terrorism, and HRSA must continue to support these vital programs.

HRSA Health Professions Programs under Title VII and VIII address the need for an adequate national workforce in the face of projected nationwide shortages of nurses, pharmacists, and other professionals. Graduates of these programs are up to 10 times more likely to practice in underserved areas, and they are up to 5 times more likely to be minorities. These programs provide support to students, programs, departments, and institutions to improve the accessibility, quality, and racial and ethnic diversity of the health care workforce. In addition to providing unique and essential training and education opportunities, these programs help meet the health care delivery needs of the areas in this country with severe health professions shortages, at times serving as the only source of health care in many rural and disadvantaged communities. The Friends are greatly concerned about the elimination of most funding for the Title VII health professions training programs and flat funding for Title VIII nurse training.

The Healthy Community Access Program is an example in which communities build partnerships among health care providers to deliver a broader range of health services to their neediest residents. Grantees are public or private entities that demonstrate a commitment to bridging service gaps and improving health outcomes for uninsured and underserved people. The Friends are very concerned that the Administration's budget proposal once again recommends eliminating this program of coordinated service delivery, an innovative program that does not duplicate other available programs.

Another vital program administered by HRSA is newborn screening. Newborn screening is a public health activity used for early identification of infants affected by certain genetic, metabolic, hormonal or functional conditions for which there is effective treatment or intervention. Screening detects disorders in newborns that, left untreated, can cause death, disability, mental retardation and other serious illnesses. Parents are often unaware that while nearly all babies born in the United States undergo newborn screening tests for genetic birth defects, the number and quality of these tests vary from state to state. Screening programs coordinated through the HRSA Bureau of Maternal and Child Health will assure that every baby born in the US receive, at a minimum, a universal core group of screening tests regardless of the state in which he/she is born.

Title 26 of the Children's Health Act of 2000 authorized funding for grants and programs to improve state-based newborn screening. This provision also called for an advisory committee to provide advice and recommendations to the Secretary for the development of grant administration policies and priorities, and to enhance the ability of the Secretary to reduce mortality or morbidity from heritable disorders. The Secretary appointed 15 members to this committee in February 2004. HRSA, together with this committee, recently published a report to be considered by the Secretary, which makes recommendations on the number and types of conditions that should be required by state programs. The Friends are very concerned that the Administration's budget did not include additional funding for such activity and that once again, the President's budget zeroed-out existing funding for the universal newborn hearing screening program. The newborn screening program is vital to ensuring that newborns are screened and treated for conditions that, if left alone, disability, mental retardation and even death.

HRSA programs improve health care service for the more than 61 million people who live in rural America. Although almost a quarter of the population lives in rural areas, only an eighth of our doctors work there. Because rural families earn less than urban families, many health problems associated with poverty are more serious, including high rates of chronic disease and infant mortality. While the recently passed Medicare prescription drug bill included several enhancements for



Medicare reimbursement for rural hospitals, this does not justify the elimination of small, targeted programs designed to improve access to health care services in rural areas. The deep \$115 million cut proposed for rural health programs has the potential to only exacerbate rural/urban health disparities seen today.

In light of many states experiencing budget crises, HRSA's State Planning Grants Program provides one-year grants to States to develop plans for providing access to affordable health insurance coverage to all their citizens. Considering that 45 million Americans are uninsured, with many individuals simultaneously being dropped from Medicaid and SCHIP rolls, there is a need for states to explore alternative approaches that provide health insurance benefits to its residents that are affordable in nature. The potential for states to share best practices as a result of this program is enormous, and therefore the Friends of HRSA is gravely concerned with this program's proposed elimination in the president's budget request.

Also, the proposed elimination of the Emergency Medical Services for Children Program is of concern considering many children who are eligible for Medicaid and SCHIP cannot enroll due to state enrollment limits and budgetary pressures. Therefore, these uninsured children will likely increasingly utilize emergency health services, as they are less likely to have a usual source of care. Not investing in improving the quality of emergency health services to children, especially at this time, may result in higher rates of death and disability among this population. Also, this program, as outlined in the midcourse review of the EMSC Five-Year Plan, 2001–2005, has been shown to make significant progress in meeting stated objectives to improve emergency health service delivery to children.

The Friends of HRSA are also concerned with the proposed flat funding of programs that make a difference in thousands of communities across the United States, and ultimately affect the lives of millions. The Maternal and Child Health Block Grant is another source of flexible funding for states and territories to address their unique needs, and remains in great need of increased, not flat, funding. The Block Grant is one of several HRSA Maternal and Child Health programs. Each year, more than 26 million pregnant women, infants and children nationwide are served by a MCH program. Of the nearly 4 million mothers who give birth annually, almost half receive some prenatal or postnatal service from a MCH-funded program. MCH programs increase immunizations and newborn screening, reduce infant mortality and developmentally handicapping conditions, prevent childhood accidents and injuries, and reduce adolescent pregnancy. Although states in theory could use MCH block grant funds to continue the universal newborn hearing screening and Emergency Medical Services for Children programs, two programs that have been proposed for elimination, in reality this is not a viable alternative. With the proposed flat funding of the block grant, funding additional programs under its auspices would mean that programs currently funded would have to be cut.

Title X of the Public Health Service Act was enacted to provide high-quality, subsidized contraceptive care to those who need but cannot afford such services, to improve women's health, reduce unintended pregnancies, and decrease infant mortality and morbidity. Title X programs provide comprehensive, voluntary and affordable family planning services to millions of low-income women and men—many of whom are uninsured—at more than 4,600 clinics nationwide. People who visit Title-X funded clinics receive a broad package of preventive health services, including breast and cervical cancer screening, blood pressure checks, anemia testing, and STD/HIV screening.

The Ryan White CARE Act programs, administered by HRSA's HIV/AIDS Bureau, are the largest single source of federal discretionary funding for HIV/AIDS health care for low-income, uninsured and underinsured Americans. We are very concerned that most programs under the Act would be flat-funded should the figures requested by the Administration be implemented, which will not be enough to meet the growing need and demand for services. The CARE Act program is an important safety net program, providing an estimated 533,000 people access to services and treatments each year. In addition to primary health care, CARE Act programs support the dissemination of drug therapies, home-based care, early intervention services, treatment adherence, case management and support. The CARE Act also funds a dental reimbursement program and the AIDS Education and Training Centers that offers specialized clinical education on the latest in HIV/AIDS care. Only the State AIDS Drug Assistance Program (ADAP), which provides medications to over 120,000 individuals those living with HIV/AIDS who would otherwise fall through the cracks, lacking private health insurance, but ineligible for Medicaid, receives an increase of \$10 million over fiscal year 2005.

Cross-cutting HRSA programs continually respond to new public health challenges. Tooth decay remains the single most chronic childhood disease in the nation. About 125 million Americans have no dental insurance; lack of access to dental care

is especially severe among children of poor, rural and minority families. A quarter of the nation's school-age children have 80 percent of all dental disease, putting them at risk for a host of related illnesses. And as new drugs help people with HIV/AIDS live longer, healthier lives, their need for regular oral health care will continue to climb. HRSA can help both groups by increasing the number of dentists in community and school-based centers and by providing greater reimbursements to hospital dental clinics and dental schools for the growing costs of treating people living with HIV/AIDS.

The members of the Friends of HRSA are grateful for this opportunity to present our views to the Subcommittee.

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## PREPARED STATEMENT OF THE INTERTRIBAL BISON COOPERATIVE

### INTRODUCTION AND BACKGROUND

My name is Ervin Carlson, a Tribal Council member of the Blackfeet Tribe of Montana and President of the InterTribal Bison Cooperative. Please accept my sincere appreciation for this opportunity to submit testimony to the honorable members of the Appropriations Sub-Committee on Labor, Health and Human Services and Education. The InterTribal Bison Cooperative (ITBC) is a Native American non-profit organization, headquartered in Rapid City, South Dakota, comprised of 54 federally recognized Indian Tribes located within 18 States across the United States.

Buffalo thrived in abundance on the plains of the United States for many centuries before they were hunted to near extinction in the 1800s. During this period of history, buffalo were critical to survival of the American Indian. Buffalo provided food, shelter, clothing and essential tools for Indian people and insured continuance of their subsistence way of life. Naturally, Indian people developed a strong spiritual and cultural respect for buffalo that has not diminished with the passage of time.

Numerous tribes that were committed to preserving the sacred relationship between Indian people and buffalo established the ITBC as an effort to restore buffalo to Indian lands. ITBC focused upon raising buffalo on Indian Reservation lands that did not sustain other economic or agricultural projects. Significant portions of Indian Reservations consist of poor quality lands for farming or raising livestock. However, these wholly unproductive Reservation lands were and still are suitable for buffalo. ITBC began actively restoring buffalo to Indian lands after receiving funding in 1992 as an initiative of the Bush Administration.

Upon the successful restoration of buffalo to Indian lands, opportunities arose for Tribes to utilize buffalo for tribal economic development efforts. ITBC is now focused on efforts to assure that tribal buffalo projects are economically sustainable. Federal appropriations have allowed ITBC to successfully restore buffalo the tribal lands, thereby preserving the sacred relationship between Indian people and buffalo. The respect that Indian tribes have maintained for buffalo has fostered a serious commitment by ITBC member Tribes for successful buffalo herd development. The successful promotion of buffalo as a healthy food source will allow Tribes to utilize a culturally relevant resource as a means to achieve self-sufficiency.

### FUNDING REQUEST FOR PREVENTATIVE HEALTH CARE INITIATIVE

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2006 in the amount of \$2,000,000 in the form of an earmark to the Department of Health and Human Service Department's budget. ITBC intends to utilize the funds to conduct a national demonstration project focused on the delivery of bison meat to Native Americans suffering from diet related diseases.

The Native American population currently suffers from the highest rates of Type 2 diabetes. The Indian population further suffers from high rates of cardio vascular disease and various other diet related diseases. Studies indicate that Type 2 diabetes commonly emerges when a population undergoes radical diet changes. Native Americans have been forced to abandon traditional diets rich in wild game, buffalo and plants and now have diets similar in composition to average American diets. More studies are needed on the traditional diets of Native Americans versus their modern day diets in relation to diabetes rates. However, based upon the current data available, it is safe to assume that disease rates of Native Americans are directly impacted by a genetic inability to effectively metabolize modern foods. More specifically, it is well accepted that the changing diet of Indians is a major factor in the diabetes epidemic in Indian Country.

Approximately 65-70 percent of Indians living on Indian Reservations receive foods provided by the USDA Food Distribution Program on Indian Reservation (FDPIR) or from the USDA Food Stamp Program. The FDPIR food package is com-

posed of approximately 58 percent carbohydrates, 14 percent proteins and 28 percent fats. Studies have shown that the FDIIR food package has not been compatible with the genetic compositions of Native Americans and has been a major factor in the high incidence of diet-related disease among Native Americans. Indians utilizing Food Stamps generally select a grain based diet and poorer quality protein sources such as high fat meats based upon economic reasons and the unavailability of higher quality protein food sources.

Buffalo meat is low in fat and cholesterol and is compatible to the genetics of Indian people. ITBC intends to develop a health care initiative that would educate Indian Reservation families of the benefits of incorporating buffalo meat into their diets. In conjunction with educating Reservation families on the benefits of buffalo meat, ITBC intends to develop methods to make buffalo meat accessible for Indian families and to promote incorporation of buffalo into their diets. ITBC intends to coordinate with Reservation health care providers in nutritional studies of Reservation populations that incorporate buffalo meat into diet packages.

ITBC believes that incorporating buffalo meat will positively impact the diets of Indian people living on Reservations. A healthy diet for Indian people that results in a lower incidence of diabetes and other diet related illnesses will reduce Indian Reservation health care costs and result in a savings for taxpayers.

#### FUNDING REQUEST FOR ITBC TRAINING AND LABOR PROGRAM

The InterTribal Bison Cooperative respectfully requests an appropriation for fiscal year 2006 in the amount of \$500,000. This amount is \$400,000 above the fiscal year 2005 appropriation for ITBC and is critical to maintain last years funding level and to develop ITBC's training and labor program.

In fiscal year 2005, the ITBC and its member Tribes were funded at \$100,000, a decrease of \$200,000 from the previous year. ITBC is now requesting \$500,000 for fiscal year 2006 for job training as part of ITBC's labor initiative. To insure the success of ITBC's buffalo restoration efforts to Indian lands, training for the various jobs related to the buffalo projects is essential. Most member Tribes of ITBC have reservation unemployment rates of 72 percent. Jobs opportunities on most Indian Reservations are limited, low-paying, and often seasonal and temporary. The jobs created by buffalo restoration to Indian lands will positively impact Tribal unemployment rates and the overall Reservation poverty levels. Raising buffalo as an economic development effort requires skilled labor in permanent employment. ITBC has developed a job training program incorporating on-the-job training and work experience for youth that specifically addresses the unique needs of managing and maintaining buffalo. ITBC's training program further focuses on strengthening the economic development opportunities of buffalo restoration with training specific to meat processing, veterinary science, wildlife and biological services, infrastructure development, business and management training, and the overall development of a skilled workforce.

Sufficient funding for job training is critical to the success of the buffalo restoration projects. The increase in funding will ensure that ITBC can provide job training, job growth training to ITBC member tribes. Without funding at the requested level, the buffalo restoration projects have less assurance of success.

#### ITBC GOALS AND INITIATIVES

In addition to developing a preventative health care initiative, ITBC intends to continue with buffalo restoration efforts and the Tribal buffalo marketing initiative.

In 1991, seven Indian Tribes had small buffalo herds, with a combined total of 1,500 animals. The herds were not utilized for economic development but were often maintained as wildlife only. During ITBC's relatively short 10-year tenure, it has been highly successful at developing existing buffalo herds and restoring buffalo to Indian lands that had no buffalo prior to 1991. Today, through the efforts of ITBC, over 35 Indian Tribes are engaged in raising over 15,000 buffalo. All buffalo operations are owned and managed by Tribes and many programs are close to achieving self-sufficiency and profit generation. ITBC's technical assistance is critical to ensure that the current Tribal buffalo projects gain self-sufficiency and become profit-generating. Further, ITBC's assistance is critical to those Tribes seeking to start a buffalo restoration effort.

Through the efforts of ITBC, a new industry has developed on Indian reservations utilizing a culturally relevant resource. Hundreds of new jobs directly and indirectly revolving around the buffalo industry have been created. Tribal economies have benefited from the thousands of dollars generated and circulated on Indian Reservations.

## CONCLUSION

ITBC has proven highly successful since its establishment to restore buffalo to Indian Reservation lands to revive and protect the sacred relationship between buffalo and Indian Tribes. Further, ITBC has successfully promoted the utilization of a culturally significant resource for viable economic development.

ITBC has assisted Tribes with the creation of new jobs, on-the-job training and job growth in the buffalo industry resulting in the generation of new money for tribal economies. ITBC is also actively developing strategies for marketing Tribally owned buffalo. Finally, and most critically for Tribal populations, ITBC is developing a preventive health care initiative to utilize buffalo meat as a healthy addition to Tribal family diets to reduce the incidence of diet-related illnesses.

ITBC strongly urges you to support its request for a \$2,000,000 earmark to the Department of Health and Human Service Department's budget to develop the critically needed preventative health care initiative utilizing Tribally produced buffalo.

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 PREPARED STATEMENT OF THE LUMMI INDIAN NATION

## WHO WE ARE

The Lummi Nation is a party to the Point Elliot Treaty of 1855. Under this Treaty we understand that the Lummi Nation has secured the protection of the United States of America and has reserved the right to govern our own lands, people and the people who enter these lands voluntarily. The Lummi Nation is a federally recognized Indian tribal government located in what is now called the State of Washington. The Lummi Nation includes a population of nearly 5,000 people. The Lummi Nation land base includes over 12,500 upland acres and 5,000 acres of tidelands. The Lummi are a fishing people with fishing rights in the San Juan Islands and much of Puget Sound and its associated waterways extending for hundreds of miles.

*Self-governing Status*

The Lummi Nation is one of the first self-governance Tribes. Although many thought the Lummi Nation was seeking to establish a new relationship with the Federal government, it was really seeking to re-establish the relationship that it started in 1855; to affirm the government-to-government relationship that began back then and reshape it into a relationship that fits today's realities, needs and goals. Each generation must continue the unbroken promise to take responsibility for the welfare of our people that began in the past and extends into the future.

*Health Disparities Index*

Over the past several years there has been growing concern over the disparities in Health care funding that is available to disadvantaged populations within the United States. Unfortunately this concern has not generated additional funding for health care services. Instead the information that there are substantial and verifiable disparities in the level of funding provided to minority population. New funding has been appropriated to study the problem and to make recommendations that will most likely include a recommendation for additional service funding.

*U.S. Civil Rights Commission Report*

The Civil Rights Report "A Quiet Crisis" was issued last year. In this report, the federal government provides a devastating indictment of the level of funding for Indian Country. This situation did not occur during the current administration, nor did it occur during the previous administration. This is not about politics. It is about human beings.

## INDIAN HEALTH CARE IMPROVEMENT ACT

The Lummi Nation wants the Congress and the Department to support that section of the proposed Indian Health Care Improvement Act which enables tribes to not only participate but to operate Medicaid Program services consistent with the need for health care service needs of their people. This proposal is budget neutral. These costs are already included in the current expenditure. This is simply re-routing an existing expenditures through the Tribal governments, which are closest to the people who are being served. This proposal enables Tribal governments to develop their own Medicaid Services plans instead of simply participating in the State's plan.

## HEAD START BUREAU—NEW HEAD START FACILITY

The Lummi Nation is proud to have operated a Head Start Program since 1969. Our Head Start Program now serves one hundred and eighteen children (118) and their families. However, the Lummi Nation Head Start Program needs to serve over two hundred (200). The limitations of the existing facility have limited the expansion of the program and its badly needed services. The Lummi Nation has completed construction of a new school facility with Bureau of Indian Affairs funding. In the process of constructing this facility the Lummi Nation planned for the construction of a new Head Start Facility adjacent to the new School Facility. Water, sewer and electrical services have been stubbed out to the site, thereby reducing the cost of constructing the facility. The first phase of construction will cost approximately \$500,000.

## ADMINISTRATION FOR CHILDREN AND FAMILIES

*Tribal Social Services Demonstration Projects*

ACF staff have informed Tribal Leadership the Department was considering a demonstration project to provide Tribes with direct access to Title IV (b) and Title IV (e) Social Services and Foster Care Services. The Lummi Nation supports the idea of a demonstration project and would eagerly participate in such a project. The Lummi Nation would support legislation that enables tribal governments to work directly with DHHS to access funding for Title IV (b), (c), (d), and (e) while maintaining their service relationship with the State services for the benefit of all Indian children.

*Unemployment and Poverty*

The Lummi Nation approaches the problems of poverty and welfare through its own experience. The Lummi Nation economy is unique. It had remained a traditional fishing economy in the 21st century. The strength of the annual salmon runs had supported the Lummi Nation economy since time immemorial. However, these runs have finally succumbed to combination of farm fish competition, over-fishing and disappearing habitat.

*Increasing Welfare Case Load*

The experience of the Lummi Nation is that TANF caseloads are increasing not decreasing. Due to the failure of the last 5 years fishing seasons the Lummi Nation fishers are being added into the existing welfare base case loads for the TANF and BIA General Assistance Programs. Each Lummi fisher person supports an additional four to five families that worked on their boat and received a share of the total income. These fishing boats have reduced by 53 percent from 700 to 373. What community in the United States could sustain this level of economic disaster? For the Lummi Nation this is the bankruptcy of nearly all its small businesses owners/operators within a short period of time.

*Funding for Tribes to Build Social Services/TANF Infrastructure*

The existing TANF funding for Tribes fails to recognize the long-term investment in the development of the State Welfare infrastructure. Therefore, Tribes are presented a less than level playing field when they seek to develop and implement welfare service programs that meet the needs of their people. The Lummi Nation urges the Committee to consider earmarking a portion of the funding provided to States for their administrative costs to support the development of Tribal TANF infrastructure. This funding should be provided directly to Tribes who have assumed the responsibility for operating TANF.

## SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

*Tribal Substance Abuse Block Grant*

The Lummi Nation has been able to have several meetings with the senior management of the Substance Abuse and Mental Health Services Administration over the past year. During one of these meetings we suggested that they re-program just one year's increase in the funding that is available to "States under the Substance Abuse Block Grant funding. Currently only the Red Lake Band of Chippewa is receiving an allocation directly from the Substance Abuse Block Grant administered by the Substance Abuse and Mental Health Services Administration. The Tribal specific Block Grant Program could be started using only the increases that are appropriated for the general population re-programmed as a Tribal only Substance Abuse Block Grant. Then Congress would subsequently appropriate enough funds for annual inflationary increases for both the State Block Grant and the Tribal Block Grant.

*Alcohol and Substance Abuse Program Infrastructure Funding*

SAMHSA has been able to support the development of State Alcohol and Substance abuse program infrastructure. While Tribal governments face the same data challenges that are posed by the operation of the Alcohol and Substance Abuse Treatment, Prevention and After-care activities. Apparently tribal governments can achieve what State governments who have access to tax bases of their own, cannot do without Federal assistance.

## DEPARTMENT OF LABOR

*Jobs Now—Job Creation and Economic Development*

In response to the economic fishing disaster for the Lummi people, of past 5 years, the Lummi Nation has created the JOBS NOW Initiative and is in the process of developing a long-term economic stimulus plan. These initiatives utilize all of the Lummi Nation projects, services, and resources to address the internal, social and economic needs of Lummi Nation families. Through this initiative the Lummi Nation has been able to register its membership in a job skills bank and identified area of job training that are in demand by the local labor market and consistent with the employment preferences of the membership.

*Lummi Nation Families Need 500 Jobs to Replace Lost Fishing Industry Jobs*

The goal of the Lummi Nation Salmon Recovery Initiative is to create 500 jobs that provide a family wage to confront the current and long-term effects of the fishing economic disaster that is facing Lummi Nation members. Therefore the Lummi Nation urges the Committee to support additional job training program funding earmarked to address the economic crisis that is facing the members of the Lummi Nation.

*Lummi Nation Dislocated Fishers Project*

The Lummi Nation is fully aware of how different, how culturally specific this economic dislocation is. The Lummi Nation expects the federal government including the Department of Labor to recognize the unique relationship that exists between the Lummi Nation and the United States of America through the Point Elliot Treaty of 1855.

The Lummi Nation anticipated that it would be afforded the full discretion allowed under the law. Instead we believe that we have been held hostage to the past experiences of the Dislocated Worker Program. Past practices are not useful guides to new situations. We are disappointed with the reaction of the Department of Labor to the needs of our community members. The situation at Lummi Nation is a real economic dislocation, not just a profit dislocation. This is not a company failure. This is not simply a matter of mismanagement and plant failure. We are not working with workers but with small businessmen who were previously successfully self-employed. The service models that are imposed by the Department of Labor are based on the plant failure model.

It is clear that the intent of the legislation is to assist workers to get jobs when the industry that supported them is no longer operable. Our situation is clearly within the intent of the authorizing legislation. The fishing industry to which our people have devoted their lives and invested their fortune has changed, due to no action or inaction on the part of the workers for whom assistance is sought.

*Negotiated Standard*

During negotiations with the Department of Labor the Lummi Nation sought and received a promise that funding would be available to meet the needs of all eligible members of the Lummi Nation. The Lummi Nation expects the Department to honor this standard and continue funding of this project until all eligible Lummi Nation members have been provided services such that they are able to secure and maintain comparable permanent employment.

*+ \$420,000.—Additional funding for Lummi Nation WIA Programs and Services*

The Lummi Nation allocation for funding under the WIA Comprehensive and Youth Programs is less than one third of what it needs to be. The Lummi Nation is requesting that the Committee review its allocations and increase the funding that is available to the Lummi Nation by three (3) times. The Lummi Nation receives \$140,000 annually to meet the needs of 5,000 people, with multiple needs including basic reading and writing skills, physical therapy, other personal issues to address prior to job training and eventually employment. The Lummi Nation needs an allocation of \$420,000.

## DEPARTMENT OF EDUCATION

*Funding for Tribal Education Departments*

This is needed by all of Indian Country. Those tribes that do not operate their own schools need the infrastructure to support their youth in the public schools. Those Tribes that do operate schools need the Department format to insure that educational services are connected to the Tribal government.

*No Child Left behind*

The United States of America has left behind Indian children. While we are supportive of many provision of the Act we are not aware of any benefits that it has brought to us. Indian children are still left behind by the lack of adequate school and preschool facilities, teachers and operating resources. While the 2006 Presidents budget Request does includes requests to maintain the 2004 funding level it is woefully inadequate. The leading cause of death in our community is abuse of alcohol and/or drugs. Children who live in such a community have significant social, developmental needs that must be addressed so that basic educational services can be of any value. The current funding level mean that Indian Children will continue to be left behind as the rest of America is catapulted into the 21st Century.

*Vocational Rehabilitation*

The Lummi Nation is a long-standing grantee of the Department's Indian Vocational Rehabilitation. We are grateful for the support of the Department for the development of the Lummi Nation Vocational Rehabilitation Program as well as the funding to provide much needed services for our membership. The Department needs to insure that the full amount of this allocation is available for the benefit of Indian people.

*477 Program*

The Lummi Nation along with other who are participating in the 477 Program are seeking to consolidate all employment and training programs, services functions and activities. The Education Department needs to fully participate in this program. The Lummi Nation urges the Committee to require the Department to meet with Tribal leadership and members of the Committee staff to identify the barriers to full participation and develop appropriate administrative and or legislative remedies.

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 PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

## SUMMARY

The proposed cuts in the fiscal year 2006 budget of the Centers for Disease Control and Prevention (CDC) fall disproportionately on local and state public health departments. The two largest proposed program cuts for CDC are a reduction of \$130 million in funding for state and local bioterrorism preparedness and elimination of the \$131 million Preventive Health and Health Services block grant program. Such funding cuts would seriously compromise the ability of the nation's governmental public health system to fulfill its mission of protecting and promoting health.

Local public health departments work every day on the front lines to combat threats to the health of their communities. They can ill afford substantial reductions in federal support for their roles as first responders to bioterrorism and other public health emergencies. Moreover, local public health departments receive about 40 percent of the Preventive Health and Health Services block grant (PHHS) funds. These enable them to carry out programs ranging from prevention of heart attack and stroke to combating West Nile virus. In states where local health departments rely on these funds to run prevention programs for which no other sources of funding are available, activities to reduce the burdens of preventable disease will be reduced.

At a time when the nation is engaged in urgent work to protect the homeland from terrorists, as well as to stop an epidemic of obesity, it is profoundly counterproductive and irrational to reduce support for local programs that are the first line of defense against the greatest threats to the health of communities. NACCHO urges Congress to continue funding these two CDC programs at levels no less than that of the current fiscal year. Those levels are \$932 million for state and local bioterrorism preparedness and \$131 million for the Preventive Health and Health Services block grant.

STRENGTHENING THE GOVERNMENTAL PUBLIC HEALTH SYSTEM TO IMPROVE HOMELAND SECURITY REQUIRES SUSTAINED FUNDING

Congress recognized in 1997 an unmet need to strengthen the nation's capacity to respond to an act of bioterrorism and initiated funding for bioterrorism preparedness in fiscal year 1999. The initial funding of about \$121 million (which included \$51 million solely for stockpiling medications) assisted CDC and state and local health departments to begin examining what plans and resources were necessary. After 9/11 and the anthrax outbreaks in the fall of 2001, Congress increased bioterrorism funding markedly and included \$940 million for building state and local capacities, of which about \$870 million was actually made available to states and localities. The Department of Health and Human Services got these funds out to states and three large cities via cooperative agreements very promptly, far ahead of other homeland security funds for states and localities.

Substantial bioterrorism preparedness funds for improving all aspects of preparedness have actually been in the hands of state health departments since August 2002, less than three years. Local public health departments, many of which have been funded for much less time, are justifiably proud of the progress they have made.

Extensive response plans, developed in collaboration with local emergency management systems, have been made. Numerous "tabletop" and real field exercises have tested local capabilities. Mass vaccination clinics have taken place, some in conjunction with the actual requirement to provide smallpox vaccine to selected first responders, others as a real response to this year's flu vaccine shortage. Communications systems and equipment that enable rapid electronic information exchange among health departments and by health departments to their communities are operational. Improved systems for disease detection are in place.

Local health departments have engaged hospitals, physicians, and other individuals and organizations in the private sector in developing their roles in responding to a serious disease outbreak. Complex logistical arrangements needed to distribute medications or equipment from the Strategic National Stockpile to stricken populations have been developed.

In some locations, genuine public health crises, such as suspected SARS cases or flu vaccine shortages, have demanded a response. In the act of the responding, local health departments and their community partners continually identify new challenges and new ways to improve their ability to respond. Improving a locality's ability to detect a disease outbreak promptly and to contain it swiftly is a continuous process. Interrupting that process through funding cuts would take the nation's bioterrorism preparedness backwards, not forward. New capacities that are now in place cannot be sustained without sustained funding.

The Administration has proposed to fund more medicines and supplies for the Strategic National Stockpile and to purchase portable medical treatment units, instead of sustaining funding for state and local capacities. Yet the acquisition of vaccines or equipment is useless unless there are trained people and established systems in place to get the vaccines or treatment to stricken populations. According to a recent report by the Government Accountability Office ("Bioterrorism: Information on Jurisdictions' Expenditure and Reported Obligation of Program Funds," February 2005), state and local governments are taking action responsibly to prepare for bioterrorism and there are not large surpluses of unspent funds. It is wholly irrational to suggest that more vaccines and supplies can improve national preparedness, if funding to sustain health departments' capacity to use those vaccines and supplies is simultaneously cut back.

The nation has a long way to go before every citizen enjoys the best possible protection by disease detection and response systems that work as quickly as humanly possible. Providing this protection is the job of the governmental public health system. No other entity can do it. NACCHO urges Congress not to cut back funds available to local public health departments, the nation's first responders to bioterrorism.

THE PHHS BLOCK GRANT IS A LINCHPIN FOR PREVENTION

Local public health departments receive approximately 40 percent of the Preventive Health and Health Services block grants nationally. The proportion varies among states from less than 5 percent to almost 100 percent. The block grant funds fulfill three critical purposes. First, they enable states to address critical unmet public health needs. The coexistence of other federal categorical public health funds does not mean that available categorical funds are sufficient or available to address all problems. They are not. Improving chronic disease prevention through screening programs and programs that promote healthy nutrition and physical activity are prime examples of activities to which many jurisdictions devote PHHS funds. Forty



percent of fiscal year 2004 block grant funds were spent on chronic disease prevention, including prevention of obesity, stroke, heart disease, cancer, diabetes, and dental caries.

Second, PHHS funds provide some flexible funding to address unexpected problems or problems that are unique to a particular geographic area. West Nile virus, a fully preventable disease spread to humans by mosquitoes, is one good example. Third, PHHS funds provide leverage for more funds and in-kind resources from non-federal sources. In one southern state, local health departments collectively used \$2.77 million in block grant funds to establish new prevention programs and generate \$5 million in additional resources for those programs.

States are fully accountable to the Department of Health and Human Services for their expenditures of block grant funds and report how much money they spend by specific program area. In those states where local health departments receive a significant amount of PHHS funds from the state, local prevention efforts will diminish. Local and state health departments are key leaders and providers of population-based prevention programs. They work to keep prevention in the public eye and they build on programs that have been proven effective in reducing disease and preventing premature death. As health care costs escalate, reducing the nation's commitment to prevention by eliminating the PHHS block grant and weakening state and local public health departments is unwise and uneconomic.

The National Association of County and City Health Officials (NACCHO) is the organization representing the almost 3,000 local public health departments in the United States.

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PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS

INTRODUCTION

I am honored to testify in support of fiscal year 2006 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNS).

Good morning Mr. Chairman. My name is Brenda Lax and I have been the Foster Grandparent Program Director with the City of Kansas City, Missouri for the past 17 years. I am here in my capacity as President of the National Association of Foster Grandparent Program Directors (NAFGPD). 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. This year we will celebrate our 40th Anniversary of engaging low-income seniors in service to children with special needs with a reception on September 21, 2005 here in Washington, DC. On behalf of NAFGPD members across the country, I would like to extend an invitation to you and your staff to join us for this special occasion.

Mr. Chairman, I would like to begin by thanking you and the distinguished members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our programs. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. I also want to acknowledge your outstanding staff for their tireless work and very difficult job they have to "make the numbers fit"—an increasingly difficult task in this budget environment.

Last year I had the great privilege of testifying before the House Subcommittee about the fiscal year 2005 budget request for FGP. While it was a great honor to be there, I was compelled to deliver some very disappointing news—a cut of some \$3.5 million was proposed for our programs across the country. Well, Mr. Chairman under your leadership the Subcommittee not only rejected this misguided cut, but provided an increase of nearly \$2 million over the fiscal year 2004 enacted level. NAFGPD was very glad to see this ill-conceived cut rejected, and we believe your action sent a message about our programs—they are alive and well and quite worthy of scarce federal resources.

Thanks to your action in the fiscal year 2005 appropriations process, Mr. Chairman, the fiscal year 2006 budget request for FGP does not suggest another significant cut to our programs. Instead, the fiscal year 2006 budget provides an increase of \$634,000 (.5 percent) for headquarters-based administrative functions such as training and technical assistance. While NAFGPD was pleased to see our programs

not slated for a cut, we remain concerned that the Corporation's request does not provide any new funding where it is needed most—in the field. All of us recognize the spending constraints placed on the President and, most importantly on you and the Appropriations Committee, Mr. Chairman. However, in a time of such scarce federal resources, NAFGPD believes strongly that any new funding should flow to our programs in the field where it is most urgently needed, not CNCS headquarters.

NAFGPD respectfully requests the subcommittee to provide \$116.440 million for the Foster Grandparent Program in fiscal year 2006, an increase of \$5.016 million over the fiscal year 2005 level. This critical funding will ensure the continued viability of the Foster Grandparent Program, and allow for important expansion of this unique program. Specifically, this proposal would fund a 3 percent cost of living increase for every Foster Grandparent Program and expansion grants to existing programs that would add 372 new low-income senior volunteers to serve children.

#### 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 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 38,700 Foster Grandparent volunteers who give over 36 million hours annually to more than 277,000 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—15 to 40 hours every week, usually 4 hours every day. FGP provides intensive pre-service orientation and at least 48 hours of ongoing 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 Americans 60 years of age or older who are living on incomes at or less than 125 percent of the poverty level the opportunity to serve 15 to 40 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.

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, childcare centers, and juvenile detention facilities. We also provide them with ongoing 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 that has been learned the hard way—through experience.

Within budgetary constraints, FGP is engaging older people who are not usually asked to serve and those usually considered as needing services rather than being able to serve: 86 percent are 65 or older and 45 percent come from various ethnic groups.

#### FGP: THE CHILDREN

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 and terminal illness. Of the children served, 7 percent are abused or neglected, 26 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, 85 percent of the children served by Foster Grandparents are under the age of 12, with 39 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. Nearly one-half of FGP volunteers serve nearly 12 million hours annually addressing literacy and emergent-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.

#### FGP: THE VOLUNTEER SITES

The Foster Grandparent Program provides agencies and organizations providing services to special-needs children with a consistent, reliable, invaluable extra pair of hands 15 to 40 hours every week to assist in providing these services. Seventy-one percent of FGP volunteers serve in public and private schools as well as sites that provide early childhood pre-literacy services to very young children, including Head Start.

#### FGP: COST-EFFECTIVE SERVICE

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 2003 valuation for one hour of volunteer service (\$17.19/hour), the value of the service given by Foster Grandparents annually is over \$618 million, and represents a 5-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 in-kind donations contributed by communities to support FGP. For example, FGP's fiscal year 2001 federal allocation was matched with \$40 million in non-federal donations from states and local communities in which Foster Grandparents volunteer. This represents a non-federal match of 42 percent, or \$.42 for every \$1.00 in federal funds invested—well over the 10 percent local match required by law.

#### NAFGPD'S FISCAL YEAR 2006 BUDGET REQUEST

Given the dramatically expanding number of low-income seniors eligible to serve and the staggering number of troubled and challenged children in America today, we respectfully request that the Subcommittee provide \$116.440 million for the Foster Grandparent Program in fiscal year 2006, an increase of \$5.016 million over fiscal year 2005. This critical funding will ensure the continued viability of the Foster Grandparent program, and allow for an expansion of this important program.

The requested increase would be allocated for the following purposes, in order of priority:

1st.—Award an administrative cost increase of 3 percent to each existing Foster Grandparent Program in order to maintain quality, enable recruitment and sustain the important work already being done by programs.

2nd.—In accordance with the Domestic Volunteer Service Act (DVSA), designate one-third of the increase over the fiscal year 2005 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.

This funding proposal will generate opportunities for approximately 372 new low-income senior volunteers contributing in excess of 400,000 hours of service annually to more than 2,000 additional children.

The message is clear: (1) the population of low-income seniors available to volunteer 15 to 40 hours every week is increasing; (2) communities need and want more Foster Grandparent volunteers and more Foster Grandparent Programs. FGP respectfully requests increased funding that will address our most pressing need: a 3 percent administrative cost increase that will enable the program to expand its reach across the nation. The Subcommittee's continued investment in FGP now will pay off in savings realized later, as more seniors stay healthy and independent through volunteer service, as communities save tax dollars, and as children with special needs are helped to become contributing members of society.

Mr. Chairman, in closing I would like to again thank you for the subcommittee's support and leadership for FGP over the years. NAFGPD takes great comfort in knowing you and your colleagues in Congress appreciate what our low-income senior volunteers accomplish every day in communities across the country.

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PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN)—representing more than 1,200 nursing schools and health care agencies, some 18,000 individual members composed of nurses, educators, administrators, public members, and 18 constituent leagues—appreciates the Subcommittee's past support for nursing education and your continued recognition of the important role nurses play in the delivery of health care services. We are concerned, however, that the advancements made by Congress to help alleviate the nursing shortage will be lost during the fiscal year 2006 appropriations process unless additional resources are expended. NLN urges your continued support for Title VIII—Nursing Workforce Development Programs by ensuring that these programs are funded at a minimum level of \$210 million for fiscal year 2006. To put this funding request into perspective, in 1974, during the last serious nursing shortage, Congress appropriated \$153 million for nurse education programs. In today's dollars that would equate to \$592 million, approximately four times what the federal government is spending now.

Today's nursing shortage is very real and very different from any experienced in the past. The current shortage is evidenced by an aging workforce and an inadequate number of people entering the profession. Schools of nursing are suffering from a continuing and growing shortage of faculty, which prevents these institutions from admitting many qualified students who are applying to their programs. A recent NLN survey of nursing programs at all levels shows that an estimated 125,000 qualified applicants were turned away from nursing programs for the academic year 2003–2004 because of the severe faculty shortage. The supply of appropriately prepared nurses and nursing faculty is inadequate to meet the needs of a diverse, aging population, and this shortfall will grow more serious over the next 5 years.

Congress did an admirable job of passing the Nurse Reinvestment Act in 2002. The new monies used to fund loans and scholarships are appreciated. However, it has become abundantly clear that significantly more funding is required to even minimally meet the existing need.

NLN's Faculty Survey conducted in 2002 concludes that not enough qualified nurse educators exist to teach the number of nurses needed to ameliorate the nursing shortage. Subsequent information indicates that this situation is getting more serious and is not expected to improve in the near future, since an inadequate number of nurse educators are currently in the education pipeline.

The NLN Survey found three trends influencing the future of nursing education over the next decade:

—*The aging of the nurse faculty population.*—An average of 1.3 full-time faculty members per program left their positions in nursing education in 2002. About half the Survey respondents had at least one unfilled budgeted full-time faculty position and some have as many as 15 such positions. 36.5 percent of faculty who left their positions in the preceding year did so because of retirement; 8.6 percent of faculty were 61 years of age or older; and 75 percent of the current faculty population is expected to retire by 2019.

Approximately 1,800 full-time faculty members leave their positions each year. About 10,000 master's level nurses graduate per year, 15 percent of whom would have to go into teaching just to maintain the status quo. Since this is highly unlikely, the gap between unfilled positions and the candidate pool will widen significantly.

—*The increasing number of part-time faculty.*—The number of part-time faculty has increased notably since 1996—nearly 17 percent in baccalaureate programs and 14 percent in associate degree programs. Part-time faculty now provides approximately 23 percent of the estimated number of faculty FTEs.

Part-time employees are often not an integral part of the design, implementation, and evaluation of the overall nursing education program. Many may hold other positions that often limit their availability to students. Further, many part-time faculty have not been prepared for the faculty role.

—*The large number of nursing faculty who are not prepared at the doctoral level.*—Approximately half the full-time faculty in baccalaureate and higher degree programs hold a doctoral degree. In associate degree programs, doctorally prepared faculty account for only 6.6 percent of the total faculty and the number is slightly more than 5 percent in diploma programs. Only 350 to 400 nursing students receive doctoral degrees each year and the pool of doctorally prepared candidates for full-time nursing professorships is very limited.

Educators without doctoral degrees may lack credibility within a university setting and have limited opportunities to assume leadership positions. Institutions with low numbers of doctorally prepared educators may be less likely to get funds to support research or educational innovations.

As important as educational incentives are for future practicing nurses, the scholarships for doctoral students who will instruct the next generation of nurses are even more critical. Please do not allow us to lose ground in the fight against the nursing shortage. Fund Title VIII—Nursing Workforce Development Programs at a level commensurate with the severity of the health care crisis facing the nation today.

Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those in this country who will need our care. If you have any questions about NLN's position or we can be of further assistance to you, please feel free to contact Kathleen Ream, NLN Manager of Government Affairs, at 703-241-3974.

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#### PREPARED STATEMENT OF THE NATIONAL MENTAL HEALTH ASSOCIATION

Thank you for this opportunity to submit testimony to the Subcommittee and to address the important issue of mental health. The National Mental Health Association (NMHA), the country's oldest and largest advocacy organization addressing all aspects of mental health and mental illness, represents over 340 affiliates throughout the country. NMHA is uniquely positioned to speak to the entire mental health and substance abuse portfolio including prevention, early intervention, treatment, and research.

NMHA would like to thank Chairman Regula and Reps. Obey and Kennedy for your leadership and for your strong support in winning increases last year for mental health programs. However, we are deeply troubled by the Administration's current proposal to cut mental health services at the Center for Mental Health Services (CMHS) by a dangerous 7 percent (from \$901 to \$837 million) and to increase funding for the National Institutes of Health (NIH) by less than 1 percent. We hope to highlight the tremendous need for mental health services in communities throughout the country and why it is imperative that we make an investment not cuts in mental health.

#### CALL TO MAKE MENTAL HEALTH A NATIONAL PRIORITY

NMHA strongly urges you to make mental health a national priority. In creating the Commission on Mental Health, President Bush emphatically declared that "Our country must make a commitment: Americans with mental illness deserve our understanding, and they deserve excellent care. I look forward to . . . fixing the [mental health] system, so that Americans do not fall through the cracks."

These are not cracks; these are, at this time, unbridgeable chasms. As we know and as corroborated in a December 2004 New York Times editorial, the robust community-based mental health system that national leaders envisioned would replace the country's reliance on warehoused institutional care never materialized. As a result, an astounding 80 percent of children entering the juvenile justice system have mental disorders, and prisons and jails have become de facto mental hospitals, but without the treatment that would allow individuals with a mental illness to control their symptoms and organize their lives.

The President's New Freedom Commission on Mental Health, the first such commission in over 25 years, recommended a fundamental transformation of the Nation's approach to mental health care. This transformation must ensure that mental

health services and supports actively facilitate recovery, and build resilience to face life's challenges—with consumers active participants in designing and developing their plans of care. The Commission also found that our nation's failure to make mental health a priority is a national tragedy. A measure of the scope of that tragedy is the disproportionately high number of individuals with mental illness in the corrections system as well as over 30,000 lives lost annually to suicide—a loss, the Commission states, that is largely preventable.

#### UNTENABLE FISCAL YEAR 2006 MENTAL HEALTH BUDGET CUTS

Although mental illness (the chronic disease of the young) ranks first in the United States in terms of causing disability, the proposed fiscal year 2006 budget for the Center for Mental Health Services at SAMHSA would shrink funding for the federal government's lead mental health agency to virtually the level of support provided the agency for fiscal year 2002. Cutting a mental health budget to fiscal year 2002 levels at a time that more than 67 percent of adults and nearly 80 percent of children who need mental health services do not receive treatment is hardly a formula for making mental health a national priority.

NMHA strongly urges the Subcommittee to reverse the proposed 7 percent cut or loss of nearly \$70 million to mental health services at the Center for Mental Health Services (CMHS).

In particular, we urge you to reverse the following proposals in the Administration's budget for the Substance Abuse and Mental Health Services Administration:

- The proposed cut in funding for a successful youth-violence prevention program by nearly a third, from \$94 to \$67 million;
- The proposed cut in funding for jail diversion program by nearly 50 percent, from \$7 to \$4 million;
- The proposed cut in funding of an additional \$40 million in CMHS' important Programs of Regional and National Significance account—in essence slashing funding from an account aimed at much needed priority programming; and
- The proposed cut in funding for substance abuse prevention by 7 percent, from \$198 to \$184 million.

In addition, we urge you to build on the Administration's proposal to:

- Level fund critical youth suicide-prevention efforts, the children's systems-of-care, the homelessness (PATH), PAIMI and elderly programs, the mental health and substance abuse block grants, as well as the Consumer TA Centers; and
- Provide an increase of only 0.4 percent, on average, for research activities at the National Institutes of Mental Health, Drug Abuse, and Alcohol Abuse and Alcoholism.

Lastly, we support the Administration's \$6 million increase request for the State Infrastructure Grants, which will likely fund 11 grants with the proposed new total of \$26 million, to assist States with planning and implementing the Commission's call for transformation of state mental health services across multiple service systems.

#### YOUTH VIOLENCE PREVENTION: A WHOLLY UNWARRANTED BUDGET CUT

Recent tragic events illustrate what we believe are critical failures in priority-setting in the SAMHSA budget. This month's horrible shootings at Minnesota's Red Lake High School, the most violent school slaying since Columbine, is a reminder that youth violence is still prevalent and underscores the need for every school house to be prepared to deal with traumatic, tragic events. Surely this incident is emblematic of the shortsightedness of the Administration's proposed devastating cut of nearly 33 percent or \$27 million to youth violence prevention—the Safe Schools/Healthy Students (SS/HS) program—at CMHS.

As CMHS' major school violence prevention program, the SS/HS initiative addresses school violence prevention through a wide range of early childhood development, early intervention and prevention, suicide prevention, and mental health treatment services. The primary objective of this grant program is to promote healthy development, foster resilience in the face of adversity, and prevent violence. The President's Commission report highlighted the need for the mental health system to coordinate better with other federal agencies. This landmark program, administered jointly with the Department of Education (Safe and Drug Free Schools Office) and the Department of Justice (Office of Juvenile Justice and Delinquency Prevention), does just that.

The Red Lake School shooting and other such shootings underscore the tremendous mental health needs of young people that too often go unmet. One in ten children suffers from a mental disorder severe enough to cause some level of impairment. Even more children experience psychiatric trauma, or emotional harm, which

is essentially a normal response to an extreme event that may or may not happen with some regularity.

This Subcommittee should make investments not only in the area of youth violence prevention, but also invest in Jail Diversion programs designed to keep young people at home and in their communities as they get care. This is not the time to cut funding for programs that help to protect our nation's youth.

#### LACK OF COMMUNITY MENTAL HEALTH SERVICES

While we call on the Subcommittee to reverse the alarming cuts proposed in the SAMHSA budget, we urge that the Subcommittee also provide needed increases in funding. To illustrate the magnitude of needs that plead for attention, we urge that you take steps to address the shocking findings highlighted by Sen. Susan Collins (R-ME) whose hearing last year spotlighted the devastating reality that, every day, about 2,000 children and adolescents are warehoused in juvenile detention centers around the country simply because community mental health services are unavailable. An estimated \$100 million of taxpayers' money is spent on the detention of these youth awaiting community mental health services. Shouldn't that \$100 million and other precious resources be invested in the community rather than in the corrections system to provide cost-effective, quality mental health services? Consider the outrage that would be heard if 2,000 young people with ANY other illness not only went without treatment, but were involuntarily institutionalized as well.

NMHA agrees with Senator Collins that "another consequence of our tattered 'safety net' for children with mental illness [is] the inappropriate use of juvenile detention centers as 'holding areas' for young people who are waiting for mental health services. Like custody relinquishment [of children with mental disorders], these inappropriate detentions are a regrettable symptom of a much larger problem, the lack of available, affordable, and appropriate mental health services and support systems."

With this tragic situation in mind, we urge you to consider, for example, a greater investment in the Children's Mental Health Services program that would allow CMHS to expand beyond the 92 grants in 46 States that have provided services to approximately 54,343 children from 1993–2004. This program, which scored highly in the OMB PART review/evaluation, has only served children in 274 or 9 percent of the 3,142 counties in the United States.

#### NEEDS ARE INCREASING, AND APPROACHING A MENTAL HEALTH STATE OF EMERGENCY

The need for mental health services is ever-escalating for both young people and adults, and gaining ever-wider recognition. To illustrate, a February 2005 study found that U.S. hospital emergency departments greatly under-diagnose psychiatric disorders. Investigators from Louisiana State University examined records of more than 33,000 patients and discovered an overall psychiatric disorder rate among patients of 5.27 percent—far below the national rate of 20 percent to 28 percent. The researchers believe this points to large numbers of missed diagnoses. Last July a county in Nevada declared a "State of Emergency" after many individuals with mental illness overcrowded the state's hospitals. In Nebraska, the state last February reported its mental health system to be in crisis. And with the fifth-highest suicide rate in the nation, West Virginia's Gazette-Mail concluded earlier this year that the state is in the midst of a "mental health crisis."

Broad societal mental health needs too often go unrecognized. As the nation grapples with an obesity epidemic, for example, there has been insufficient recognition of the link to mental health. Yet mental health issues are often closely intertwined with other chronic illness. In the case of obesity, for example, we can expect individuals who suffer from obesity to be at risk for heart disease. Two decades of NIMH research have shown that people with heart disease are more likely to suffer from depression than otherwise healthy people, and conversely, that people with depression are at greater risk for developing heart disease. With sharp cutbacks in the already modest (PRNS) funding available to the Center for Mental Health Services to address priority needs, any opportunity that might exist to address such comorbidities appears futile. Yet such a focus could pave the way for the one in three people who have survived a heart attack and experience major depression in a given year to improve their overall health and lessen the fiscal burden on the nation's health care system.

#### RETURNING SOLDIERS

It has been reported that through the end of September 2004, nearly 900 troops had been evacuated from Iraq by the Army for psychiatric reasons, included attempts or threatened attempts at suicide. And a study of members of combat infan-

try units deployed to Iraq in 2003 published in the *New England Journal of Medicine* (July 1, 2004), researchers found evidence of major depression, anxiety, or PTSD after combat duty in approximately one of every six of these troops. Dr. Stephen C. Joseph, an assistant secretary of defense for health affairs from 1994 to 1997, declared that “the mental health consequences are going to be the medical story of [the Iraqi] war.” We should not assume, however, that those bearing the psychic scars of this war will necessarily seek treatment from the Defense Department or the Department of Veterans Affairs. The study in *New England Journal* was particularly troubling in that regard in finding that most veterans who appeared to have combat-related mental health problems avoided seeking the treatment available in the military, due principally to stigma. That finding suggests that for many veterans war-related mental health problems may go unaddressed for a period of time. In many instances, an already overburdened public mental health system may be called on to meet their needs.

At a minimum, this problem calls for a robust, multi-pronged campaign to renew and more fiercely combat the enormous stigma in key sectors of American society, such as among service-members. Where stigma and misperceptions regarding mental health problems fuel resistance to early intervention, one can foresee that these problems will simply persist and worsen. Yet with a sharply diminished budget, it is highly unlikely that SAMHSA could even consider a new anti-stigma effort.

#### SUICIDE

Yet another very troubling dimension of the SAMHSA budget is its “status quo” approach to public health crisis. Both the Institute of Medicine and the President’s New Freedom Commission on Mental Health have highlighted that mental illness plays a major role in the over 650,000 attempted suicides in America every year—30,000 suicides are completed. Almost twice as many individuals die from suicide than homicide yet hundreds of millions are spent on law enforcement and corrections facilities to prevent and protect Americans from homicides while suicide prevention funding under the proposed CMHS budget would be held to a mere \$16.5 million. We urge the Subcommittee to heed this disparity and bring funding for suicide prevention efforts more closely in line with the scope of this public health crisis.

The tragedy that befell Sen. Gordon Smith and his family when his son took his life did shine a spotlight on this unspeakable crisis. Last year, Congress enacted the Garrett Lee Smith Memorial Act to: (a) support the planning, implementation, and evaluation of organized activities involving statewide youth suicide intervention and prevention strategies; (b) authorize grants to institutions of higher education to reduce student mental and behavioral health problems; and (c) authorize funding for the national suicide prevention resource center. The program will provide early intervention and assessment services, including screening programs, to youth who are at risk for mental or emotional disorders that may lead to a suicide attempt, and that are integrated with school systems, educational institutions, juvenile justice systems, substance abuse programs, mental health programs, foster care systems, and other child and youth support organizations.

Suicide is a problem of enormous scope and demands a response commensurate with its enormity. The truly tragic aspect to suicide is how largely preventable this crisis is. It is not just young people at risk of suicide deaths, older Americans are also at great risk. We urge the Subcommittee to increase both youth-suicide prevention funding and support for the Elderly program at CMHS to deal with suicide and other issues endemic to an aging population.

#### CLOSING

Shrinking CMHS program funding to fiscal year 2002 dollar levels is a very troubling response to a landmark Presidential commission’s call to make mental health a national priority. But a budget decline of this magnitude would have concrete implications in communities across this country. It would, for example, mean closing the door to states and communities that badly need help to improve mental health service-delivery. It would mean no help to anguished school systems that are struggling to achieve the twin goals of school-safety and healthy-students in the face of the threat of more Columbines and Red Lakes. It would mean despair for young people languishing in juvenile detention facilities across the country while they wait for community mental health treatment and families forced to relinquish custody of their children to secure desperately needed mental health services.

Without a seismic shift in the level of priority the Federal government gives to mental health, and a corresponding investment in research, supports and services, we can expect to see a disproportionate numbers of individuals with mental illness who attempt and complete suicide or languish in corrections facilities.



By making mental health a more robust funding priority, this Subcommittee could dramatically change the lives of millions of Americans, improving not only their well-being but our nation's productivity. And by investing in early intervention services and in an array of other mental health services and supports, precious resources at the state and federal level would be saved by stemming the flow of resources being spent in corrections or other systems that deliver mental health services that are not as cost-effective and at a lower quality than providing those services in the community.

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#### PREPARED STATEMENT OF THE NATIONAL NURSING CENTERS CONSORTIUM

The NNCC (National Nursing Centers Consortium) appreciates the opportunity to submit written comments for the record regarding funding for nursing workforce and research programs in fiscal year 2006. This testimony does not include a monetary request. Instead, the NNCC requests that this subcommittee support the creation of a new grant program under the jurisdiction of the Health Resources and Services Administration's (HRSA's) Bureau of Health Professions (BHP) that would enable the Centers for Medicare and Medicaid Services (CMS) to issue nurse-managed health centers (NMHCs) prospective payment reimbursement for their Medicare and Medicaid patients.

#### NNCC BACKGROUND

The NNCC is the first nation wide association of nurse-managed health centers (NMHCs) in the United States. The organization currently represents over 100 NMHCs and individual members in 35 states. These centers are typically community-based non-profit organizations or are affiliated with university-based schools of nursing. The fact that many NNCC member centers are affiliated with schools of nursing allows them to act as teaching centers for new nurses entering the workforce. Along with fulfilling this important role with regard to nursing education, these centers also provide a host of primary care, health promotion and disease prevention services to medically underserved patients living in both urban and rural communities. NNCC member centers are run by nurse practitioners in partnership with the communities they serve. Many NMHCs have established community advisory boards that give the community a role in determining the future of the center and the services provided. Along with nurse-practitioners, these services may also be provided clinical nurse specialists, registered nurses, health educators, community outreach workers, health care students and collaborating physicians.

The vision of the NNCC is to improve the health of communities through neighborhood-based health care services that are accessible, acceptable, and affordable. The mission is to strengthen the capacity, growth, and development of nurse-managed health centers to provide quality health care services to vulnerable populations and to eliminate health disparities in underserved communities.

#### THE FINANCIAL CRISIS FACED BY NURSE-MANAGED HEALTH CENTERS

Many NMHCs were initially established with the help of Nurse Practice and Retention grants from the BHP. However, of the 70 grantees that received Division of Nursing (DON), grants to establish nurse-managed health centers between 1993-2001, 27 or 39 percent have been forced to close. There are two main reasons why such a high percentage of DON funded NMHCs are no longer in operation. The first reason is that DON has shifted its funding priorities to nurses working in acute care settings, and is no longer funding NMHCs. The second reason is that even though a recent study conducted by the NNCC and sponsored CMS found that NMHCs are safety-net providers, they do not have access to the prospective payment system (PPS), which is offered to other safety-net providers such as Community Health Centers (CHCs) and Federally Qualified Health Centers (FQHCs).

Under PPS, CHCs/FQHCs are able to offset the cost of caring for the uninsured because they receive a higher level of reimbursement for their Medicare and Medicaid patients. Even though NMHCs also see a high percentage of uninsured patients they cannot offset these costs through PPS. Without PPS, NMHCs are forced to depend on low capitation payments from managed care organizations (MCOs) and unreliable private grants. These payments and grants are not sufficient to cover the costs of operating NMHCs.

For example, the average cost of caring for a Medicaid recipient at a NMHC is about \$540 per year. However, Medicaid MCOs pay an average annual capitation payment of about \$144 for each Medicaid patient. This means that capitation payments only cover about 26 percent of the costs associated with caring for Medicaid

patients. NMHCs are forced to seek outside funding to recover the other 74 percent of these costs. Assuming the NMHC is able to cover these costs, the center must then take into account the costs associated with caring for their uninsured clients that are and not eligible for capitation payments. About 46 percent of the clients receiving care at NNCC member centers around the nation are uninsured.

In contrast, CHCs and FQHCs with access to PPS are able to recover about 89 percent of the costs associated with their Medicaid clients. This increased revenue allows these centers to direct a higher percentage of their resources to covering the cost of caring for their uninsured patients. In addition, CHCs receive an average payment of \$250 for each uninsured patient. PPS helps to ensure that CHCs/FQHCs remain financially viable. If NMHCs do not also gain access to PPS reimbursement many more of these centers will be forced to close leaving thousands of medically underserved and uninsured clients without access to critical primary care services. Congress itself has recognized the tremendous financial challenges faced by NMHCs, and has published language, "encouraging HRSA to provide alternative means to secure cost-based (or PPS) reimbursement for NMHCs" (Senate Report 108-345 (2005) p.37).

Earlier this year the Senate Appropriations Committee praised NMHCs for the important work they are doing to reinforce America's health care safety-net. The committee stated, "Nurse-Managed Health Centers (NMHCs) serve a dual function in strengthening the health care safety-net by providing health care to populations in underserved areas and by providing the clinical experiences to nursing students that are mandatory for professional development." (Senate Report 108-345 (2005) p.37). If Congress truly values NMHCs this subcommittee should move to ensure that they have access to PPS reimbursement.

NNCC requests that this subcommittee support the creation of a new grant program under which HRSA's BPHr would be allowed to distribute grants through which CMS could issue NMHCs PPS reimbursement. The most likely place for BPHr to find the authority to issue such grants would be under Title VIII of the Public Health Service Act (PHSA). Placing the new grant program under Title VIII of the PHSA would allow NMHCs to retain their emphasis on education and nursing workforce development. The NNCC also requests that any NMHCs, which previously received start up funding through DON, be automatically granted access to the newly created PPS. As mentioned above, there are still about 48 NMHCs in operation around the country which were established with the help of DON grants. However, shifting funding priorities at DON have left these centers in need of a stable source of funding. Granting them automatic access to PPS would make them financially viable and allow them to provide a full range of primary care, health promotion and disease prevention services to their patients. These centers record close to 600,000 client encounters each year. Lastly, CHCs receive approximately \$250 every year for each of their uninsured patients. BPHr should be given the discretion to provide similar grant funding to NMHCs that provide care to a high percentage of uninsured clients.

#### CONCLUSION

We thank you for this opportunity to discuss the financial crisis faced by NMHCs and the significance of maintaining their financial sustainability. The NNCC is ready to assist policy makers in granting NMHCs PPS reimbursement, and has already drafted a model bill that would accomplish this goal. If the above steps are taken the NNCC believes the future of these important safety-net providers will be secure for years to come.

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#### PREPARED STATEMENT OF THE NATIONAL ORGANIZATIONS RESPONDING TO AIDS (NORA) COALITION

##### RECOGNIZING THE CHALLENGES AND LOOKING TO THE FUTURE

The year 2005 brought with it a new Congress and a new Administration, yet for people living with, and at risk for, HIV and the organizations and agencies that serve them, things have remained much the same. For the fourth year in a row federal funding for the domestic HIV/AIDS portfolio remains level, and for the past two years funding has been reduced through funding rescissions. For the fifth consecutive year, the Centers for Disease Control and Prevention (CDC) maintains that there are 850,000-950,000 people living with HIV in the United States, despite a

minimum of 40,000 new infections each year.<sup>1</sup> And once again we find ourselves challenged to make a noticeable difference in the course of the HIV epidemic.

Since 2000, the CDC has estimated that there were 850,000–950,000 people living with HIV in the United States. Since that time, the CDC has reported that there are approximately 40,000 new HIV infections, and 15,000 deaths from AIDS related causes, in the United States each year.<sup>2</sup> (This is a minimum number; recent data suggests that we may be actually seeing 43,000–44,000 additional new infections each year.) Thus, by simply doing the math it would seem that today, in 2005, there are roughly 125,000 more people living with HIV in this country than there were just five years ago—for a total of 975,000–1,075,000 HIV positive Americans. In other words, 1 million people.<sup>3</sup>

Twenty-four years after the start of the HIV epidemic one million people are living in the United States with HIV—and that number continues to grow each and every day. Despite all the progress that has been made, from the development of new treatments and therapies to increased availability of testing and counseling services, the epidemic here at home is still far from over.

The U.S. domestic response has historically been a patchwork of services, ranging from the work of community-based organizations to that of agencies of the federal government, each of which continues to play a critical role in addressing the epidemic. Since the beginning the thread that has bound all of these pieces together has been the financial support of Congress and the White House. Unfortunately, recent fiscal constraints have caused that thread to fray—to the point where some of the pieces are threatening to come undone. It is increasingly clear that unless we reengage ourselves in the real work of responding to this epidemic we will no longer be able to maintain the public health systems that have until now have been the true successes in addressing HIV in the United States.

Of special note, of the 1 million people who are currently living with HIV in the United States, CDC and the Health Resources and Services Administration (HRSA) estimate that roughly one half are accessing regular medical care.<sup>4</sup> On one level that is a very important accomplishment. 500,000 people are receiving the live-saving treatment and medical support that they need because our government made an investment and a commitment to help through the establishment of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and through the commitment of additional resources to existing programs. However, the fact remains that the other half—another 500,000—are not in care, either because they are unaware of their HIV status or because of financial and/or other barriers that are keeping them from getting the care and treatment that they need. This grim statistic has remained unchanged for the past five years. The challenge before us now is to find a way to tip the balance.

If we are going to provide care and support services for those 500,000 Americans currently not in care we must first face up to the reality of the challenge that lies before us. Most of the programs within the domestic federal HIV portfolio have been level-funded and/or cut for the past four fiscal years. Many are now facing their lowest funding levels in recent memory—despite the fact that they are seeing an increasing demand for services. We are now finding ourselves straining to meet the needs of the 500,000 we already serve, all the while aware of the need to reach an additional 500,000 whose needs we have not even begun to assess or address. Despite all of our best efforts we are still not reaching the people who need us most. Without access to testing and counseling, and subsequently care and treatment, these people remain unaware of the realities of their HIV infection, and thus unable to maintain their own health and prevent further transmission of the virus. This is simply unacceptable.

Both CDC and HRSA have recently identified the half a million HIV positive people not in care as a top priority for their HIV programs. Beginning with the 2000 reauthorization of the Ryan White CARE Act, HRSA has focused attention on what it has termed “unmet need,” individuals who are HIV positive and aware of their status, but not in care. CARE Act grantees have received instructions from HRSA to prioritize this population in the delivery of services in an attempt to successfully connect these individuals to care. However, no additional resources have been allocated to grantees for this task, and many report that they are already overburdened

<sup>1</sup>Centers for Disease control and Prevention, “Basic Statistics,” 2003. <<<http://www.cdc.gov/hiv/stats.htm#hivest>>>

<sup>2</sup>Fleming, P., et al., “HIV Prevalence in the U.S. 2000,” 9th Conference on Retroviruses and Opportunistic Infections, February 2002.

<sup>3</sup>Ovadiya, Iris, and Tytel, Jessica, AIDS Action.

<sup>4</sup>Fleming, P., et al., “HIV Prevalence in the U.S. 2000,” 9th Conference on Retroviruses and Opportunistic Infections, February 2002.

by their current client load. For example, in the Washington, D.C. metro area newly diagnosed HIV positive clients are being placed on 3 month long waiting lists for doctor's appointments.

In 2003, CDC launched Advancing HIV Prevention (AHP), a new initiative "aimed at reducing barriers to early diagnosis of HIV infection and, if positive, increasing access to quality medical care, treatment, and ongoing prevention services."<sup>5</sup> One of the primary goals of this national initiative is to increase access to HIV counseling, testing, and referral to care. Since the first funds were awarded in 2003, AHP has shown success in linking people to testing through the use of new rapid test technologies; however, it remains to be seen whether or not the CDC can successfully link these people to care—and whether or not HRSA's already overburdened care system can maintain them in services.

Last year NORA chose to focus on building upon our past successes. This year we must look to what we still have left to do. The AHP and unmet need initiatives are working, but we can not expect them to be the definitive solution. The HIV epidemic in this country continues to evolve, and we continue to face unanticipated policy and program challenges. In the past year alone we have seen the initial phases of implementation of the Medicare Modernization Act, the expansion of rapid testing technologies, and emerging concerns about the Food and Drug Administrations (FDA) drug approval process. At the same time the Department of Health and Human Services has committed itself to the goal of reducing by half annual HIV infections in this country by 2010, after realizing that the 2005 goal was out of reach. The federal government must commit to fund, manage, and monitor the domestic response, or else we will find ourselves falling even farther behind in our response to the epidemic.

The challenge before us today is significant, but it is not insurmountable. If we commit to funding that truly meets the needs of people living with, and at risk for, HIV infection then we can change the course of the epidemic.

We know how to provide care.

We know what it takes to link people to medical treatment.

We know how to support its communities living with HIV.

Now is the time to turn knowledge into action.

The chart that follows is NORA's funding recommendations for fiscal year 2006.

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<sup>5</sup>Centers for Disease Control and Prevention, "Advancing HIV Prevention: New Strategies for a Changing Epidemic," September 2003. <<<http://www.cdc.gov/hiv/partners/AHP-brochure.htm>>>

NORA FISCAL YEAR 2006 APPROPRIATIONS REQUESTS FOR FEDERAL HIV/AIDS PROGRAMS

Program	Fiscal year 2006 need	Fiscal year 2005 appropriation	President's fiscal year 2006 request	Change from fiscal year 2005	Fiscal year 2006 NORA recommendations	Change from fiscal year 2005
<b>DEPARTMENT OF HEALTH AND HUMAN SERVICES</b>						
Minority HIV/AIDS Initiative (To be added across multiple HHS programs and included in fiscal year 2002 program totals as indicated).	\$855 million	\$399 million <sup>1</sup>	\$399 million	.....	\$610 million	+ \$411 million
ACF: Runaway and Homeless Youth Act Programs	.....	104 million	114 million	+ \$10 million	140 million	+ 36 million
Agency for Healthcare Research and Quality	.....	319 million	319 million	.....	440 million	+ 121 million
CDC: Total—HIV, STD, TB line	2.33 billion	961.2 million	957.3 million	- 4 million	2.33 billion	+ 1.27 billion
CDC: HIV Prevention and Surveillance	.....	662.6 million	686.6 million	- 4 million	1.5 billion	+ 813.4 million
CDC: STD Prevention	.....	159.7 million	159.7 million	.....	351 million	+ 191.3 million
CDC: TB Prevention	.....	138.9 million	138.9 million	.....	287.3 million	+ 148.4 million
CDC: Viral Hepatitis (Infectious Disease Control line)	.....	17.36 million	17.36 million	.....	100.24 million	+ 82.88 million
CDC: DASH (Chronic Disease Prevention and Health Promotion line)	.....	56.75 million	56.76 million	+ 0.1 million	88.25 million	+ 31.49 million
FDA	.....	1.45 billion	1.5 billion	+ 50 million	1.57 billion	+ 116 million
HRSA: Ryan White CARE Act Total	3.2 billion	2,048 billion	2,058 billion	+ 10 million	2.56 billion	+ 513 million
Title I	.....	610 million	610 million	.....	725 million	+ 115 million
Title II: Care	.....	334 million	334 million	.....	384 million	+ 50 million
Title II: ADAP	.....	787 million	797 million	+ 10 million	1,09 billion	+ 303 million
Title III	1.5 billion (non-add)	196 million	196 million	.....	236.6 million	+ 41 million
Title IV	.....	72.53 million	72.53 million	.....	113.25 million	+ 40.72 million
Part F: AETCS	.....	35 million	35 million	.....	45 million	+ 10 million
Part F: Dental Reimbursement	.....	13.3 million	13.3 million	.....	19 million	+ 5.7 million
HRSA: Consolidated Health Centers	.....	1,733 billion	2,038 billion	+ 304.2 million	2,038 billion	+ 304.2 million
HRSA: Title V	.....	724 million	724 million	.....	755 million	+ 31 million
HRSA: Title X	.....	286 million	286 million	.....	350 million	+ 66 million
Indian Health Service: HIV/AIDS Program	.....	2.68 million	2.79 million	+ 0.1 million	10 million	+ 7.32 million
NIH Office of AIDS Research	3.327 billion	2.92 billion	2.93 billion	+ 12 million	3.1 billion	+ 200 million
Office of the Secretary: Office of HIV/AIDS Policy	5 million	.....	.....	.....	2 million	+ 2 million
SAMHSA: Center for Substance Abuse Treatment Block Grant <sup>2</sup>	.....	1.78 billion	1.78 billion	.....	1.85 billion	+ 71 million
SAMHSA: Center for Substance Abuse Treatment—other	.....	422.4 million	447.1 million	+ 24.7 million	472 million	+ 50 million
SAMHSA: Center for Substance Abuse Prevention <sup>3</sup>	.....	198.7 million	184.3 million	- 14.4 million	210 million	+ 11 million
SAMHSA: Mental Health Block Grant <sup>4</sup>	.....	432.8 million	432.8 million	.....	471.5 million	+ 38.9 million
SAMHSA: Center for Mental Health Services—other <sup>4</sup>	.....	176.7 million	144.1 million	- 32.6 million	191.8 million	+ 15.1 million
SAMHSA: GBHI	.....	40.1 million	34.4 million	- 5.7 million	42.5 million	+ 1.7 million
SAMHSA: PATH	.....	54.8 million	54.8 million	.....	59.8 million	+ 5 million

NORA FISCAL YEAR 2006 APPROPRIATIONS REQUESTS FOR FEDERAL HIV/AIDS PROGRAMS—Continued

Program	Fiscal year 2006 need	Fiscal year 2005 appropriation	President's fiscal year 2006 request	Change from fiscal year 2005	Fiscal year 2006 NORA recommendations	Change from fiscal year 2005
DEPARTMENT OF EDUCATION (DOE)						
Protection and Advocacy for Human Rights .....		16.6 million .....	16.6 million .....		22 million .....	+ 5.4 million
DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)						
HOPWA .....	2.8 billion .....	282 million .....	268 million .....	- 14 million .....	385 million .....	+ 103 million
McKinney-Vento Homelessness Assistance Grant Program .....		1.241 billion .....	1.44 billion .....	+ 199 million .....	1.572 billion .....	+ 331 million
GLOBAL HIV/AIDS PROGRAMS						
<i>President's Emergency Plan for AIDS Relief (PEPFAR)</i>						
HIV/AIDS Programs .....	6.7 billion .....	2.9 billion .....	3.16 billion .....	+ 265 million .....	4.61 billion .....	+ 1.7 billion
<i>Global Fund to Fight AIDS, Tuberculosis and Malaria (non-add)</i>						
Global Fund .....	1.5 billion .....	435 million .....	300 million .....	- 135 million .....	1.5 billion .....	+ 1.06 billion

<sup>1</sup> NOTE.—All fiscal year 2004 amounts include the .80 percent rescission.  
<sup>2</sup> The numbers in this chart reflect the entire budget of SAMHSA for Substance Abuse Treatment; HIV/AIDS programs are included in this total.  
<sup>3</sup> The numbers in this chart reflect the entire budget of SAMHSA for Substance Abuse Prevention; HIV/AIDS programs are included in this total.  
<sup>4</sup> The numbers in this chart reflect the entire budget of SAMHSA for Mental Health Services; HIV/AIDS programs are included in this total.

## PREPARED STATEMENT OF THE NORTH AMERICAN BRAIN TUMOR COALITION

I am Gary L. Kornfeld, a nine-year survivor of a grade 3 oligoastrocytoma and Chair of the North American Brain Tumor Coalition (NABTC). On behalf of the Coalition, I am pleased to offer these comments regarding brain tumor research for the record of the Labor, Health and Human Services, and Education Appropriations Subcommittee. The NABTC, a network of 12 brain tumor organizations, is dedicated to improving treatments for brain tumors and ensuring individuals with brain tumors access to high quality care. The volunteers who comprise the NABTC are survivors, family members, friends, and caregivers, and we know firsthand the devastating effects that brain tumors can have. We are working hard to reduce the suffering from brain tumors and improve the outlook for all who receive this diagnosis.

Each year, approximately 190,000 people in the United States and 10,000 in Canada will be diagnosed with a primary or metastatic brain tumor. Approximately 40,000 individuals in the United States will be diagnosed with primary brain tumors; of this total, more than 18,000 will be diagnosed with malignant brain tumors. Brain tumors are a leading cause of death from childhood cancer, accounting for almost a quarter of cancer deaths in children up to 19 years of age. Brain tumors are the second leading cause of cancer death in young adults ages 20–39.

These numbers, as frightening as they are, do not convey the complete story. The treatment of brain tumors is very difficult, and factors that contribute to these treatment challenges are the location of these tumors and the fact that there are more than 120 different kinds of tumors. Standard therapies for brain tumors include surgery, radiation therapy, and chemotherapy, used either individually or in combination.

## RECENT ADVANCES IN TREATMENT

There have been recent advances in the treatment of glioblastoma multiforme (GBM), or grade IV malignant glioma, which usually causes death in a year. Researchers have found that concurrent administration of a chemotherapy drug, temozolomide, and radiation therapy results in a clinically meaningful survival benefit of two and one-half months for newly diagnosed glioblastoma patients.

These findings were published in the *New England Journal of Medicine* on March 10, 2005.<sup>1</sup> Temozolomide with radiation can be a very significant development for patients with GBM, and the brain tumor community applauds this development. However, much more must be done to extend and improve the lives of those affected by brain tumors. Progress against brain tumors still comes much too slowly.

The NABTC believes treatment strides will come through an enhanced investment in brain tumor research and improved dissemination of information about the best available care for brain tumors. Researchers in the Glioma Outcomes Project recently reported troubling gaps in care of individuals with brain tumors, suggesting that more work needs to be done to guarantee that the best possible therapies are available to all with brain tumors.<sup>2</sup>

## ENHANCE THE INVESTMENT IN BRAIN TUMOR RESEARCH

In 2000, the National Cancer Institute (NCI) and National Institute of Neurological Disorders and Stroke (NINDS) published the report of a brain tumor research advisory panel, called the Brain Tumor Progress Review Group. This report included an aggressive and thoughtful plan for moving brain tumor research and treatments forward. In 2000, the NABTC endorsed the Progress Review Group plan and urged implementation of its key research recommendations. In 2005—half a decade after the report's publication—the NABTC finds that the report still describes a valid and vital plan for brain tumor research. While the continuing relevance of the report is in part a testament to the vision of the Progress Review Group, it is primarily a testament to the troubling lack of progress in brain tumor research and treatment and the failure to implement the report's recommendations.

To advance brain tumor research, the NABTC recommends that:

—NCI and NINDS implement the recommendations of the Brain Tumor Progress Review Group. To ensure that we do not look back from 2010 and observe limited progress on the Progress Review Group plan, the NABTC requests that NCI and NINDS submit to Congress a brain tumor research plan, including timelines and a budget for implementation of the PRG report.

<sup>1</sup>Stupp, et al., "Radiotherapy Plus Concomitant and Adjuvant Temozolomide for Glioblastoma," *New England Journal of Medicine*, March 10, 2005.

<sup>2</sup>Chang, et al., "Patterns of Care for Adults With Newly Diagnosed Malignant Glioma," *Journal of the American Medical Association*, February 2, 2005.

- The Directors of NCI and NINDS appoint leaders of their extramural brain tumor programs without delay. Strong scientific management is necessary to ensure that the nation's financial investment in brain tumor research is utilized as effectively as possible. Extramural research coordinators should be appointed at each institute to ensure that there is proper leadership on brain tumor research issues.
  - Congress provide adequate funding for existing brain tumor research efforts. There are several structures or systems for clinical research on brain tumors, including the brain tumor consortia and the brain tumor specialized programs of research significance (SPOREs), but these programs are not adequately funded to allow investigation of all promising brain tumor treatments and to ensure correlative studies as part of trials.
  - NINDS and NCI convene a special workshop on brain tumor research. Brain tumor research is an area where cross-disciplinary research approaches are absolutely critical, and a workshop on a cutting-edge brain tumor research topic would likely stimulate innovative research efforts. A workshop is an activity that could be undertaken by NINDS in collaboration with NCI.
- For individuals with brain tumors and their families, friends, and caregivers, the NABTC urges a greater sense of urgency among the leaders of NCI and NINDS regarding brain tumor research.

#### ELIMINATE THE TWO-YEAR WAITING PERIOD FOR MEDICARE

Although we realize Medicare is not in the jurisdiction of this Subcommittee, we nevertheless would like to direct your attention to important legislation, introduced by Senator Jeff Bingman (D-NM) and Representative Gene Green (D-TX), that would eliminate the two-year waiting period for Medicare benefits for those who have established eligibility for Social Security Disability benefits. For many individuals with brain tumors, the current 24-month waiting period can result in delays in access to care that extends or improves life.

Thank you again for the opportunity to offer this brief statement on brain tumor research and care.

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#### PREPARED STATEMENT OF THE ONCOLOGY NURSING SOCIETY

The Oncology Nursing Society (ONS) appreciates the opportunity to submit written comments for the record regarding funding for cancer and nursing related programs in fiscal year 2006. ONS, the largest professional oncology group in the United States composed of more than 31,000 nurses and other health professionals, exists to promote excellence in oncology nursing and the provision of quality care to those individuals affected by cancer. As part of its mission, the Society honors and maintains nursing's historical and essential commitment to advocacy for the public good.

This year more than 1.37 million Americans will be diagnosed with cancer and more than 570,000 will lose their battle with this terrible disease. Despite these grim statistics, significant gains in the War Against Cancer have been made through our nation's investment in cancer research and its application. Research holds the key to improved cancer prevention, early detection, diagnosis, and treatment, but such breakthroughs are meaningless unless we can deliver them to all Americans in need. Recent studies have reported 126,000 registered nurse vacancies in hospitals and 13,900 registered nurse vacancies in nursing homes. These statistics create a sizeable barrier to ensuring that all people benefit from breakthroughs in cancer research.

To ensure that all people with cancer have access to the comprehensive, quality care they need and deserve, ONS advocates on-going and significant federal funding for cancer research and application, as well as funding for programs that help ensure an adequate oncology nursing workforce to care for people with cancer. The Society stands ready to work with policymakers at the local, state, and federal levels to advance policies and programs that will reduce and prevent suffering from cancer and sustain and strengthen the nation's nursing workforce.

#### SECURING AND MAINTAINING AN ADEQUATE ONCOLOGY NURSING WORKFORCE

Over the last 10 years, the setting in which treatment for cancer is provided has changed dramatically. An estimated 80 percent of all Americans receive cancer care in community settings including cancer centers, physicians' offices, and hospital outpatient departments. Treatment regimens are as complex, if not more so, than regimens given in the inpatient setting a few years ago. Oncology nurses are on the



front lines in the provision of quality cancer care for individuals with cancer—administering chemotherapy, managing patient therapies and side-effects, working with insurance companies to ensure that patients receive the appropriate treatment, providing counseling to patients and family members, and engaging in myriad other activities on behalf of people with cancer and their families.

Overall, age is the number one risk factor for developing cancer. Approximately 77 percent of all cancers are diagnosed at age 55 and older. Currently, Medicare beneficiaries account for more than 50 percent of all cancer diagnoses and 64 percent of cancer deaths. Over the next 10 to 15 years the number of Medicare beneficiaries with cancer is estimated to double while more than 1.1 million registered nursing vacancies will need to be filled by 2012 to meet growing patient demand and replace retiring nurses. With an increasing number of people with cancer needing high quality health care, coupled with an inadequate nursing workforce, our nation could quickly face a cancer care crisis of serious proportion with limited access to quality cancer care, particularly in traditionally underserved areas. A study in the *New England Journal of Medicine* found that nursing shortages in hospitals are associated with a higher risk of complications—such as urinary tract infections and pneumonia, longer hospital stays, and even patient death. Without an adequate supply of nurses, there will not be enough qualified oncology nurses to provide the quality cancer care to a growing population of people in need and patient health and well being could suffer.

Further, of additional concern is that our nation also will have a shortage of nurses available and able to conduct cancer research and clinical trials. With a shortage of nurses in cancer research, the War against Cancer will take longer because of unfulfilled staffing needs coupled with the reality that in some practices and cancer centers resources could be funneled away from cancer research to pay for the hiring and retention of oncology nurses to provide direct patient care. Without a sufficient supply of trained, educated, and experienced oncology nurses, our nation will falter in its delivery—or application—of the benefits from our federal investment in research.

ONS has joined with others in the nursing community in advocating \$210 million as the fiscal year 2006 funding level necessary to support implementation of the Nurse Reinvestment Act and the range of nursing workforce programs housed at the U.S. Health Resources and Services Administration (HRSA). Enacted in 2002, the Nurse Reinvestment Act included new and expanded initiatives, including loan forgiveness, scholarships, career ladder opportunities, and public service announcements to advance nursing as a career. Despite the enactment of this critical measure, HRSA fails to have the resources necessary to meet the current and growing demands for our nation's nursing workforce. For example, in fiscal year 2004 HRSA received 4,873 applications for the Nurse Education Loan Repayment Program, but only had funding to award 857—a rate of 17.6 percent. Also in fiscal year 2004, the agency received 8,806 applications for the Nursing Scholarship Program, but only could fund 126—a rate of 1.4 percent. Further exacerbating the current situation is that nursing programs turned away more than 125,000 qualified students last year, in part due to a shortage of faculty. If funded sufficiently, the components and programs of the Nurse Reinvestment Act would help address the multiple factors contributing to the nationwide nursing shortage, including the shortage of faculty, decline in nursing student enrollments, and poor public perception of nursing as a viable and worthwhile profession.

ONS strongly urges Congress to provide HRSA with a minimum of \$210 million in fiscal year 2006 to ensure that the agency has the resources necessary to fund a higher rate of Nurse Education Loan Repayment and Nursing Scholarship applications as well as implement other essential endeavors to sustain and boost our nation's nursing workforce. Nurses—along with patients, family members, hospitals, and others—have joined together in calling upon Congress to provide this essential level of funding. One Voice Against Cancer (OVAC)—a collaboration of more than 45 national nonprofit organizations representing millions of Americans—has added a request of \$210 million for the Nurse Reinvestment Act funding to its fiscal year 2006 appropriations advocacy agenda. ONS and its allies have serious concerns that without full funding, the “Nurse Reinvestment Act” will prove an empty promise; the current and expected nursing shortage will worsen and people will not have access to the quality cancer care they need and deserve.

BOOST OUR NATION'S INVESTMENT IN CANCER PREVENTION, EARLY DETECTION, AND AWARENESS

Approximately two-thirds of cancer cases are preventable through lifestyle and behavioral factors and improved practice of cancer screening. Although the potential

for reducing the human, economic, and social costs of cancer by focusing on prevention and early detection efforts remains great, our nation does not invest sufficiently in these strategies. While as a nation we spend almost a trillion dollars a year on our health care system, we only allocate about one percent of that amount for population-based prevention. By the year 2020, cancer and other chronic disease expenditures will reach one trillion dollars or 80 percent of health care costs. The nation must make significant and unprecedented federal investments today to address the burden of cancer and other chronic diseases, and to reduce the demand on the healthcare system and diminish suffering in our nation both for today and tomorrow.

As the nation's leading prevention agency, the Centers for Disease Control and Prevention (CDC) plays an important role in translating and delivering at the community level what is learned from research—especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research. Therefore, ONS joins with our partners in the cancer community—including OVAC—in calling on Congress to provide additional resources for physical activity, nutrition, and tobacco control programs and other cancer-related screening, prevention, and public health education efforts supported through the CDC to support and expand much-needed and proven effective cancer prevention, early detection, and risk reduction efforts. Specifically, ONS advocates the appropriation of \$404 million in fiscal year 2006 for the Centers for Disease Control and Prevention's (CDC) comprehensive cancer, ovarian cancer, breast and cervical cancer early detection, cancer registries, prostate cancer, colorectal cancer, and skin cancer programs. ONS also urges an increase funding for the CDC's physical activity, nutrition, and tobacco-control programs to help reduce risk factors for developing cancer and other chronic diseases, diminish suffering from cancer, and decrease the demand on the healthcare system.

- \$250 million for the National Breast and Cervical Cancer Early Detection Program;
- \$65 million for the National Cancer Registries Program;
- \$25 million for the Colorectal Cancer Prevention and Control Initiative;
- \$25 million for the Comprehensive Cancer Control Initiative;
- \$20 million for the Prostate Cancer Control Initiative;
- \$5 million for the National Skin Cancer Prevention Education Program;
- \$9 million for the Ovarian Cancer Control Initiative;
- \$5 million for the Geraldine Ferraro Blood Cancer Program;
- \$145 million for the National Tobacco Control Program; and
- \$70 million for the Nutrition, Physical Activity, and Obesity Program.

#### SUSTAIN AND SEIZE CANCER RESEARCH OPPORTUNITIES

Our nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). ONS has joins with the entire cancer community in advocating \$30.1 billion for the NIH in fiscal year 2006. This will allow NIH to sustain and build on its research progress resulting from the recent NIH budget doubling effort while avoiding the severe disruption to that progress that would result from a minimal increase.

Cancer research is producing extraordinary breakthroughs—leading to new therapies that translate into longer survival and improved quality of life for cancer patients. We have seen extraordinary advances in cancer research resulting from our national investment that have produced effective prevention, early detection and treatment methods for many cancers. To that end, ONS calls upon Congress to allocate \$5.21 billion to the National Cancer Institute (NCI) in fiscal year 2006 to continue our battle against cancer.

The National Institute of Nursing Research (NINR) supports basic and clinical research to establish a scientific basis for the care of individuals across the life span—from management of patients during illness and recovery to the reduction of risks for disease and disability and the promotion of healthy lifestyles. These efforts are crucial in translating scientific advances into cost-effective health care that does not compromise quality of care for patients. Additionally, NINR fosters collaborations with many other disciplines in areas of mutual interest such as long-term care for older people, the special needs of women across the life span, bioethical issues associated with genetic testing and counseling, and the impact of environmental influences on risk factors for chronic illnesses such as cancer. ONS joins with the nursing community in advocating an allocation of \$160 million for NINR in fiscal year 2006.

## CONCLUSION

ONS stands ready to work with policymakers to advance policies and support programs that will reduce and prevent suffering from cancer this year and sustain and strengthen our nation's nursing workforce. Moreover, ONS maintains a strong commitment to working with Members of Congress, other nursing societies, patient organizations, and other stakeholders to ensure that the oncology nurses of today continue to practice tomorrow and that we recruit and retain new oncology nurses to meet the unfortunate growing demand that we will face as the baby boom generation ages. We thank you for this opportunity to discuss the funding levels necessary to ensure that our nation has a sufficient nursing workforce to care for the patients of today and tomorrow and that our nation continues to make gains in our fight against cancer.

## PREPARED STATEMENT OF THE PROCTER &amp; GAMBLE COMPANY

Procter & Gamble appreciates the opportunity to provide testimony in support of funding for the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM) and pain and distress research under the jurisdiction of the Labor, Health and Human Services, Education and Related Agencies Subcommittee in fiscal year 2006.

As a leader in the development of alternatives to animal testing, P&G is committed to eliminating animal testing for products intended for human use. We are working on a global basis with governments and academia to eliminate regulations that require unnecessary animal testing and to promote the acceptance of alternatives. To date, P&G has devoted significant resources to this effort and helped to develop more than 50 proven alternative methods. Despite these advances, it is acknowledged that state-of-the-art science cannot replace animal research at present and far more research is needed, by governments, academia and the private sector, for the development, promotion and validation of alternative test methods.

## INTERAGENCY COORDINATING COMMITTEE ON THE VALIDATION OF ALTERNATIVE METHODS (ICCVAM)

We were very pleased that Congress enacted Public Law 106-545 by unanimous voice vote in both chambers in 2000. This legislation, introduced by Senator Mike DeWine (R-OH) and Representatives Ken Calvert (R-CA) and Tom Lantos (D-CA), strengthened and made permanent the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). The statute has already begun to enhance the federal government's capacity to evaluate and adopt chemical testing methods that are often faster, cheaper, and more scientifically sophisticated than current methods, as well as more responsive to the public's concerns about the welfare of animals used in toxicity testing. Public Law 106-545 has streamlined the process by which these better methods are validated and assessed, and has eased institutional barriers within federal agencies that discourage their use.

ICCVAM performs an invaluable "win-win" function for regulatory agencies and stakeholders in industry, public health, and animal protection by assessing the suitability of new toxicological test methods that have interagency application. These new (and newly revised) methods include alternative methods that can limit animal use or suffering in testing. After appropriate independent peer review of a new test method, ICCVAM provides its assessment of the new test to the federal agencies that regulate the particular endpoint that the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies' regulatory mandates. This streamlined approach to assess the validation status of new test methods has reduced the regulatory burden of individual agencies, provided "one-stop shopping" for industry, animal protection, and public health advocates to consider test methods, and set uniform criteria for what constitutes a validated test method.

ICCVAM arose from an initial mandate in the NIH Revitalization Act of 1993 for the National Institute of Environmental Health Sciences (NIEHS) to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established an ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from 14 regulatory and research agencies developed NIH Publication No. 97-3981, Validation and Regulatory

Acceptance of Toxicological Test Methods. This report has become the “sound science” guide for consideration of new test methods by the federal agencies and interested stakeholders. After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS’ National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Methods (NICEATM). Representatives from federal regulatory and research agencies have continued to meet, with advice from NICEATM’s Scientific Advisory Committee and independent peer review committees, to assess the validation of new toxicological test methods.

Since its inception, ICCVAM has conducted rigorous evaluations of several test methods and has concluded that these methods are scientifically valid, i.e., have been adequately validated, and are acceptable for specific purposes. These methods include Corrositex, Epiderm, Episkin, and Transcutaneous Epithelial Resistance assays for assessing skin corrosivity; the 3T3 NRU Phototoxicity assay for assessing phototoxicity; the Local Lymph Node Assay for assessing skin sensitization; and the Up and Down Method and various cytotoxicity assays for assessing acute systemic toxicity. In turn, the appropriate regulatory agencies have incorporated these methods into their regulatory practices.

The open public comment process, input by interested stakeholders, and the continued commitment by various federal agencies have all enhanced the ICCVAM process. Now, under Public Law 106–545, ICCVAM is poised to go beyond its largely passive role of assessing the validation status of test methods that have been developed and validated by industry and others. ICCVAM should adopt a more proactive role in developing and validating promising tests methods in partnership with outside stakeholders, to ensure that a steady stream of new test methods are available for review and adoption by the federal government. Such a proactive stance and partnership with stakeholders will enable the federal government to better harness the potential of emerging technologies to meet the challenge of efficiently testing large numbers of chemicals with minimal cost in terms of money and animal lives. With a more proactive approach, ICCVAM could, for example, explore the potential of investigator-initiated and small business grant programs to further its mission.

Adequate funding should be provided for ICCVAM to put the resources in place to ensure the federal government and industry have the best available tools with which to assess the toxic properties of chemicals in commerce. To accomplish this, we respectfully request an earmark of \$3.6 million for fiscal year 2006 and the following Committee Report language:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges NIEHS to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution, and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program’s Road Map and Vision for NTP’s toxicology program in the 21st century.”

#### PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than \$11 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that reduce the amount of pain and distress to which research animals are subjected, nor methods that replace or reduce the use of vertebrate animals in research. NIH may receive \$28.8 billion in fiscal year 2006 if Congress fulfills the President’s budget request. Out of this funding, we seek \$2.5 million (0.009 percent) for research and development focused on identifying and alleviating animal pain and distress. In addition to our request for a specific funding amount, we also urge the Committee to specify in report language that this research should be conducted in conjunction with, or “piggy-backed” onto, ongoing research that already causes pain and distress. Infliction of pain and distress on additional animals is unnecessary, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that is believed to involve moderate to significant pain and/or distress.

The large extent to which animals are used in federally-funded research underscores the importance of earmarking funds for pain and distress research. NIH has a statutory mandate to conduct or support research into alternative methods that produce less pain and distress in animals. This was specified in the NIH Revitalization Act of 1993 regarding a plan for the use of animals in research. Earmarked

funding will assist NIH in meeting this mandate. Additionally, researchers themselves often comment publicly at scientific meetings about the urgent need for funding in order to properly understand and mitigate pain and distress in research animals and to follow Animal Welfare Act and Public Health Service policy requirements to minimize pain and distress.

It is well known that uncontrolled, undetected, and unalleviated pain and distress has adverse effects on animal welfare, which leads to adverse effects on the quality of science. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when pre-clinical animal research results are applied to humans in clinical trials.

A 2001 survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Seventy-five percent of the American public opposes research that causes severe animal pain and/or distress, even when it is health-related. Despite this public concern, NIH has failed to sponsor research and development aimed at determining how to minimize animal suffering and distress in the laboratory.

During the past several years, our organization has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. Furthermore, while human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering).

We urge the Committee to make this small investment of \$2.5 million to promote animal welfare and enhance the integrity of scientific research. We also respectfully request this accompanying committee report language:

"The Committee provides \$2.5 million to support research and development focused on improving methods for recognizing, assessing, and alleviating pain and distress in research animals. No pain and distress should be inflicted solely for the purpose of this initiative, since the investigations can and should be conducted in conjunction with ongoing research that is believed to involve pain and distress under Government Principle IV of Public Health Service Policy, which assumes that procedures that cause pain and distress in humans may cause pain and distress in animals."

Again, we appreciate the opportunity to share our views regarding priorities for the Labor, Health and Human Services, Education and Related Agencies Appropriation Act of fiscal year 2006. We hope the Committee will be able to accommodate these modest requests that will benefit animals, enhance effectiveness of toxicological testing, and improve the quality of research. Thank you for your consideration.

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PREPARED STATEMENT OF THE SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

On behalf of the Society for Animal Protective Legislation (SAPL) and Doris Day Animal League I would like to discuss several important issues within the jurisdiction of this committee. In addition, SAPL endorses the funding request by the Doris Day Animal League for fiscal year 2006 to operate the National Institute of Environmental Health Sciences' (NIEHS) National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) activities for fiscal year 2006.

CRIMINAL ANIMAL CRUELTY CHARGES FILED AGAINST NIH'S ALAMOGORDO PRIMATE FACILITY

For years, the NIH funded the New Mexico-based Coulston Foundation primate testing lab with millions of taxpayer-funded dollars despite the lab's continued violations of the Animal Welfare Act. Compliance with federal animal welfare laws is a

requirement for receipt of federal funds. The Coulston situation resulted in unprecedented regulatory action by the U.S. Department of Agriculture, international media interest, and intense Congressional scrutiny. The NIH's actions at Coulston prompted the House Committee on Energy and Commerce to launch a broad investigation of the mismanagement of billions of dollars in taxpayer-funded grants by NIH.

Under the intense pressure from Congress, the NIH eventually stopped funding the Coulston lab. The agency assumed ownership of the facility located on Holloman Air Force Base, renamed it the Alamogordo Primate Facility (APF), and in June 2001 awarded Charles River Laboratories with a 10-year, \$42 million contract to operate the lab, which houses approximately 265 government-owned chimpanzees. The NIH is legally responsible for the "day-to-day management" of the APF including its "associated animal activities." The APF is an intramural NIH lab and is listed under the agency's Animal Welfare Assurance.

One would think that after the years of Coulston abuses—and the accompanying NIH malfeasance that prompted a Congressional investigation—the agency would be that much more careful to ensure that the lab it now directly owns and manages would comply with the most basic precepts of animal welfare and simple human decency.

One would be wrong.

In September 2004, New Mexico District Attorney Scot Key filed multiple counts of criminal animal cruelty, accusing the NIH's handpicked contractor, Charles River Laboratories, and APF Director, veterinarian Rick Lee, of institutional negligence in the deaths of two chimpanzees and the near-death of a third. The D.A.'s independent criminal investigation found that it was "standard practice" for Charles River to leave critically ill chimpanzees in the "care" of security guards after trained animal care staff repeatedly walked off, clocking out at the end of the workday around 4:00 p.m.

Because the APF is a federal research facility, it is required to comply with the Animal Welfare Act, but the USDA has no jurisdiction to enforce it. In 2001, the New Mexico legislature, prompted by the continuing abuses at Coulston and the federal government's inability to stop them, amended the state's animal cruelty statute to remove the blanket exemption for research facilities.

In September 2003, the NIH was informed that the D.A. had initiated a criminal investigation against Charles River; that APF Director Lee had illegally threatened employees with lie detector tests in an attempt to find out who had leaked information about the treatment of the chimpanzees; and that the allegations were worse than anything ever documented at the Coulston lab. On October 1, 2003, an ad hoc NIH consultant, veterinarian Thomas Butler, conducted a one-day site visit along with the NIH official, Dr. Raymond O'Neill, in charge of overseeing the contract with Charles River. Butler's "site visit" report—compiled in less than one day by an ad hoc NIH consultant with no law enforcement authority—was neither thorough nor an investigation. Indeed, it completely failed to address the heart of the criminal charges: Charles River's abandonment of the three chimpanzees—including Rex, who was unconscious and vomiting—to security guards. In stark contrast to the NIH consultant's report, multiple eyewitnesses named in the D.A.'s months-long independent criminal investigation corroborated the criminal charges.

On March 23, 2005, New Mexico judge Jerry Ritter accepted Charles River's argument that it was engaged in the practice of veterinary medicine, and dismissed the charges; he issued no written opinion regarding the other legal technicalities. By making this argument, Charles River and the NIH have conceded that for them, the "practice of veterinary medicine" constitutes intentional and repeated abandonment of critically ill or injured chimpanzees to once-per-hour observation by untrained security guards.

Charles River never denied the facts alleged by the D.A. in the criminal charges, and the judge's decision did not deny the merits of the case. For now, Charles River and the NIH are accountable to absolutely no legitimate law enforcement authority. Neither the D.A., the USDA, nor the New Mexico Veterinary Board have any jurisdiction over the APF. The only "oversight" is provided by the NIH—the very definition of a conflict of interest—whose malfeasance at this very same facility when it was operated by the Coulston Foundation prompted a Congressional investigation of the entire agency.

After the years of abuse at Coulston, the situation at this government-owned facility descended into alleged criminal animal cruelty while the agency was paying Charles River millions of tax dollars annually, including \$175,000 in maximum bonus incentives. Charles River and the NIH have never denied the cold, cruel facts alleged by the D.A. in criminal charges resulting from a months-long independent criminal investigation conducted by a 24-year police veteran.

Charles River and the NIH cannot be allowed to evade their culpability by hiding behind legal technicalities, half-truths and the typical NIH whitewash. This small-town District Attorney was attempting to uphold the law and do the job that a \$28 billion federal agency has refused to do. We urge Congress to step into this gaping void of oversight and hold accountable the perpetrators of this unconscionable cruelty and their violation of the most basic standards of simple human decency. Congress should continue to actively investigate NIH's mismanagement of the APM and hold public hearings into the situation.

NIH FAILS TO ADDRESS THIS SUBCOMMITTEES CONCERN ON ILLEGALLY ACQUIRED DOGS AND CATS

Approximately 90,000 dogs and cats are used for experimentation in the United States each year. The vast majority of these animals are obtained from breeders who raise the animals under controlled conditions and have extensive information on their genetic background and health and vaccination status. In addition, some dogs and cats are being bred for experimentation at research facilities like the University of Texas, and in some cases, inexpensive random type animals are purchased directly from animal pounds.

Despite extensive documentation strongly discouraging the practice, some research facilities are foot-dragging by continuing to buy dogs and cats from random source dealers. These dealers, with a Class B license designation by the U.S. Department of Agriculture (USDA), are notorious for selling animals to laboratories that have been acquired illegally and for their widespread failure to comply with other minimum requirements under the Animal Welfare Act.

The saga of C.C. Baird is a prime example of the problem. Baird was a licensed dealer who sold random source dogs and cats for experimentation for about 15 years. More than a year and a half ago, 126 animals were seized by federal authorities because their health was in jeopardy. And shortly thereafter USDA finally filed charges against him for hundreds of violations of the Animal Welfare Act stating, "The violations alleged in this complaint are of the utmost seriousness, and include severe mistreatment and neglect of a multitude of animals in respondents' custody, falsification of health certificates for dogs and cats that respondents sold to research facilities, multitudinous record-keeping deficiencies and instances of noncompliance with the barest standards of care, husbandry and housing for dogs and cats." The charges against Baird included failure to provide adequate veterinary care and illegal acquisition of animals.

—Dog Dealer's Day of Reckoning: <http://www.awionline.org/pubs/Quarterly/03-52-4/524p1011.htm>

—A Glimpse Behind the Kennel Door: <http://www.awionline.org/pubs/Quarterly/04-53-3/533p16.htm>

—Random Source Dealer Surrenders: <http://www.awionline.org/pubs/Quarterly/05-54-1/541p2.htm>

Despite all of this, several registered research facilities including the University of Missouri continued to purchase animals from him. Unless NIH gives proper direction, some institutions will continue to place a higher priority on a cheap, ready supply of dogs than ensuring that animals are legally acquired and properly cared for. Thankfully, Baird has finally been put out of business. In fact, less than 20 Class B dealers remain, but the problems will persist until their number is reduced to zero.

NIH has told this Subcommittee that it is "committed to ensuring the appropriate care and use of animals in research." However, NIH has left the decision of whether or not to buy dogs and cats from random source dealers "to the local level on the basis of scientific need." NIH defends the use of Class B dealers arguing that these dealers are needed to obtain "animals that may not be available from other sources, such as genetically diverse, older, or larger animals." In fact, in the rare circumstance that a researcher asserts the need for such animals, they can be obtained directly from pounds as noted previously.

The distinction between non-purpose-bred animals from pounds versus Class B dealers must be made. By using Class B dealers (middlemen) instead of pounds, researchers are contributing to the problem. In their search to fill researchers' demands for "genetically diverse, older or larger animals," random source dealers and their suppliers may be stealing pets from backyards and farms or they are acquiring animals through fraud by collecting animals offered "free to a good home."

All animals used in research should be obtained from legitimate sources.

Taxpayer dollars, in the form of NIH extramural grants, must not continue to fund purchase of dogs and cats from dealers whose modus operandi are pet theft, acquisition of pets by fraud, payments made under the table and other illegal activi-

ties. Proper oversight of NIH's dispersal of extramural grants is urgently needed. We respectfully request that this Subcommittee include the following language in the HHS appropriations bill: "None of these funds shall be used for research which utilizes dogs and/or cats obtained from random source dealers."

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PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing is an alliance of four national nursing organizations—the American Association of Colleges of Nursing (AACN), the American Nurses Association (ANA), the American Organization of Nurse Executives (AONE), and the National League for Nursing (NLN). Focused on leadership and excellence in nursing, the Tri-Council represents the breadth of the nursing profession including practicing nurses, nurse executives, nurse educators, and nurse researchers.

The Nursing Workforce Development Programs under Title VIII of the Public Health Service Act strive to meet the health needs of the nation by assuring an adequate supply and distribution of qualified nursing personnel. These Programs increase access to quality care through improved composition, diversity, and retention of the nursing workforce; improved quality of nursing education and practice; and the identification of and use of data, and program performance measures and outcomes to make informed decisions on nursing workforce issues. The Tri-Council for Nursing urges Congress to ensure that adequate funding is available to address the critical nursing shortage through the Nursing Workforce Development Programs authorized by Title VIII of the Public Health Service Act.

This testimony highlights the fundamental importance of the Nursing Workforce Development Programs as they relate to an adequately prepared nursing workforce. As an example, we would like to bring the public health role of nurses and the vital services they are providing to this nation today to the forefront of your attention.

Nurses are a critical, but often unrecognized, component of the federal medical response to major emergencies and disasters, both natural and manmade. In the case of a major emergency, nurses have and will continue to be called upon to assist with chemoprophylaxis (oral or injectable medications/vaccinations) of hundreds of thousands or millions of Americans. The Office of Public Health Preparedness at the Health Resources and Services Administration (HRSA) estimates that a population of 100,000 people attacked by biological weapons would require 200 personnel working 100 hours just to deliver chemoprophylaxis. This effort would require approximately 16,171 trained persons for a city the size of New York. Nurses will also be called upon to assist with the planned use of "special needs shelters" during disasters. People in special needs shelters may include an insulin-dependent diabetic who requires frequent monitoring, epileptic persons with a history of unstable seizure activity, and persons with disabilities requiring assistance with activities of daily living.

Today's nursing shortage is very real and very different from any experienced in the past. It is evidenced by acute shortages of registered nurses (RNs) who are adequately prepared to meet patient care needs in a changing health care environment across the country. Although applications and enrollments for nursing programs have increased due to the major marketing efforts of corporations and health care providers, a serious nursing faculty shortage prevents the expansion of nursing programs to educate the number of nurses needed now and in the future. Studies have shown that unless dramatic steps are taken, the supply of appropriately prepared nurses will fall far short of what is needed to meet the needs of a diverse population and that this shortfall will grow more serious over the next 20 years. Since RNs represent the largest portion of our health care workforce, the shortage threatens the very essence of our health care system.

In February 2004, the Bureau of Labor Statistics reported that registered nursing would have the greatest job growth of all professions in the United States in the years spanning 2002 to 2012. During this ten-year period, health care facilities will need to fill more than 1.1 million RN job openings. HRSA projects that, absent aggressive intervention, the RN workforce will fall 29 percent below requirements by the year 2020.

The increasing health care demands of an aging population and changes in the country's nursing work-force have combined to create a shortage unlike any other. A fundamental shift has occurred in the RN workforce over the last two decades. As occupational opportunities for young women have expanded, and the changing health care environment has increased stresses on nursing, the number of young people entering the profession has declined resulting in a steady and dramatic increase in the average age of the nurse. Today, the average working RN is more than 43 years old.



## NURSES—INCREASING ACCESS TO QUALITY PATIENT CARE

Studies have shown that insufficient numbers of nurses contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the May 30, 2002, *New England Journal of Medicine* reported that higher levels of nursing care correlate with better patient care. Another study published in the October 23, 2002, *Journal of the American Medical Association* found that among the surgical patients studied, a pronounced correlation existed between nursing shortages and both patient mortality and failure to rescue.

By the year 2025, 68.3 percent of the current nursing workforce will be among the first of 78 million baby boomers reaching retirement age and enrolling in the Medicare program. By 2030, 20 percent of the population—70 million—will be older Americans, more than twice their number in 1999. The emerging complex health and social conditions of an aging population demonstrate the need for more and experienced nurses to care for this special population. Funding to support additional research and education in this area is needed.

Nurses can increase the public's access to quality primary health care through advanced practice registered nurses (APRNs), RNs who have attained advanced expertise in the clinical management of health conditions. Typically, an APRN holds a master's degree with advanced didactic and clinical preparation beyond that of the RN. Practice areas include, but are not limited to, anesthesiology, family medicine, gerontology, pediatrics, mental health, and midwifery. APRNs include:

Nurse Practitioners (NPs) who diagnose and treat common illnesses and injuries; provide immunizations; manage high blood pressure, diabetes, and other chronic problems; order and interpret lab tests; and counsel patients on adopting healthy lifestyles. Research confirms that NPs improve the public's access to high quality care at a cost savings to the system while a landmark study published in 2000 in the *Journal of the American Medical Association* indicates that NP quality of care is equal to that of physicians.

Clinical Nurse Specialists (CNSs) who provide care in a range of specialty areas, such as oncology, neonatal, and obstetric/gynecological nursing, pediatrics, and psychiatric/mental health while working in hospitals and other clinical sites. CNSs develop quality assurance procedures and serve as educators and consultants. An estimated 69,000 CNSs are currently in practice.

Certified Nurse-Midwives (CNMs) who provide prenatal and gynecological care to normal healthy women; deliver babies in hospitals, private homes, and birthing centers; and continue with follow-up postpartum care. Of all visits to CNMs, 90 percent are for primary, preventive care that includes gynecologic care such as annual exams and reproductive health visits.

Certified Registered Nurse Anesthetists (CRNAs) who administer more than 65 percent of all anesthetics given to patients each year, and are the sole anesthesia providers in approximately two-thirds of all rural hospitals.

As more acute public health needs exist in our communities, nurses, through their professional qualifications and sheer numbers, are at the very core of the nation's public health infrastructure.

"Nurse managed centers" (NMCs) play an important role in the health services delivery system and offer a unique approach to primary care that emphasizes health promotion and disease prevention, particularly in underserved communities. They often serve at-risk persons who might not otherwise receive health care. About half of all their patients are uninsured and many are unable to turn elsewhere for medical care. In the Philadelphia region, for example, nurses at nurse-managed health centers see their patients almost twice as often as other providers see theirs; their patients are hospitalized 30 percent less and use the emergency department 15 percent less often than those patients of other health care providers. Unfortunately, NMCs often struggle or fail to remain financially viable; the centers themselves need a safety net to survive financially.

The Nursing Workforce Development Programs of Title VIII provide the ability to maintain and expand the availability of a qualified nursing workforce and facilitate the integration of underrepresented populations into nursing.

*Section 811.*—The Advanced Education Nursing Program—funds traineeships for individuals preparing to be nurse practitioners, nurse midwives, nurse administrators, and public health nurses. In addition, grants are awarded to nursing schools to support education and training of APRNs.

*Section 821.*—The Nursing Workforce Diversity Program—funds grants to increase nursing education opportunities for individuals who are from disadvantaged backgrounds by providing student stipends, pre-entry preparation, and retention activities. These opportunities ensure a culturally diverse workforce to provide health care for a culturally diverse patient population.

*Section 831.*—The Nurse Education, Practice and Retention Program—provides grant support for academic and continuing education projects designed to strengthen the nursing workforce. Several of this program’s priorities apply to quality patient care including developing cultural competencies among nurses and providing direct support to establishing or expanding NMCs in non-institutional settings to improve access to primary health care in medically underserved communities. It also serves to provide grants to eligible entities to improve retention of nurses and enhanced patient care.

*Section 846.*—The Loan Repayment and Scholarship Programs—is divided into two primary components. The Nursing Education Loan Repayment Program assists individual registered nurses by repaying up to 85 percent of their qualified educational loans over three years in return for their commitment to work at health facilities with a critical shortage of nurses. Similarly, the Nurse Scholarship Program provides financial aid to individual nursing students in return for working a minimum of two years in a health care facility with a critical nursing shortage.

*Section 855.*—The Comprehensive Geriatric Education Grant Program—focuses on training, curriculum development, faculty development, and continuing education for nursing personnel caring for the elderly.

#### NURSES—EDUCATING THE FUTURE

At nursing schools across the nation, a surge of qualified applicants, who could ease the worsening shortage of nurses, is being turned away because schools of nursing are suffering from a continuing and growing shortage of faculty. This situation is not expected to improve in the near term, since an adequate number of nurse educators are currently not in the education pipeline.

The nursing faculty shortfall is driven by health care jobs that offer better pay than faculty positions and by fewer nurses pursuing the doctorate required for full-time teaching positions. Just as with the nursing workforce, the faculty is graying and a wave of retirements is expected about the same time when more care will be needed for aging baby boomers. An insufficient faculty was the top reason cited by nursing schools for not accepting all qualified applicants into entry-level programs for the 2004–2005 academic year. Just as important as educational incentives are for future practicing nurses, the scholarships for doctoral students who will instruct the next generation of nurses are even more critical.

Title VIII funding bolsters existing programs to increase the number of qualified nurse faculty.

*Section 846A.*—The Nurse Faculty Loan Program—supports the establishment and operation of a loan fund within participating schools of nursing to assist RNs to complete their education to become nursing faculty. The Program provides a cancellation provision in which 85 percent of the loan may be cancelled over four years in return for serving full time as faculty in a school of nursing.

*Section 811.*—The Advanced Education Nursing Program—provides trainee support for individuals preparing to be nurse educators. These funds support master’s and doctoral programs, combined RN/master’s degree programs, and post-nursing master’s certificate programs.

#### SUMMARY

While the Tri-Council for Nursing is encouraged by a recent resurgence of interest in the nursing profession, we are concerned that the funding levels for the Title VIII—Nursing Workforce Development Programs are insufficient to assist qualified students to enter, advance, and remain within the nursing profession. The nursing shortage will continue to worsen if significant investments are not made in these Title VIII programs. Recent efforts have shown that aggressive and innovative strategies can help avert the impending nursing shortage—if they are adequately funded. The contributions of nurses in our health care system are complex and multifaceted, and are directly impacted by the level of federal funding that supports nursing programs.

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#### PREPARED STATEMENT OF PATIENT SERVICES INCORPORATED (PSI)

##### PATIENT SERVICES INCORPORATED MEDICAL INSURANCE AND CO-PAYMENT ASSISTANCE CASE MANAGEMENT PROGRAM FOR HEPATITIS C

PSI believes that its 16 years of proven patient assistance and results can and will translate into providing successful solutions to two major challenges in healthcare policy that the United States is currently facing:

- Providing standard comprehensive health insurance coverage for the uninsured and the underinsured in this country.
- Developing a public-private partnership to solving this problem in light of the tightening budget constraints at the federal and state government levels.

With our goals and vision in mind, PSI would use the federal resources to further develop and augment the Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C to save federal and state government resources in this era of fiscal austerity. PSI intends to do this by:

- Assisting Medicaid eligible patients affected with the Hepatitis C virus (HCV) by transitioning these patients into the private insurance market. According to our research, 10 percent to 15 percent of the Hepatitis C patient population on Medicaid who are responding positively to the Pegylated Alpha Interferon/Ribavirin Combination treatment regimen can return to work. A positive response to the regimen can be defined as having such a low amount of the virus in your cell system that the viral load is undetectable. This portion of the population can re-enter the workforce, thus returning to the status of taxpayer and transition off the Medicaid roles.
- PSI will use a portion of the federal funds to purchase health insurance premiums through State High-Risk policies, Guaranteed Issue policies, and/or Open Enrollment policies for these patients thus freeing up Medicaid dollars. These patients will then be eligible to re-enter the workforce, and ultimately be covered by an employer funded benefits package.
- Assisting the segment of the Hepatitis C patient population not eligible for Medicaid, such as those patients enrolled in the Medicare program, state assistance programs, as well as those patients underinsured or uninsured.
  - PSI can assist patients on Medicare by satisfying the co-payment for the expensive, but life-altering treatment regimens.
  - PSI can assist those patients receiving treatments through state assistance programs by transitioning them into the private insurance market.
  - PSI can assist those patients who are uninsured and underinsured by transitioning them into the private insurance market.

Over the last 9 years, PSI has proven that as an organization it can be an effective steward of taxpayer's dollars. For a \$1 million investment by the federal government, PSI believes it can assist 1,200 to 1,500 patients. This investment could have the potential once fully implemented to save the federal and state governments \$10 million a year.

*Is your project a labor, health and human services, or education request?*

Health and Human Services

*Within the Labor, Health and Human Services, Education Appropriations Bill, the specific account within which funding is sought*

Centers for Medicare and Medicaid Services (CMS): Research, Demonstration and Evaluation Program.

*Amount Requested*

\$1,000,000 for fiscal year 2006; \$1,000,000 for fiscal year 2007; \$1,000,000 for fiscal year 2008.

*How, specifically the federal funds will be spent, if obtained?*

PSI asks Congress to establish a demonstration project through the Department of Health and Human Services, Centers for Medicare and Medicaid Services, which will assist Medicare and Medicaid eligible individuals, who are infected with the Hepatitis C virus (HCV) and desiring assistance, to identify and subsidize individual health insurance policies. By providing premium and co-payment assistance, PSI will save federal Medicare and Medicaid dollars.

PSI will begin the Medical Insurance and Co-payment Assistance Management Program for Hepatitis C by the Summer of 2005.

*Federal funding history of the organization*

This is the first year that Patient Services Incorporated has made a federal funding request.

*List the amount state, local and private funds being used to support the project. Indicate the proposed federal share of the project*

PSI is in the final stages of development of a co-payment assistance program with private sector industry. The industry support will provide PSI with funds to develop a disease management program for patients infected with Hepatitis C. This program

would provide PSI with key funds to launch this pilot program, which would provide pharmacy co-payment assistance for the treatment regimen of Hepatitis C.

The private funds provided to PSI will initially assist 100 patients nationwide. PSI will also continue to reach out to other manufacturers of Hepatitis C treatments for further development of this program. The infusion of federal resources will assist in developing the PSI Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C into a more comprehensive program.

Proposed federal share: \$1 million per year, for 3 years.

*Report language requested*

Recommend Report Language Centers for Medicare and Medicaid Services, Program Management of the Medicare and Medicaid Research, Demonstration and Evaluation program.

The committee has included \$1,000,000 for a demonstration project/pilot program with Patient Services Incorporated of Midlothian, Virginia to save federal health care costs by subsidizing private health insurance coverage for individuals suffering from the Hepatitis C virus (HCV). The committee requests a report on the results of this unique and potentially cost-saving program.

*Members of Congress are you working with on this request*

Senator John Warner (R-VA) and Senator George Allen (R-VA).

*Please share any additional information you deem important*

Currently there is authorization for programs such as PSI's proposal under the following bills:

(1) Centers for Medicare and Medicaid Research, Demonstration and Evaluation Program is an existing, statutory program.

(2) The Medicare Modernization Act authorizes demonstration projects for innovative programs to reduce federal health care costs, and for chronic care improvement pilot projects.

Pertinent background information and justification for this appropriations request:

*Patient Services Incorporated Demonstration Project/Pilot Program: Covering the Uninsured with Chronic and Catastrophic Illness*

PSI is a national, non-profit organization committed to supporting people with specific chronic illnesses and conditions by locating and securing solutions with health insurance by paying health insurance premiums and pharmacy co-payments in order to help improve their quality of life. PSI's vision for the future is to become the premier national non-profit organization in developing strategies and programs through collaboration with federal and state governments, corporations and individuals to address gaps in public and private health care coverage.

PSI asks Congress to establish a demonstration project through the Department of Health and Human Services, Centers for Medicare and Medicaid Services, which will assist Medicare and Medicaid eligible individuals, who are infected with the Hepatitis C virus (HCV) and desiring assistance, to identify and subsidize individual health insurance policies. By providing premium and co-payment assistance, PSI will save federal Medicare and Medicaid dollars.

*Background on PSI*

Founded in 1989, PSI has spent the last fifteen years working with patients from the chronic disease community. PSI currently assists patients nationwide with the expensive costs of seventeen chronic illnesses and acute conditions. A few examples are those with Hemophilia, Alpha 1, Rheumatoid Arthritis, Crohn's Disease, Immune Deficiencies, Psoriasis and Multiple Sclerosis. PSI saves families from becoming financially devastated when a member is diagnosed with an expensive chronic illness. The PSI model provides the means for patients to become insured and have choices of treatments and providers.

Private contributors, foundations, and corporate sponsors donate resources to PSI. PSI uses these resources to help families avoid turning to government sponsored social service programs. Families are offered assistance based upon the severity of their medical and financial needs, which is determined through an application process, a procedure that is unique to PSI. PSI has developed a sliding scale formula specifically designed to capture the working middle class person, providing the family with a safety net from financial ruin and assuring a successful return to work outcome. PSI does this by working with patients to gain access to insurance through State High Risk Insurance Pools, Open Enrollment, and Guaranteed Issue health insurance policies. PSI also assists patients in maintaining COBRA policies for

those who qualify. PSI is committed to working with the chronically ill to ensure that they have the resources to meet their specific and costly health care needs.

PSI is in the unique position of tackling head-on the acute problem of locating and ultimately paying for health insurance for the uninsured population in the United States. Currently the United States Census Bureau reports that there are over 44 million Americans who have no health insurance for a time period of one year or more. However, over 80 million Americans are without health insurance for some period of time during any given year. PSI can assist individuals in both categories. Since 1996, PSI also has successfully worked with State Health Department Title V programs, such as, Children With Special Health Care Needs and Childrens Rehabilitative Services (Medicaid). The PSI model has saved the Commonwealth of Virginia over \$12 million since 1996 and the state of Kentucky over \$5 million in program costs since 2000.

In 2002, the U.S. Department of Health and Human Services' Office of the Inspector General issued a positive opinion endorsing the PSI model of premium assistance and sanctioning the co-payment assistance for Medicare patients. The Centers for Medicare and Medicaid Services acknowledged in its recent 641 Replacement Drug Demonstration Project that charitable organizations, like PSI, can assist patients with the out of pocket expenses associated with certain replacement drugs.

It is no secret the chronic illnesses are both financially and emotionally draining for patients and families to cope with. Treating chronic conditions also accounts for the largest percentage of spending within the Medicare budget. The costliest five percent of Medicare beneficiaries account for about half of all Medicare spending each year. PSI has developed programs to help many of the families afflicted by these costly diseases; their Medical Insurance and Co-payment Assistance Case Management Program for Hepatitis C holds a great deal of promise for individuals and families who are affected by this virus and the accompanying complications.

#### *Hepatitis C*

The Hepatitis C virus (HCV) is a disease of the liver that has potentially fatal outcomes. In the majority of Hepatitis C cases, infection becomes chronic and slowly damages the liver over many years. During this time, the liver damage can lead to cirrhosis (scarring) of the liver, end-stage liver disease, and liver cancer. In the United States, Hepatitis C affects close to 4 million people, making the disease more prevalent than HIV/AIDS infection. The costs for providing care for patients with HCV-associated liver disease in the United States are estimated to range from \$758 million to several billion dollars annually. Hepatitis C infections are expected to increase to 10.8 million Americans in the next decade, leading to a major drain on government health resources and increased health costs.

Hepatitis C can be treated; early diagnosis and treatment are crucial to being able to control the progression of the disease and reduce the chances of further liver damage. There are instances where the treatment has taken a protracted time to show any positive results in lowering the viral load of patients, and in certain cases the treatment may not change the progression of the disorder. Currently, the National Institutes of Health (NIH) recommends that Hepatitis C patients receive pegylated alpha interferon treatment in combination with the antiviral drug, Ribavirin. Three different agents are used in this treatment approach:

—*Alpha Interferons*.—A protein made naturally by your body to boost your immune system and to regulate other cell functions. All of the currently approved treatments for chronic Hepatitis C include some form of natural or synthetic alpha interferon.

—*Pegylated Alpha Interferon*.—Made by attaching a large water-soluble molecule call polyethylene glycol (PEG) to the alpha interferon molecule. These modified alpha interferons stay in the body longer and studies show they are more effective in producing a sustained viral response in patients with chronic Hepatitis C.

—*Ribavirin*.—An antiviral drug that is used with manufactured forms of alpha interferon for the treatment of chronic Hepatitis C. Ribavirin by itself has not been shown to be effective against the Hepatitis C virus, but in combination with forms of alpha interferon is a much more successful treatment than alpha interferon alone.

The Pegylated Alpha Interferon/Ribavirin Combination treatment regimen is expensive; according to the 2003 Red Book Update, the costs range from \$24,000 to \$48,000 for the drug alone. These costs do not include fees for administering the drugs, laboratory visits, and medical tests associated with HCV. Hepatitis C is an expensive chronic illness; PSI is able to work with the federal government to assist this community to ensure that it receives quality care in an economically efficient way.

## PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

## INTRODUCTION

Mr. Chairman and members of the subcommittee, I am Dr. Carol Barnes of the University of Arizona and President of the Society for Neuroscience (SfN). I am here today in my capacity as the President of SfN to urge your support of biomedical research. SfN represents the entire range of scientific research endeavors aimed at understanding the nervous system and translating this knowledge to the treatment and prevention of nervous system disorders. It fosters the broad interdisciplinarity of the field, which uses multiple perspectives to study the nervous system of organisms ranging from invertebrates to humans across various stages of development, maturation, and aging.

## WHAT IS THE SOCIETY FOR NEUROSCIENCE?

The Society for Neuroscience is a nonprofit membership organization of basic scientists and physicians who study the brain and nervous system. Neuroscience includes the study of brain development, sensation and perception, learning and memory, movement, sleep, stress, aging, and neurological and psychiatric disorders. It also includes the molecules, cells, and genes responsible for nervous system functioning and human behavior.

The 36,000 members of SfN include basic researchers studying the many neuroscience disciplines and clinicians specializing in neurology, neurosurgery, psychiatry, ophthalmology, and related fields. In 1970, neuroscience barely existed as a separate discipline. Today, there are more than 300 training programs in neuroscience alone. The field of neuroscience has made startling discoveries that have transformed our understanding of the healthy brain and helped to deliver treatments of disorders affecting millions.

## NATIONAL INSTITUTES OF HEALTH'S NEUROSCIENCE BLUEPRINT

The NIH Neuroscience Blueprint is a framework to enhance cooperation among 15 NIH Institutes and Centers that support research on the nervous system. Over the past 10 years, driven by the science, the NIH neuroscience Institutes and Centers have increasingly joined forces through initiatives and working groups focused on specific disorders. The Blueprint builds on this foundation, making collaboration an everyday part of how the NIH does business in neuroscience. By pooling resources and expertise, the Blueprint can take advantage of economies of scale, confront challenges too large for any single institute, and develop research tools and infrastructure that will serve the entire neuroscience community.

Last year, the Blueprint participants developed a set of initiatives focused on tools, resources, and training with immediate impact because they would build on existing programs. These initiatives include an inventory of neuroscience tools funded by the NIH and other government agencies, enhancement of training in the neurobiology of disease for basic neuroscientists, and expansion of ongoing gene expression database efforts, such as the Gene Expression Nervous System Atlas (GENSAT).

Advances in the neurosciences and the emergence of powerful new technologies offer many opportunities for Blueprint activities that will enhance the effectiveness and efficiency of neuroscience research. Blueprint initiatives for fiscal year 2006 will include systematic development of genetically engineered mouse strains of critical importance to research on the nervous system and its diseases and training in critical cross cutting areas such as neuroimaging and computational biology.

Several of the most common causes of death and disability, as well as hundreds of rare disorders, affect the brain, spinal cord, or nerve cells in the eye, ear, or elsewhere in the body. The vast array of nervous system disorders encompasses mental illness, neurological disease, drug and alcohol abuse, chronic pain conditions, developmental disorders, and dementias of aging. Numerous problems of hearing, vision, and other senses also include a brain component, and are serious health issues.

In fiscal year 2006, NIH intends to allocate \$26 million, with \$14 million contributed by collaborating institutes and centers, for Blueprint initiatives as follows:

- Neuromouse Project*.—developing genetically engineered mouse strains specifically for nervous system disease research;
- Cross-Institute Neuroscience Training Programs*.—training in critical cross-cutting areas such as neuroimaging and computational biology;
- Neuroscience Core Grants*.—supporting specialized, interdisciplinary “core” centers that might focus on areas such as animal models, cell culture, computer modeling, DNA sequencing, drug screening, gene vectors, imaging, microarrays, molecular biology, or proteomics and their applications to neuroscience research;

—*Translation of Discoveries*.—accelerating the translation of basic neuroscience discoveries into better ways to treat and prevent nervous system diseases; and  
 —*Analytical Methods and Conceptual Models*.—spurring the development of new analytical methods and conceptual models to study disease and allow for increased coordination among public education and outreach campaigns involving the brain and nervous system.

#### ACCOMPLISHMENTS

The Society for Neuroscience would like to thank you for your past support. In the last 10 years, funding from the NIH and the Department of Veterans Affairs has helped scientists make great progress in helping people in many areas, including:

1. *Bipolar disorder*.—Also known as manic depression, bipolar disorder is a serious brain disease that causes extreme mood swings, from intense feelings of euphoria (mania) to deep depression. Past funding from NIH and the Department of Veterans Affairs has helped scientists make great progress in understanding bipolar disorders and, thus, in diagnosing and treating the illness. Using the latest brain imaging technologies, scientists have also discovered that brain function and structure in people with bipolar disorder differs markedly from that in people without the illness. Researchers have found a significant decrease in the size of the amygdala, a part of the brain that governs emotions, in people with bipolar disorder. Other studies have found a decrease in the density of gray matter in the brains of people with bipolar disorder. These and other exciting new findings are helping to pave the way for the design of new drugs that directly target specific genes or areas of the brain.

2. *Alzheimer's Disease & Normal Aging*.—Alzheimer's disease, one of the most frightening memory-robbing disorders, hampers the lives of some 4 to 5 million older Americans, costing the United States at least \$100 billion in medical care and lost productivity each year. Fortunately, NIH-funded research has helped to generate new treatments that can aid memory loss. These medications slow memory deterioration in some patients and allow others to resume normal lives. Additional gains can and must be made in the field of memory research in order to benefit a wider range of people, and to reduce the financial burden of care. Recent studies on animal models suggest that the outlook could improve with treatments that target brain mechanisms to enhance memory. Additionally, research into Alzheimer's disease and its effects on memory have also led to important advances in how memory can be optimized in normal aging. This would clearly benefit the remaining millions of Americans who are looking toward successful aging.

3. *Depression & Heart Disease*.—Depression is a biologically based brain disorder that affects about 10 percent of Americans over the age of 18. Depressed people feel intensely sad and worthless and have a diminished sense of emotional well-being. Among other diseases such as alcoholism and stroke, people with depression have an increased risk for heart disease, particularly coronary artery disease. In otherwise healthy people, depression doubles the risk for coronary artery disease. Furthermore, for those with coronary artery disease, there is evidence that depression influences outcomes, particularly mortality, following a heart attack. Additionally, for those undergoing coronary artery bypass grafting, there is increasing evidence that depression is associated with poorer outcomes. Studies from Johns Hopkins University reveal that patients with severe depression are up to five times more likely to have poorer outcomes such as the return of chest pain, heart attacks, or death. Despite much progress in understanding the biology of depression in the past decade, much remains to be done. The mechanisms of the interaction between depression and outcomes with cardiac disease are not clear. Nor is it known if treatment of depression, even mild depression, would lead to more favorable outcomes for those with cardiac problems. NIH-funded research might help us answer these complicated questions in order to save lives and money.

#### THE AMERICAN BRAIN COALITION

Last year, the Society for Neuroscience, along with the American Academy of Neurology, started the American Brain Coalition (ABC). ABC is a nonprofit organization that brings together patients with disabling brain disorders, the families of those that suffer, and the professionals that research and treat diseases of the brain. The mission of the ABC is to reduce the burden of brain disorders, and advance the understanding of the brain.

Because the brain is the center of human existence and the most complex living structure known, ABC advocates for collaboration among researchers and doctors who treat disorders of the brain. As seen with depression and heart disease, the

brain plays a vital role in conditions once believed to be unrelated to the brain. It is only through more research that we will begin to further understand, prevent, and treat neurological and psychiatric diseases.

FISCAL YEAR 2006 BUDGET REQUEST

The Society for Neuroscience supports the Ad Hoc Group for Medical Research Funding request of a 6 percent increase for NIH in fiscal year 2006. This will help NIH to carry out its Blueprint initiatives and help people affected by neurological disorders lead healthier, productive lives. Furthermore it will help sustain the infrastructure for innovative discoveries necessary to compete as a worldwide leader in biomedical research.

The request is based on the following information:

- \$1 billion is needed to cover biomedical research inflation, which is projected to be 3.5 percent;
- \$560 million is needed to replace the evaluation set-aside (an amount taken from each institute), which this year amounted to 2.4 percent (it used to be 1 percent); and
- The total number of research project grants (RPGs) is declining by 402 from what it was in fiscal year 2005.

Mr. Chairman, thank you for the opportunity to testify before this committee.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES

On behalf of The Humane Society of the United States (HSUS) and our more than 8.6 million supporters nationwide, we appreciate the opportunity to provide testimony on our top funding priorities for the Labor, Health and Human Services, Education and Related Agencies Subcommittee in fiscal year 2006.

INTERAGENCY COORDINATING COMMITTEE ON THE VALIDATION OF ALTERNATIVE METHODS (ICCVAM)

We were very pleased that Congress enacted Public Law 106–545 by unanimous voice vote in both chambers in 2000. This legislation, introduced by Senator Mike DeWine (R-OH) and Representatives Ken Calvert (R-CA) and Tom Lantos (D-CA), strengthened and made permanent the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). The statute has already begun to enhance the federal government’s capacity to evaluate and adopt chemical testing methods that are often faster, cheaper, and more scientifically sophisticated than current methods, as well as more responsive to the public’s concerns about the welfare of animals used in toxicity testing. Public Law 106–545 has streamlined the process by which these better methods are validated and assessed, and has eased institutional barriers within federal agencies that discourage their use.

ICCVAM performs an invaluable “win-win” function for regulatory agencies and stakeholders in industry, public health, and animal protection by assessing the suitability of new toxicological test methods that have interagency application. These new (and newly revised) methods include alternative methods that can limit animal use or suffering in testing. After appropriate independent peer review of a new test method, ICCVAM provides its assessment of the new test to the federal agencies that regulate the particular endpoint that the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies’ regulatory mandates. This streamlined approach to assess the validation status of new test methods has reduced the regulatory burden of individual agencies, provided “one-stop shopping” for industry, animal protection, and public health advocates to consider test methods, and set uniform criteria for what constitutes a validated test method.

ICCVAM arose from an initial mandate in the NIH Revitalization Act of 1993 for the National Institute of Environmental Health Sciences (NIEHS) to “(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use.” In 1994, NIEHS established an ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from 14 regulatory and research agencies developed NIH Publication No. 97–3981, Validation and Regulatory Acceptance of Toxicological Test Methods. This report has become the “sound science” guide for consideration of new test methods by the federal agencies and in-



terested stakeholders. After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Methods (NICEATM). Representatives from federal regulatory and research agencies have continued to meet, with advice from NICEATM's Scientific Advisory Committee and independent peer review committees, to assess the validation of new toxicological test methods.

Since its inception, ICCVAM has conducted rigorous evaluations of several test methods and has concluded that these methods are scientifically valid, i.e., have been adequately validated, and are acceptable for specific purposes. These methods include Corrositex, Epiderm, Episkin, and Transcutaneous Epithelial Resistance assays for assessing skin corrosivity; the 3T3 NRU Phototoxicity assay for assessing phototoxicity; the Local Lymph Node Assay for assessing skin sensitization; and the Up and Down Method and various cytotoxicity assays for assessing acute systemic toxicity. In turn, the appropriate regulatory agencies have incorporated these methods into their regulatory practices.

The open public comment process, input by interested stakeholders, and the continued commitment by various federal agencies have all enhanced the ICCVAM process. Now, under Public Law 106-545, ICCVAM is poised to go beyond its largely passive role of assessing the validation status of test methods that have been developed and validated by industry and others. ICCVAM should adopt a more proactive role in developing and validating promising tests methods in partnership with outside stakeholders, to ensure that a steady stream of new test methods are available for review and adoption by the federal government. Such a proactive stance and partnership with stakeholders will enable the federal government to better harness the potential of emerging technologies to meet the challenge of efficiently testing large numbers of chemicals with minimal cost in terms of money and animal lives. With a more proactive approach, ICCVAM could, for example, explore the potential of investigator-initiated and small business grant programs to further its mission.

Adequate funding should be provided for ICCVAM to put the resources in place to ensure the federal government and industry have the best available tools with which to assess the toxic properties of chemicals in commerce. To accomplish this, we respectfully request an earmark of \$3.6 million for fiscal year 2006 and the following Committee Report language:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges NIEHS to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution, and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program's Road Map and Vision for NTP's toxicology program in the 21st century.”

#### PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than \$11 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that reduce the amount of pain and distress to which research animals are subjected, nor methods that replace or reduce the use of vertebrate animals in research. NIH may receive \$28.8 billion in fiscal year 2006 if Congress fulfills the President's budget request. Out of this funding, we seek \$2.5 million (0.009 percent) for research and development focused on identifying and alleviating animal pain and distress. In addition to our request for a specific funding amount, we also urge the Committee to specify in report language that this research should be conducted in conjunction with, or “piggy-backed” onto, ongoing research that already causes pain and distress. Infliction of pain and distress on additional animals is unnecessary, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that is believed to involve moderate to significant pain and/or distress.

The large extent to which animals are used in federally-funded research underscores the importance of earmarking funds for pain and distress research. NIH has a statutory mandate to conduct or support research into alternative methods that produce less pain and distress in animals. This was specified in the NIH Revitalization Act of 1993 regarding a plan for the use of animals in research. Earmarked funding will assist NIH in meeting this mandate. Additionally, researchers themselves often comment publicly at scientific meetings about the urgent need for fund-

ing in order to properly understand and mitigate pain and distress in research animals and to follow Animal Welfare Act and Public Health Service policy requirements to minimize pain and distress.

It is well known that uncontrolled, undetected, and unalleviated pain and distress has adverse effects on animal welfare, which leads to adverse effects on the quality of science. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when pre-clinical animal research results are applied to humans in clinical trials.

A 2001 survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Seventy-five percent of the American public opposes research that causes severe animal pain and/or distress, even when it is health-related. Despite this public concern, NIH has failed to sponsor research and development aimed at determining how to minimize animal suffering and distress in the laboratory.

During the past several years, our organization has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. Furthermore, while human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering).

We urge the Committee to make this small investment of \$2.5 million to promote animal welfare and enhance the integrity of scientific research. We also respectfully request this accompanying committee report language:

"The Committee provides \$2.5 million to support research and development focused on improving methods for recognizing, assessing, and alleviating pain and distress in research animals. No pain and distress should be inflicted solely for the purpose of this initiative, since the investigations can and should be conducted in conjunction with ongoing research that is believed to involve pain and distress under Government Principle IV of Public Health Service Policy, which assumes that procedures that cause pain and distress in humans may cause pain and distress in animals."

Again, we appreciate the opportunity to share our views and top priorities for the Labor, Health and Human Services, Education and Related Agencies Appropriation Act of fiscal year 2006. We hope the Committee will be able to accommodate these modest requests that will benefit animals, enhance effectiveness of toxicological testing, and improve the quality of research. Thank you for your consideration.

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#### PREPARED STATEMENT OF VOICES FOR NATIONAL SERVICE

Mr. Chairman and Members of the Subcommittee, Voices for National Service, formerly known as the Save AmeriCorps Coalition, is a coalition of community-based organizations, faith-based groups, state commissions, private sector partners, institutions of higher education, and others interested in promoting national service through AmeriCorps and other vehicles. We look forward to working with you to strengthen AmeriCorps and national service as you oversee the entire budget of the Corporation for National and Community Service for the first time.

In light of AmeriCorps 10th Anniversary, it is appropriate to review some of the goals Congress set for AmeriCorps in 1993: "to meet the unmet human, educational, environmental and public safety needs of the United States; to renew the ethic of civic responsibility and the spirit of community throughout the United States; to expand educational opportunity by rewarding individuals who participate in national service with an increased ability to pursue higher education or job training; to encourage citizens of the United States, regardless of age, income, or disability, to engage in full-time or part-time national service; and, to provide tangible benefits to the communities in which national service is performed."

We believe that those who do service through AmeriCorps, as part of school or community-based service-learning, or senior volunteer programs, through their churches synagogues and mosques, and community-based organizations are part of one of the great currents of American history: working with one's neighbor to build a better community and a better nation. President Bush captured this theme when, in his State of the Union Address in 2002, he said:

"My call tonight is for every American to commit at least 2 years—4,000 hours—over the rest of your lifetime to the service of your neighbors and your nation. . . . Our country [also] needs citizens working to rebuild our communities. We need mentors to love children, especially children whose parents are in prison. And we need more talented teachers in troubled schools."

#### GOVERNMENT SPONSORED SERVICE IS DEEPLY ROOTED IN OUR HISTORY

It was almost a century ago that philosopher William James spoke of service as "the moral equivalent of war" and said if there "were a conscription of the whole youthful population to form for a certain number of years a part of the army enlisted against Nature, the injustice would tend to be evened out . . . ."

Since that speech in 1906, Presidents from Franklin D. Roosevelt to George W. Bush have proposed that Americans serve both here and abroad to improve conditions for those who need support. They recognized that serving made better citizens and better Americans, that government—in conjunction with community-based institutions—has a role to play in solving our most intractable problems and that service must be real, not make-work.

In 1933, President Roosevelt spoke to Civilian Conservation Corps (CCC) members in Warm Springs, Georgia and told them that "You are rendering a real service, not only to this community but to this part of the State and the whole State. It is permanent work, it is work that is going to be useful for a good many generations to come. That is why, one reason why, the people of this country as a whole believe in the Civilian Conservation Corps . . . ."

It is difficult to believe that nearly half a century has passed since President Kennedy challenged a new generation by saying "And so, my fellow Americans: ask not what your country can do for you—ask what you can do for your country." Kennedy's Peace Corps proposal included many of the principles embodied in AmeriCorps:

"In establishing our Peace Corps we intend to make full use of the resources and talents of private institutions and groups. Universities, voluntary agencies, labor unions and industry will be asked to share in this effort . . . making it clear that the responsibility for peace is the responsibility of our entire society. . . . We will only send abroad Americans who are wanted by the host country—who have a real job to do—and who are qualified . . . . Programs will be developed with care, and after full negotiation . . . . Life in the Peace Corps will not be easy. There will be no salary and allowances will be at a level sufficient only to maintain health and meet basic needs."

#### NATIONAL SERVICE HAS BROAD BIPARTISAN SUPPORT

The roots of AmeriCorps are contained in national service legislation enacted in 1990 and signed by President George H.W. Bush. It reflected his belief, articulated in his Inaugural address, that "America is never wholly herself unless she is engaged in high moral principle. We as a people have such a purpose today. It is to make kinder the face of the Nation and gentler the face of the world. My friends, we have work to do." To address these issues, he said "we will do the wisest thing of all: We will turn to the only resource we have that in times of need always grows—the goodness and the courage of the American people." He called for:

"A new engagement in the lives of others, a new activism, hands-on and involved, that gets the job done. We must bring in the generations, harnessing the unused talent of the elderly and the unfocused energy of the young. For not only leadership is passed from generation to generation, but so is stewardship. And the generation born after the Second World War has come of age. The old ideas are new again because they are not old, they are timeless: duty, sacrifice, commitment, and a patriotism that finds its expression in taking part and pitching in."

Exactly seven years less one day before September 11, President Clinton swore in the first class of AmeriCorps members. Reflecting many of the themes articulated by President Bush, he told them that "Service is never a simple act, it's about sacrifice for others and about accomplishment for ourselves, about reaching out, one person to another, about all our choices gathered together as a country to reach

across all our divides. It's about you and me and all of us together—who we are as individuals and what we are as a nation. Service is a spark to rekindle the spirit of democracy in an age of uncertainty.”

Like Presidents Roosevelt, Kennedy, and Bush, President Clinton also understood that each generation owes something to the nation for what it has received as well as to those who follow:

“And your generation is no exception. We look at you now. And we know you are no generation of slackers. Instead you are a generation of doers. And you want to give something back to the country that has given so much to you. The only limit to our future is what we're willing to demand of ourselves today. Generations of Americans before us have done the groundwork. Now, it falls to all of us to build on their foundations.”

Two years ago, AmeriCorps was in crisis; its very survival in doubt. At that time, virtually every governor, more than 150 mayors, hundreds of university presidents, and corporate and civic leaders publicly recognized the good that AmeriCorps had accomplished since its creation 10 years ago. More than 100 editorials in large and small newspapers throughout the nation provided ample evidence of how AmeriCorps members improved their communities.

President George W. Bush's support, important bipartisan legislative initiatives to improve the management of the Corporation for National and Community Service, installation of a new leadership team, and the rulemaking process still underway not only helped to save AmeriCorps but to remind us that service is the responsibility of all Americans.

#### STRENGTHENING COMMUNITIES

AmeriCorps members serve in more than 900 local and state nonprofit organizations, public agencies, and faith-based organizations funded by the Corporation for National and Community Service through both state commissions as well as national nonprofit AmeriCorps programs including Teach for America, the National Association of Community Health Centers, the Red Cross, Habitat for Humanity, City Year, Public Allies, the National Association of Service and Conservation Corps, Jumpstart for Young Children, the Sisters of Notre Dame, and the Experience Corps.

They serve to address problems within four broad categories: “unmet human, educational, environmental, or public safety needs.” Communities identify their needs and choose the model that is most appropriate to meeting those needs. This is a bottom up, not a top-down program.

AmeriCorps members also help strengthen Homeland Security and prevent or mitigate the effects of natural disasters. Recently, AmeriCorps members from Minnesota and Washington State joined colleagues serving in Florida to bring a measure of relief to victims of devastating hurricanes. They helped mobilize the largest volunteer disaster response in American history, repaired damaged homes, and distributed food and water to victims and community volunteers. Indeed, since September 11, 2001 the AmeriCorps program has expanded its work in public safety, public health, disaster relief, and homeland security.

AmeriCorps members teach in underserved schools, tutor and mentor youth including the children of prisoners, run after-school programs, build affordable housing, provide public health services, prevent forest fires and do disaster relief, run after-school programs, and help communities respond to disasters. Hundreds of AmeriCorps state programs clean rivers and streams, enrich after school programs, support local law enforcement by providing meaningful alternatives to gangs, deliver services to the elderly, and meet other needs defined by the communities in which they serve.

This year, for example, AmeriCorps members are serving more than 2 million children and youth, providing valuable resources to reach the President's goal of having all children able to read by third grade. They are also helping to recruit and train more than 600,000 community volunteers.

AmeriCorps members leverage community resources as well as perform direct service. In fiscal year 2003, AmeriCorps members recruited more than 529,000 community volunteers an increase of almost 275,000 (from the previous year when the Corporation stopped recruiting new members and new volunteers because of its self-imposed recruitment freeze). Last year, AmeriCorps programs generated more than \$165 million from non-Corporation partners, \$70 million more than in the previous year.

## ACCOMPLISHMENTS

According to the State Profiles and Performance Report 2002–2003 published by the Corporation for National and Community Service (December 2004), examples of what AmeriCorps members accomplished include (but are not limited to):

- In Alaska, members tutored almost 6,000 students in grades 1 through 12 and assessed 485 homes for energy efficiency.
- In Florida, members recruited 2,000 community volunteers to provide education services, maintained and expanded 200 acres of habitat for threatened and endangered species, and built 40 homes for low-income families.
- In Georgia, almost 7,500 homeless individuals received referrals to permanent or transitional housing.
- In Indiana, 2,400 juveniles participated in career development activities for offenders or ex-offenders.
- In Iowa, more than 4,800 elementary and middle students received tutoring and mentoring support, and 32,000 received education and training about the environment.
- In Kentucky, members staged eight forums to educate more than 1,000 at-risk elderly about home safety and conducted 265 Home Safety Assessments for seniors.
- In Maine, members made 600 presentations on disaster preparedness, benefiting more than 36,000 people and almost 1,300 people participated in after-school activities designed to reduce violence in public housing.
- In Maryland, members removed 453 tons of trash, improving the quality of storm water run-off into the Chesapeake Bay and 1,900 homeless families received food, clothing, or furniture.
- In Minnesota, members constructed 151 housing units for low income seniors or people with disabilities, planted almost 142,000 trees, and conserved more than 10,000 acres of habitat and land.
- In Mississippi, members trained 715 people with disabilities in life skills, helped train mentally, or developmentally, disabled adults for employment, and mentored 1,100 low income and underachieving middle school students.
- In Montana, members constructed 54 miles of fence to protect wild- or park lands, maintained 309 miles of trails, roads, and other public areas, and increased access to technology for more than 1,100 youth, parents, and members of the community.
- In Nevada, 3,200 students in grades 1 through 12 received tutoring, 577 homeless veterans received employment-related counseling, and almost 1,000 women benefited from anti-victimization counseling and workshops on preventing domestic violence.
- In New Mexico, almost 24,400 people participated in after-school sports and violence avoidance activities, 400 adults received instruction in basic skills development and GED training, and 138 homeless families found homes.
- In New York, members transported 1,000 children to medical appointments, delivered meals and snacks to about 58,000 children and seniors, and provided literacy activities to almost 17,000 children.
- In Ohio, members trained more than 9,000 youth in conflict resolution, built repaired, or rehabilitated 364 housing units, and provided educational support services to 1,500 students during the summer months.
- In Oregon, 7,000 students benefited from updating high school Career Centers with college, military, apprenticeship, and trade school information, planted almost 5,000 trees, and grew and distributed more than 900 pounds of produce.
- In Pennsylvania, members tutored almost 14,600 elementary and high school students and more than 6,800 citizens received either needs assessment or support in the areas of domestic violence, foster care, mental health, and housing for homeless veterans.
- In Tennessee, more than 900 people received access to health care, almost 200 children had their immunizations ensured, and more than 1,300 senior women received informational materials about breast cancer.
- In Washington, almost 37,000 students benefited from out of class enrichment activities like field trips, about 6,600 peer tutors were recruited, and more than 19 miles of rivers, river banks, beaches, and fish habitat were restored or conserved, benefiting local salmon runs.
- In Wisconsin, members organized or packed 290 tons of food to be distributed to community agencies and provided after-school tutoring or mentoring services to more than 1,200 students.

—In West Virginia, more than 3,200 children received tutoring in a six-week summer literacy program, helping to realize an average four month gain in literacy skills.

According to the Corporation's National Performance Benchmarking Survey, "57 percent of organizations' AmeriCorps partners reported that AmeriCorps members 'considerably' helped them increase their involvement in partnerships and coalitions. (29 percent reported 'moderately' helped)." Also, three quarters of grantees said that "AmeriCorps had increased 'by a considerable amount' the number of end beneficiaries served." About "83 percent of grantees reported that AmeriCorps members helped their organization either 'considerably' (53 percent) or 'moderately' (30 percent) in leveraging additional volunteers." And, "more than 75 percent of organizations receiving disaster and emergency readiness and preparedness training from AmeriCorps programs have become better prepared by conducting emergency drills, changing organization operations, or preparing emergency kits."

With your support, in the next fiscal year, approximately 40,000 AmeriCorps members will provide tutoring to students, help operate after-school programs, increase Americans' access to health care, and provide support for families in crisis. In addition, more than 5,000 children of prisoners will receive services provided by AmeriCorps members.

In 2004, the Corporation for National and Community Service celebrated its tenth anniversary. In the last decade, more than 400,000 young Americans dedicated themselves to either full or part-time service through AmeriCorps to improve their communities and their country. At the same time, AmeriCorps members earned Education Awards worth more than \$1 billion.

#### SERVICE CHANGES THOSE WHO SERVE

Serving in AmeriCorps also changes those who serve. According to the recent study conducted by Abt Associates "Serving Country and Community: A Longitudinal Study of Service in AmeriCorps" participation in AmeriCorps "resulted in statistically significant positive impacts on members' connection to community, participation in community-based activities, and personal growth through service. While AmeriCorps members increased their level of civic engagement . . . scores for comparison group members typically showed little or no change. . . ." "Additionally, there was a positive and significant effect of AmeriCorps participation on volunteering for members without prior volunteering experience. These results are important because they reflect the capacity of AmeriCorps to strengthen existing beliefs in and commitments to civic engagement and community service, and to awaken new ones."

The Abt study also reported that service in AmeriCorps "had a meaningful impact on both attitudinal and behavioral employment outcomes." It increased "the work skills of AmeriCorps members" and motivated "members to choose public service careers, such as teaching, social work, and military service."

Thus, AmeriCorps proves its value everyday in communities across the country and by changing the lives of AmeriCorps members.

#### THE FISCAL YEAR 2006 REQUEST

We are hopeful that under your leadership local communities throughout the nation will continue to be served by as many as 75,000 AmeriCorps members. At the same time, we want to make clear that we are as committed to the quality of the service as to reaching a specific number of AmeriCorps members.

We very much appreciate the increase in funding that Congress provided in fiscal year 2004 to save AmeriCorps. It must be noted, however, that funding for AmeriCorps grants has declined from the fiscal year 2004 enacted high of \$312 million to the proposed \$275 million, a cut of more than 10 percent. At the same time funding for the Trust has increased from \$129 to a proposed \$146 million.

The Voices for National Service Coalition believes that it will require \$442 million to achieve the number of AmeriCorps members proposed by the Corporation for National and Community (75,000) while maintaining the historical balance between full-time, part-time, and Education award only AmeriCorps members. To sustain this level of service, we urge you to fund AmeriCorps at the level proposed by President Bush in his fiscal year 2005 budget. We are very concerned that with operating costs increasing, recruiting the same number of AmeriCorps members with \$20 million fewer dollars than the President proposed just last year may force the Corporation to make programmatic compromises that will undermine the historic nature and fundamental character of AmeriCorps. While we support the Corporation's desire to increase the number of "effective, lower cost programs, such as professional

and teacher corps” we remain convinced that responsiveness to local needs requires the Corporation to support a mix of higher, as well as lower, cost programs.

We also want to call the Committee’s attention to two other elements of the Corporation’s request. First, we support the Corporation’s proposal to eliminate the cap on National Direct grants. We share its concern that “capping funding for National Direct grants may prevent [it] from supporting outstanding service programs.” Second, we are concerned about the Corporation’s failure to seek funds for the Challenge Grant program. Challenge grants promote competition and are an important tool which programs can use to leverage additional private sector funds. If the Corporation truly wants to achieve program sustainability by reducing dependence on federal grants, it ought to increase Challenge Grant funds rather than eliminate them. The response to Challenge Grants has been overwhelming and we believe the program’s success justifies its continuation.

#### PROMOTING QUALITY AND INCREASING EFFICIENCY

As you begin your difficult work this year, Voices for National Service urges you to consider the following themes that will further increase the Corporation’s effectiveness and meet its goal of “put [ting] the customer first”:

1. Education Award Only slots should be a tool for state flexibility and cost-effectiveness. They should not become a way to increase the number of AmeriCorps members “on the cheap.” We believe that the current ratio between full- and part-time members and recipients of Education Awards should be maintained and that no more than 40 percent of the AmeriCorps portfolio should be allocated to Education Award Only programs. This will allow states to reduce cost per member, and be responsive to both local resources and local needs.

2. The Corporation must continue to affirm its commitment to diversity of AmeriCorps members and be sensitive to geographic diversity as well as racial, ethnic, and socio-economic diversity. Corporation policy should reflect an understanding of the difficulties that programs in rural areas and inner-cities have in recruiting private sector and philanthropic dollars and the fact that programs whose enrollment focus is on low-income, out of school and minority young people are likely to have greater difficulty recruiting and retaining members than programs that recruit more affluent members.

3. The Re-fill Rule should be fully restored. While we appreciate the Corporation’s effort to reintroduce its slot refill policy, the present one-to-one, one-time-only policy is not sufficient to ensure that programs can meet local needs. AmeriCorps programs that enroll significant numbers of economically and educationally disadvantaged corps members are likely to experience higher rates of attrition and lower rates of retention. Reverting to its prior practice of allowing programs to completely re-fill vacated slots at any time during the year would allow greater participation in AmeriCorps, encourage participants with a broad array of backgrounds to participate, and ultimately allow programs—and AmeriCorps as a whole—to provide deserving people, often highly disadvantaged, the opportunity to pursue their educational goals.

#### CONCLUSION

For the last 70 years, Presidents of both parties, and their Congressional champions, have recognized that service programs with government support, the active support of community-based organizations, faith-based institutions, and the private sector can play an important role in strengthening communities, teaching the virtues of civic engagement, and strengthening the bonds that connect us as a people. Service is not only an effective strategy for attacking our problems, it is a way to remind Americans of all ages that we have a responsibility to give something back to our country.

We believe that AmeriCorps has made substantial progress in meeting these ambitious goals and look forward to working with you to improve the lives of all Americans through service.

Thank you for the opportunity to provide this testimony.

#### NATIONAL INSTITUTES OF HEALTH

#### PREPARED STATEMENT OF THE ALPHA-1 FOUNDATION

#### SUMMARY OF RECOMMENDATIONS

The Alpha-1 Foundation requests an allocation in the budget to enable the CDC, National Center for Birth Defects and Developmental Disabilities to implement a

national targeted Alpha-1 detection program. The Foundation recommends that CDC receive \$2 million in fiscal year 2006 for implementation.

The Foundation recommends that NHLBI enhance its portfolio of research and education on the fourth leading cause of death in the United States, Chronic Obstructive Pulmonary Disease (COPD), including genetic risk factors such as Alpha-1 Antitrypsin Deficiency.

The Foundation commends NIH on the roadmap and recommends that NHLBI, NIDDK, NHGRI, NIEHS, and other institutes establish an Alpha-1 inter-institute coordinating committee to facilitate collaboration on this genetic lung and liver disease.

The Foundation encourages HRSA to collect additional data to evaluate the impact of the new lung transplant organ allocation system being implemented by the Organ Procurement and Transplantation Network/United Network for Organ Sharing.

The Foundation supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

Mr. Chairman and members of the Subcommittee thank you for the opportunity to submit testimony for the record on behalf of the Alpha-1 Foundation.

#### THE ALPHA-1 FOUNDATION

The Alpha-1 Foundation is a national not-for-profit organization dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1 Antitrypsin (Alpha-1) Deficiency. The Foundation has built the research infrastructure with private investment, funding over \$15,000,000 in grants from basic to social science, establishing a national patient registry, tissue and DNA bank, translational laboratory, assisting in fast track development of new therapeutics, and stimulating the involvement of the scientific community. The Foundation has invested the resources to support clinical research which follows the roadmap established by the NIH; uniquely positioning it for a perfect private public partnership. There is a lack of awareness of the insidious nature of the early symptoms of the lung and liver disease associated with this genetic condition by both medical care providers and the public. It is our hope that the federal government will leverage the Foundation's investment with support for a national Alpha-1 targeted detection program.

#### ALPHA-1 IS SERIOUS AND LIFE THREATENING

Alpha-1 is the leading genetic risk factor for Chronic Obstructive Pulmonary Disease (COPD) and is often misdiagnosed as such. Alpha-1 afflicts an estimated 100,000 individuals in the United States with fewer than 5 percent accurately diagnosed. These are people who know they are sick and as yet have not put a name to their malady. Although Alpha-1 testing is recommended for those with COPD this standard of care is not being implemented. In addition, an estimated 20 million Americans are the undetected carriers of the Alpha-1 gene and may pass the gene on to their children. Of these 20 million carriers, 7–8 million may be at risk for lung or liver disease.

The pulmonary impairment of Alpha-1 causes disability and loss of employment during the prime of life (20–40 years old), frequent hospitalizations, family disorganization, and the suffering known only to those unable to catch their breath. Fully half of those diagnosed require supplemental oxygen. Lung transplantation, with all its associated risks and costs, is the most common final option. Alpha-1 is the primary cause of liver transplantation in infants and an increasing cause in adults. Alpha-1 liver disease currently has no specific treatment aside from transplantation. The cost to these families in time, energy and money is high and often devastating. Alpha-1 also causes liver cancer.

Alpha-1 is a progressive and devastating disorder that in the absence of proper diagnosis and therapy leads to premature death; in spite of the availability of therapeutics for lung disease and preventative health measures that can be life-prolonging. It is estimated that untreated individuals can have their life expectancy foreshortened by 20 or more years. Yet early detection, the avoidance of environmental risk factors and pulmonary rehabilitation can significantly improve health.

#### THE MEDICAL NEEDS OF THE ALPHA-1 COMMUNITY HAVE GONE UNMET

Alpha-1 is a hidden killer that desperately needs new therapies. There is a lack of awareness of the insidious nature of the early symptoms of the lung and liver disease associated with this genetic condition by both medical care providers and the public.



Currently, the only specific therapy for Alpha-1 lung disease is intravenous augmentation therapy produced from pooled human plasma at an average annual cost of \$50,000–\$100,000. This therapy increases the plasma levels of the deficient protein and appears to slow or halt the progression of the pulmonary disease described above. There is currently nothing available to regenerate lung tissue and restore lung function.

In addition, Alpha-1 liver disease is equally life threatening, as is the case with many chronic liver conditions, often reaching an advanced stage with few symptoms and little warning. Advanced liver disease is often untreatable, and many with Alpha-1 have erroneously been told they have alcoholic liver disease because of the lack of physician awareness.

#### ALPHA-1 AND COPD

As the fourth leading cause of death, COPD is a major public health concern. Data indicates that not all individuals who smoke develop lung disease leading many to conclude that COPD has significant genetic and environmental risk factors. As the most significant genetic risk factor for COPD, Alpha-1 has much to tell us about the pathogenesis of lung disease. Discoveries and advances made in Alpha-1 will impact the larger 10–24 million individuals living with COPD.

#### DETECTION

The Alpha-1 Foundation conducted a pilot program in the state of Florida where we garnered the knowledge and experience necessary to launch an awareness and National Targeted Detection Program (NTDP). The goals of the NTDP are to educate the medical community and people with COPD and liver disease, alerting them that Alpha-1 may be an underlying factor of their disease; and stimulating testing for Alpha-1. This effort will uncover a significant number of people who would benefit from early diagnosis, treatment and preventative health measures.

The Foundation distributes the American Thoracic Society/European Respiratory Society (ATS/ERS) “Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency” to physicians, nurses and respiratory therapists. Additionally, health care practitioners and the COPD community are being targeted through press releases, newsletter articles and various website postings.

The national implementation of the NTDP is enhanced through the 7 Clinical Resource Network Centers of the National Heart, Lung, Blood Institute of the National Institutes of Health; 51 Foundation affiliated Clinical Resource Centers; large pulmonary practices and various teaching hospitals and universities. The NTDP also employs a direct to consumer approach targeted to people with COPD.

The Alpha-1 Foundation’s Ethical Legal and Social Issues (ELSI) Working Group endorsed the recommendations of the ATS/ERS Standards Document which recommends testing symptomatic individuals or siblings of those who are diagnosed with Alpha-1. Early diagnosis in Alpha-1 can significantly impact disease outcomes by allowing individuals to seek appropriate therapies, and engage in essential life planning. Unfortunately, seeking a genetic test may lead to discrimination against individuals who have no control over their inherited condition. The absence of federal protective legislation has caused the ELSI to recommend against population screening and genetic testing in the neonatal population. The Foundation commends the Senate for passing the Genetic Non-Discrimination Act of 2005 and is working to ensure that the House takes the same positive action.

The Alpha-1 Coded Testing (ACT) Trial, funded by the Alpha-1 Foundation and conducted at the Medical University of South Carolina offers a free and confidential finger-stick test that can be completed at home. The results are mailed directly to the participants. The ACT Trial has offered individuals the opportunity to receive confidential test results since September of 2001, to date over 2,400 test kits have been requested.

#### ALPHA-1 RESEARCH

The Alpha-1 Foundation believes that significant federal investment in medical research is critical to improving the health of the American people and specifically those affected with Alpha-1. The support of this Subcommittee has made a substantial difference in improving the public’s health and well-being.

The Foundation requests that the National Institutes of Health increase the investment in Alpha-1 Antitrypsin (AAT) Deficiency and that the Centers for Disease Control and Prevention initiate a federal partnership with the Alpha-1 community to achieve the following goals:

- Promotion of basic science and clinical research related to the AAT protein and AAT Deficiency;

- Funding to attract and train the best young clinicians for the care of individuals with AAT Deficiency;
- Support for outstanding established scientists to work on problems within the field of AAT research;
- Development of effective therapies for the clinical manifestations of AAT Deficiency;
- Expansion of awareness and targeted detection to promote early diagnosis and treatment.

#### SPECIFIC AREAS OF CONCERN AND RECOMMENDATIONS

1. The Foundation requests an allocation in the budget to enable the CDC, National Center for Birth Defects and Developmental Disabilities to implement a national targeted Alpha-1 detection program. The Foundation recommends that CDC receive \$2 million in fiscal year 2006 for implementation.

2. The Foundation recommends that NHLBI enhance its portfolio of research and education on the fourth leading cause of death in the United States, Chronic Obstructive Pulmonary Disease (COPD), including genetic risk factors such as Alpha-1 Antitrypsin Deficiency.

3. The Foundation commends NIH on the roadmap and recommends that NHLBI, NIDDK, NHGRI, NIEHS, and other institutes establish an Alpha-1 inter-institute coordinating committee to facilitate collaboration on this genetic lung and liver disease.

4. The Foundation encourages HRSA to collect additional data to evaluate the impact of the new lung transplant organ allocation system being implemented by the Organ Procurement and Transplantation Network/United Network for Organ Sharing.

5. The Foundation supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

#### ALPHA-1 FAST FACTS

Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of the most common fatal genetic diseases, 95 percent of those with Alpha-1 are undiagnosed.

Alpha-1 is commonly misdiagnosed as asthma and Chronic Obstructive Pulmonary Disease (COPD) as symptoms are similar. It usually takes seven years and five physicians to be accurately diagnosed after the onset of symptoms.

The World Health Organization (WHO) and the American Thoracic Society/European Respiratory Society recommends that all individuals with chronic obstructive pulmonary disease (an estimated 10–24 million Americans) as well as adults and adolescents with asthma (an estimated 14.6 million Americans) be tested for Alpha-1.

Alpha-1 is more prevalent than Cystic Fibrosis. An estimated 20 million Americans are undetected carriers of the Alpha-1 gene and may be at risk for lung and/or liver disease and may pass the gene on to their children.

Alpha-1 is a life-threatening adult onset lung disease that is progressive and irreversible. It is a major reason for lung transplantation. Nothing repairs lung tissue damage but early diagnosis allows individuals to engage in preventative health strategies and receive appropriate therapy which saves health care dollars.

Alpha-1 can also manifest as liver disease (5–10 percent) in adults as well as newborns for which the only treatment is a liver transplant. Alpha-1 is a leading cause of liver transplants in newborns.

#### COMMON SYMPTOMS OF ALPHA-1 INCLUDE

- Recurring respiratory infections
- Shortness of breath or awareness of one's breathing
- Non-responsive Asthma or Year-Round Allergies
- Rapid deterioration of lung function without a history of significant smoking
- Decreased exercise tolerance
- Chronic liver problems
- Elevated liver enzymes

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to present its recommendations on issues related to fiscal year 2006 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older

Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP would like to thank the Subcommittee for its continued strong support for increased funding for the National Institutes of Health (NIH) over the last several years, particularly the additional funding you have provided for the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

There are serious concerns, shared by AAGP and researchers, clinicians, and consumers that there exists a critical disparity between appropriations for research, training, and health services and the projected mental health needs of older Americans. This disparity is evident in the convergence of several key factors:

- demographic projections inform us that, with the aging of the U.S. population, there will be an unprecedented increase in the burden of mental illness among aging persons, especially among the baby boom generation;
- this growth in the proportion of older adults and the prevalence of mental illness is expected to have a major direct and indirect impact on general health service use and costs;
- despite the fact that effective treatment exists, the current mental health needs of many older adults remain unmet;
- the number of physicians being trained in geriatric mental health research and clinical care is insufficient to meet current needs, and this workforce shortfall is projected to become a crisis as the U.S. population ages over the next decade;
- a major gap exists between research, mental health care policy, and service delivery; and
- despite recent significant increases in appropriations for support of research in mental health, the allocation of NIMH and CMHS funds for research that focuses specifically on aging and mental health is disproportionately low, and woefully inadequate to deal with the impending crisis of mental health in older Americans.

#### DEMOGRAPHIC PROJECTIONS AND THE MENTAL DISORDERS OF AGING

With the baby boom generation nearing retirement, the number of older Americans with mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems. A national crisis in geriatric mental health care is emerging and has received recent attention in the medical literature. Action must be taken now to avert serious problems in the near future. While many different types of mental and behavioral disorders can occur late in life, they are not an inevitable part of the aging process, and continued research holds the promise of improving the mental health and quality of life for older Americans.

The current number of health care practitioners, including physicians, who have training in geriatrics is inadequate. As the population ages, the number of older Americans experiencing mental problems will almost certainly increase. Since geriatric specialists are already in short supply, these demographic trends portend an intensifying shortage in the future. There must be a substantial public and private sector investment in geriatric education and training, with attention given to the importance of geriatric mental health needs. We will never have, nor will we need, a geriatric specialist for every older adult. However, without mainstreaming geriatrics into every aspect of medical school education and residency training, broad-based competence in geriatrics will never be achieved. There must be adequate funding to provide incentives to increase the number of academic geriatricians to train health professionals from a variety of disciplines, including geriatric medicine and geriatric psychiatry.

Current and projected economic costs of mental disorders alone are staggering. The direct medical expense to care for a patient with Alzheimer's disease ranges from \$18,000 to \$36,000 a year per patient, depending on the severity of the disease. In addition, there are substantial indirect costs associated with caring for an Alzheimer's disease patient including social support, care giving, and often nursing home care. It is estimated that total costs associated with the care of patients with

Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and family burden. These psychiatric symptoms, associated with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent. Although NIA has supported extensive research on the cause and treatment of Alzheimer's, treatment of these behavioral and psychiatric symptoms has been neglected and should be supported through NIMH.

Depression is another example of a common problem among older persons. Approximately 30 percent of older persons in primary care settings have significant symptoms of depression; and depression is associated with greater health care costs, poorer health outcomes, and increased mortality. Of the approximately 32 million Americans who have attained age 65, about five million suffer from depression, resulting in increased disability, general health care utilization, and increased risk of suicide. Older adults have the highest rate of suicide rate compared to any other age group. Comprising only 13 percent of the U.S. population, individuals age 65 and older account for 19 percent of all suicides. The suicide rate for those 85 and older is twice the national average. More than half of older persons who commit suicide visited their primary care physician in the prior month—a truly stunning statistic.

The enormous and widely underestimated costs of late-life mental disorders justify major new investments. The personal and societal costs of mental illness and addictive disorders are high, but advances in research and treatment will help save lives, strengthen families, and save taxpayer dollars.

#### THE BENEFITS OF RESEARCH ON PUBLIC HEALTH

The U.S. Surgeon General's Report on Mental Health (1999) and the Administration on Aging Report on Older Adults and Mental Health (2001) underscore the prevalence of mental disorders in older persons and provide evidence that research has led to the development of effective treatments. These reports summarize research findings showing that treatments are effective in relieving symptoms, improving functioning, and enhancing quality of life. Preliminary findings suggest that these interventions reduce the need for expensive and intensive acute and long-term services. However, it is also well demonstrated that there is a pronounced gap between research findings on the most effective treatment interventions and implementation by health care providers. This gap can be as long as 15 to 20 years. These reports stress the need for translational and health services research focused on identifying the most cost-effective interventions, as well as creating effective methods for improving the quality of health care practice in usual care settings. A major priority (neglected to date) is the development of a health services research agenda that examines the effectiveness and costs of proven models of mental health service delivery for older persons.

Special attention also needs to be paid to inadequately or poorly studied, serious late-life mental disorders. Illnesses such as schizophrenia, anxiety disorders, alcohol dependence and personality disorders have been largely ignored by both the research community and the funding agencies, despite the fact that these conditions take a major toll on patients, their care givers, and society at large. Many of AAGP's members are at the forefront of groundbreaking research on Alzheimer's disease, depression, and psychosis among the elderly, and we strongly believe that more research funds must be focused in these areas. Improving the treatment of late-life mental health problems will benefit not only the elderly, but also their children, whose lives are often profoundly affected by their parents' illness.

While the funding increases supported by this Subcommittee in recent years have been essential first steps to a better future, a committed and sustained investment in research is necessary to allow continuous progress on the many research advances made to date.

#### NATIONAL INSTITUTE OF MENTAL HEALTH

In his fiscal year 2006 budget, the President proposed an increase of \$200 million for the National Institutes of Health (NIH), which would bring the entire NIH budget to a level of \$28.8 billion. However, this 0.7 percent increase over the fiscal year 2005 funding level pales in comparison with recent annual double-digit increases. A decline in adequate funding increases could have a devastating impact on the ability of NIH to sustain the ongoing, multi-year research grants that have been initiated in recent years.

For NIMH, the President is proposing \$1.418 billion for scientific and clinical research, a 0.4 percent increase over the agency's fiscal year 2005 appropriation of

\$1.412 billion. It is important to note that from fiscal year 1999 through fiscal year 2005, NIMH received increases that lagged behind the increases received by many of the other NIH institutes. Furthermore, the increase proposed by the Administration for NIMH for fiscal year 2006 is lower than that proposed for most of the other institutes at NIH. As Congress moves forward with deliberations on the fiscal year 2006 budget, AAGP believes that NIMH should receive a percentage increase that, at the very minimum, is equal to the average percentage increase for the other NIH institutes.

Commendable as recent funding increases for NIH and NIMH have been, AAGP would like to call to the Subcommittee's attention the fact that these increases have not always translated into comparable increases in funding that specifically address problems of older adults. Data supplied to AAGP by NIMH indicates that while extramural research grants by NIMH increased 59 percent during the five-year period from fiscal year 1995 through fiscal year 2000 (from \$485,140,000 in fiscal year 1995 to \$771,765,000 in fiscal year 2000), NIMH grants for aging research increased at less than half that rate: only 27.2 percent during the same period (from \$46,989,000 to \$59,771,000). Furthermore, despite the fact that over the past four years, Congress, through Committee report language, has specifically urged NIMH to increase research grant funding devoted to older adults, this has not occurred.

AAGP is pleased that NIMH has recently renewed its emphasis on mental disorders among the elderly, and commends the recent creation of a new Aging Treatment and Prevention Intervention Research Branch at NIMH. AAGP would like the scope of this Branch increased into a comprehensive aging Branch that is responsible for all facets of clinical research, including translational, interventions, and disease-based psychopathology. The Branch should also be given adequate resources to fulfill its primary mission within NIMH.

In addition to supporting research activities at NIMH, AAGP supports increased funding for research related to geriatric mental health at the other institutes of NIH that address issues relevant to mental health and aging, including the National Institute of Aging (NIA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Neurological Disorders and Stroke.

#### CENTER FOR MENTAL HEALTH SERVICES

It is also critical that there be adequate funding increases for the mental health initiatives under the jurisdiction of the CMHS within SAMHSA. While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. SAMHSA provides funding to State and local mental health departments, which in turn provide community-based mental health services to Americans of all ages, without regard to the ability to pay. AAGP was pleased that the final budgets for fiscal years 2002, 2003, 2004, and 2005 included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this Subcommittee and its House counterpart on this initiative, which is a very important first step in addressing the mental health needs of the nation's senior citizens. Increasing this mental health outreach and treatment program must be a top priority, as it is the only Federally funded services program dedicated specifically to the mental health care of older adults.

Funding for the dissemination and implementation of evidence-based practices in "real world" care settings must also be a top priority for Congress. Despite significant advances in research on the causes and treatment of mental disorders in older persons, there is a major gap between these research advances and clinical practice in usual care settings. The greatest challenge for the future of mental health care for older Americans is to bridge this gap between scientific knowledge and clinical practice in the community, and to translate research into patient care. Adequate funding for this geriatric mental health services initiative is essential to disseminate and implement evidence-based practices in routine clinical settings across the states. Consequently, we would urge that the \$5 million for mental health outreach and treatment for the elderly included in the CMHS budget for fiscal year 2005 be increased to \$20 million for fiscal year 2006.

Of that \$20 million appropriation, AAGP believes that \$10 million should be allocated to a National Evidence-Based Practices Program, which will disseminate and implement evidence-based mental health practices for older persons in usual care settings in the community. This program will be a collaborative effort, actively involving family members, consumers, mental health practitioners, experts, professional organizations, academics, and mental health administrators. With \$10 million dedicated to a program to disseminate and implement evidence-based practice in geriatric mental health, there will be an assured focus on facilitating accurate,

broad-based sustainable implementation of proven effective treatments, with an emphasis on practice change and consumer outcomes. Such a program should include several development phases including identification of a core set of evidence-based practices, development of evidence-based implementation, and practice improvement toolkits and field-testing of evidence-based implementation. This program will provide the foundation for a longer-term national effort that will have a direct effect on the well-being and mental health of older Americans.

The Community Mental Health Services Block Grant Program distributes funds to 59 eligible States and Territories through a formula based upon specified economic and demographic factors. Applications must include an annual plan for providing comprehensive community mental health services to adults with a serious mental illness and children with a serious emotional disturbance. Because the mental health needs of our Nation's elderly population are often not met by existing programs and because the need for such services is dramatically and rapidly increasing, AAGP recommends that SAMHSA require States' plans to include specific provisions for mental health services for older adults. Experience has demonstrated that States do not make adequate provisions for older adults. This population, which has unique needs, has been neglected in the planning process. Steps need to be taken to ensure that adequate mental health services are available to them.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

One of the most valuable resources in our efforts to improve access to and the quality of geriatric mental health services is the Agency for Healthcare Research and Quality (AHRQ). In recent years the Agency has supported important research on mental health topics including studies on children's mental health issues, the impact of mental health parity on consumers' share of mental health costs, improving care for depression in primary care, and cultural issues in the treatment of mental illness in minority populations. This work has led to important contributions to the mental health literature, and the advancement of effective diagnosis and treatment of mental illness. We applaud these efforts and urge the Committee to increase support for the critical work of this Agency.

However, we are concerned that the research agenda of the Agency has not given more attention to geriatric mental health issues. The prevalence of undiagnosed and untreated mental illness among the elderly is alarming. Conditions such as depression, anxiety, dementia, and substance abuse in older adults are often misdiagnosed or not recognized at all by primary and specialty care physicians. There is accumulating evidence that depression can exacerbate the effects of cardiac disease, cancer, strokes, and diabetes. Research has also shown that treatment of mental illness can improve health outcomes for those with chronic diseases. Effective treatments for mental illnesses in the elderly are available, but without access to physicians and other health professionals with the training to identify and treat these conditions, far too many seniors fail to receive needed care.

AAGP believes there is an urgent need to translate findings from aging-related biomedical and behavioral research into geriatric mental health care. By utilizing the resources of the evidence-based practice centers under contract to AHRQ, results from geriatric mental health research can be evaluated and translated into findings that will improve access, foster appropriate practices, and reduce unnecessary and wasteful health care expenditures. We urge the Committee to direct AHRQ to support additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population. We also believe a high priority should be given to the dissemination of scientific findings about what works best, to encourage physicians and other health professionals to adopt "best practices" in geriatric mental health care.

#### CONCLUSION

Based on AAGP's assessment of the current need and future challenges of late life mental disorders, we submit the following fiscal year 2006 funding recommendations:

1. The current rate of funding for aging grants at NIMH and CMHS is inadequate. Funding for NIMH and CMHS aging-related health services grants should be increased to be commensurate with current need—at least three times their current funding levels. In addition, the substantial projected increase in mental disorders in our aging population should be reflected in the budget process in terms of dollar amount of grants and absolute number of new grants.

2. To help the country's elderly access necessary mental health care, previous years' funding of \$5 million for evidence-based mental health outreach and treatment for the elderly within CMHS must be increased to \$20 million.

3. A fair grant review process will be enhanced by committees with specific expertise and dedication to mental health and aging.

4. Adequate infrastructure and funding within both NIMH and CMHS to support the development of initiatives in aging research, to monitor the number and quality of applicants for aging research grants, to promote funding of meritorious projects, and to manage those grant portfolios.

5. The scope of the recently formed Aging Treatment and Prevention Intervention Research Branch at NIMH should be increased to include all relevant clinical research, including translational, interventions, and disease-based psychopathology, and must receive NIMH's full support so it may fulfill its primary mission.

6. AHRQ should undertake additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population, and dissemination of information on best practices.

7. Funding for NIAAA must be increased by at least 20 percent to enable it to undertake more research and collect more data focused on issues such as the link between alcohol use and late-life suicide and the impact of alcohol use across the lifespan.

AAGP strongly believes that the present research infrastructure, professional workforce with appropriate geriatric training, health care financing mechanisms, and mental health delivery systems are grossly inadequate to meet the challenges posed by the expected increase in the number of older Americans with mental disorders. Congress must support funding for research that addresses the diagnosis and treatment of mental illnesses, as well as programs for delivery of geriatric mental health services that increase the quality of life for those with late-life mental illness.

AAGP looks forward to working with the members of this Subcommittee and others in Congress to establish geriatric mental health research and services as a priority at NIMH, CMHS, AHRQ and NIAAA.

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PREPARED STATEMENT OF THE AMERICAN AUTOIMMUNE RELATED DISEASES ASSOCIATION

The American Autoimmune Related Diseases Association (AARDA) is the only national voluntary health agency advocating for the over 100 autoimmune diseases as a genetically and clinically interrelated family, like cancer. AARDA's aim is to initiate, foster and facilitate collaboration in autoimmune awareness, education, advocacy and research. AARDA initiated, supports and facilitates the National Coalition of Autoimmune Patient Groups (NCAPG), a coalition of 25 voluntary health agencies focusing on individual autoimmune diseases.

The family of autoimmune diseases is under-recognized and as a result poses a major healthcare problem in the United States. These diseases afflict over 22 million Americans, more than twice as many as cancer. Treatment costs exceed \$120 billion per year and are rising rapidly, putting autoimmune disease's financial burden on the same level as heart and stroke disease and cancer. Autoimmune diseases are one of the top ten leading causes of death in females under the age of 65.

Autoimmune diseases are a major cause of chronic disability, further increasing their financial burden on society. Well-known autoimmune diseases include lupus, rheumatoid arthritis, multiple sclerosis, and juvenile (Type 1) diabetes. Lesser-known are scleroderma, Crohn's disease, myasthenia gravis, polymyositis, autoimmune liver diseases, Sjögren's syndrome and autoimmune blood disorders.

There is a huge disparity in autoimmune disease research funding compared to other major disease groups, such as cancer and heart disease. And some autoimmune diseases get a disproportionate amount of research funding compared to the others.

Congress addressed these issues in the Children's Health Act of 2000, which mandated the National Institutes of Health (NIH) Autoimmune Disease Coordinating Committee to develop an integrated Autoimmune Diseases Research Plan to address the entire family of autoimmune diseases and their common underlying cause—the immune system mistakenly attacking healthy body tissue and organs. All NIH institutes, the CDCP, VA, FDA and many patients' organizations provided input to develop and review the Research Plan. It is an excellent plan recommending an integrated cost-effective approach to autoimmune disease research and information dissemination.

Some of the Autoimmune Diseases Research Plan's recommendations have been implemented, but most have not. Much remains to be done, especially in the new and promising research areas identified in the Plan. AARDA strongly supports additional funding for the NIH Autoimmune Disease Coordinating Committee to further

expand implementation of the Autoimmune Diseases Research Plan. This additional funding will allow the Coordinating Committee to pursue promising research in the areas of environmental triggers, biomarkers and underlying disease mechanisms to help identify individuals at risk of developing an autoimmune disease and develop techniques to prevent the disease or minimize its impact.

AARDA respectfully requests Congress to appropriate \$40 million for the NIH Autoimmune Disease Coordinating Committee to expand implementation of the Autoimmune Diseases Research Plan to study environmental triggers of autoimmune disease. This research will pay for itself many times over by helping to reduce the major financial burden the family of autoimmune diseases places on our country.

On behalf of the many millions afflicted with an autoimmune disease and their families, thank you for the opportunity to address this important issue as Congress develops the Labor, HHS fiscal year 2006 budget. For More information, contact Virginia T. Ladd, Director, American Autoimmune Related Diseases Assoc., 22100 Gratiot, Eastpointe, MI., 48021, 586-776-3900 (p) 586-776-3903 (F)

#### PREPARED STATEMENT OF THE AMERICAN BRAIN COALITION

##### WHAT IS THE AMERICAN BRAIN COALITION?

The American Brain Coalition (ABC) is a nonprofit organization that seeks to reduce the burden of brain disorders and advance the understanding of the functions of the brain. ABC, unlike any other organization, brings together all types of organizations representing the 50 million individuals affected by brain disorders. This includes the afflicted patients, the families of those that suffer, the caregivers, and the professionals that research and treat diseases of the brain.

ABCs' goals are to: (1) promote research funding and progress towards cures, (2) help to build a healthcare system that is more responsive to people with both acute and chronic brain disorders, and (3) advance public understanding about the causes, impacts, and consequences of neurologic and psychiatric illness in our society.

The brain is the center of human existence, and the most complex living structure known. As such, ABC members have a broad range of interests. Among others, the coalition includes organizations and individuals that:

- are clinicians who treat neurological diseases
- are scientists who research the brain, including the neurological and psychiatric disorders that affect it
- investigate basic and clinical aspects of epilepsy
- fund research on Rett Syndrome, a debilitating neurological disorder
- are pioneers in educational and vocational training for the mentally retarded
- have family members affected by mental health conditions, such as depression, schizophrenia, and obsessive-compulsive disorder
- are affected by Parkinson's disease and essential tremor

##### CONGRESSIONAL SUPPORT ACCELERATES DISCOVERY

The National Institutes of Health (NIH), the world's premier medical research enterprise, is leading the way in research related to the brain. Thanks to this subcommittee, Congress held to its commitment to double the budget of the NIH in the late 1990s and early 2000s. The primary goal for the added funds was to discover better treatments and cures for human disease. Since then, scientists have amassed a wealth of medical knowledge. Today, researchers have a greater understanding of how the brain and nervous system function due to NIH-funded research. On behalf of the millions of Americans suffering from a disorder of the brain, ABC thanks the Chairman and Ranking Member for their continued support of this life altering research.

Many recent scientific discoveries, including those in neurology and psychiatry, have just begun to show their potential. Some accomplishments that are a direct result of NIH research include:

- The development of drugs that reduce the severity of symptoms for those suffering with multiple sclerosis and Parkinson's disease
- The identification of stroke treatment and prevention methods
- The discovery of a new class of anti-depressants that produce fewer side effects than their predecessors
- The creation of new drugs to help prevent epileptic seizures
- The expansion of treatments for the psychotic symptoms of schizophrenia

Insights into the biology of schizophrenia, post-traumatic stress disorder, and other diseases have led to the development of enhanced diagnostic techniques, bet-



ter prevention methods, and more effective treatments. Simply put: the result of Congressional support for research leads to improved patient care.

#### WHAT COMES NEXT? THE FUTURE OF RESEARCH

ABC supports NIH in its entirety, with a more specific interest in the institutes and centers that focus on diseases and disorders of the brain and nervous system. Because the brain affects all parts of the body, brain research is broad and must be conducted across institutes in order to fully understand the diseases that affect so many Americans.

The NIH Neuroscience Blueprint is a framework to enhance cooperation among 15 NIH institutes and centers that support this research. Over the past 10 years, driven by the science, the NIH neuroscience institutes and centers have increasingly joined forces through initiatives and working groups focused on specific disorders. The Blueprint builds on this foundation, making collaboration an everyday part of how the NIH does business in neuroscience. By pooling resources and expertise, the Blueprint can take advantage of economies of scale, confront challenges too large for any single institute, and develop research tools and infrastructure that will serve the entire neuroscience community.

The Neuroscience Blueprint encourages the collaboration necessary in order to advance basic science and to develop new more effective bedside treatments. The following diseases, along with many others, have the potential to be greatly affected from this research.

1. *Stroke*.—Research has already led to the development of more effective stroke treatments, the identification of new prevention methods, and the creation of improved rehabilitation techniques. Despite much progress in stroke research over the past decade, much remains to be done.

With continued funding, therapies to reverse paralysis of limbs may be possible. A preliminary analysis indicates that the resulting financial benefits from reduced medical care, a quicker return to work, and improved quality of life outweigh the costs of therapy. Future studies seek to refine the technique, called constraint-induced movement therapy to further improve outcomes and lower costs.

2. *Epilepsy*.—Research in the field of Epilepsy has already led to the discovery of genetic mutations that play a role in how seizures begin. Additionally, research has aided in the development of a new generation of antiepileptic drugs and better brain scanning techniques that assist in diagnosis.

With continued funding, additional drug therapies might be developed to control seizures. Currently, up to one-third of patients are resistant to drug therapy. More research must be done in order to improve the quality of life for these people. One promising approach may be to use gene therapy to modify the excitability of hyperactive brain cell circuits. Additionally, increased funding might aid in the development of devices that are implanted into the brain that could forewarn doctors and patients of an impending seizure. These tiny devices could then deliver the drugs directly to the epileptic brain region in doses that could be regulated by the patient or doctor. Much more work is needed before such a system could be widely used.

3. *Bipolar Disorder*.—Past funding from NIH and the Department of Veterans Affairs has helped scientists make great progress in understanding bipolar disorder. Today, we know that bipolar disorder is a biologically based disorder, and not a result of a weak personal character. Using the latest brain imaging techniques, scientists have discovered that the brain function and structure in patients with bipolar disorder differs markedly from that in people without the illness.

Continued funding for research could lead to the development of tests for earlier diagnosis and treatment, as well as drug therapies to prevent or reverse the progressive loss of brain cells that occurs with bipolar disorder. Already, scientists are exploring the possibility for low-dose lithium as a preventative measure against atrophy and loss of cells. Research on lithium may prove advantageous for a variety of diseases, including schizophrenia and Alzheimer's disease.

Only with continued funding will scientists be able to bring hope to the millions of Americans suffering from a brain disorder.

#### BEYOND HELPING PEOPLE: FEDERAL INVESTMENTS IN RESEARCH ARE ECONOMICALLY BENEFICIAL

Not only does research save lives, but it is a good investment for the future of America. We know that illness is expensive. Depressive diseases alone cost U.S. businesses \$83 billion in medical expenditures, suicide-related costs, absences from work, and reduced productivity while at work. The annual cost of Alzheimer's disease in the United States is over \$100 billion, with more than \$30 billion of that amount paid out by Medicare. As the baby boomers age, without effective therapy,

the number of people affected by Alzheimer's will quadruple. This number is only expected to increase.

NIH-funded research could alleviate some of the financial strains that brain disorders place on businesses, government, and families. For example, a one month delay in admitting Alzheimer's patients to nursing homes could save \$1 billion per year. Without additional research, the economic burden placed on U.S. resources will be exacerbated.

In addition to helping control costs, the federal investment in research helps stimulate local economies. NIH dollars are sent to every state in the country, helping to employ thousands of people. According to the Bureau of Labor Statistics, nearly 1 million people in the United States are employed in the biosciences. This number is projected to grow at an annual rate of 13 percent.

#### RECOMMENDATION

As the Subcommittee considers the fiscal year 2006 appropriations for the Department of Health and Human Services, we urge you to support a 6 percent increase in funding for the National Institutes of Health in order to sustain the pace of recent discoveries.

Treatments for diseases and disorders of the brain will only be possible if the NIH, the world's leading medical research enterprise, has a longstanding commitment from Congress.

ABC's request is based on the following information:

- \$1 billion is needed to cover biomedical research inflation, which is projected to be 3.5 percent;
- \$560 million is needed to replace the evaluation set-aside (an amount taken from each institute), which this year amounted to 2.4 percent (it used to be 1 percent); and
- The total number of research project grants (RPGs) is declining by 402 from what it was in fiscal year 2005.

Thank you for the opportunity to provide testimony to this Subcommittee.

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#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF CARDIOLOGY

More than 70 million Americans are living with cardiovascular disease, with more than 900,000 of them dying this year from disease-related complications. In fact, heart disease claims more lives than cancer, diabetes, and chronic respiratory diseases combined. As physicians toil to keep these patients alive, another group of individuals is working just as hard to fight the ravages of heart disease: Medical researchers.

The American College of Cardiology (ACC), a 33,000-member nonprofit professional medical society advocating for quality cardiovascular care, supports increased federal funding of medical research and urgently calls on Congress to continue to invest in future cardiovascular care.

As with any financial outlay, there needs to be a healthy return on investment. The same holds true for medical research, and the ACC believes the data speaks loudly. Between 1982 and 2002, death rates attributed to cardiovascular diseases declined by 37 percent. This remarkable achievement can be attributed to clinically proven treatments and techniques for managing heart disease. These life-saving technology advances and treatments originate with cutting-edge research. Without federally-funded clinical trials, there would not be stents or statins, ICDs or AEDs, and millions more Americans would die prematurely from cardiovascular disease.

Each year, agencies such as the National Institutes of Health (NIH) release groundbreaking studies that fundamentally change the course of medicine. This year was no exception. Initially presented at the ACC's Annual Scientific Session in early March and published March 31, 2005, in *The New England Journal of Medicine*, *The Women's Health Study* has left its mark on the cardiovascular world. This 10-year study of 40,000 healthy women showed that aspirin did not reduce the risk of major cardiovascular events, a stark contrast to the effects of aspirin in men. In addition, researchers concluded that many women, especially those 65 and older, may benefit from taking low-dose aspirin every other day with the primary goal to prevent stroke. The results of this study hold immediate implications for the treatment of women at risk for heart disease, but also point to the broader role of understanding and adjusting for gender in the development of medical regimens.

Compelling cardiovascular research conducted by the NIH and the National Heart, Lung and Blood Institute (NHLBI) is critical to physicians winning the fight against heart disease. The ACC does not believe that President Bush's proposed fiscal year 2006 budget reflects the commitment needed to these critical research insti-

tutions. Under the President's plan, the National Institutes of Health (NIH) would receive a 0.5 percent increase, which is significantly less than the current rate of inflation. As one of 27 institutes falling under the NIH umbrella, the NHLBI stands to receive a pittance of this modest increase. The Centers for Disease Control and Prevention (CDC) fare even worse, facing millions of dollars in actual funding cuts for fiscal year 2006.

In order to continue life-saving cardiovascular research and education, the ACC supports the following fiscal year 2006 appropriations funding levels:

- \$30 billion for the NIH, including \$2.3 billion for heart research and \$341 million for stroke research
- \$3.1 billion for the NHLBI, including \$1.9 billion for heart and stroke-related research
- \$55.6 million for the CDC's Heart Disease and Stroke Prevention Program

These allocations will enable core cardiovascular research that improves clinical outcomes and quality of care. As the medical landscape continues to shift with the introduction of new technology and more complex caseloads, evidence-based research serves as the foundation of clinical guidelines that direct physician practice. The ACC draws on federally-funded research to craft documents that set the standard for cardiovascular care and guide the practice of our members worldwide.

Adequately funding research today will reap dividends tomorrow, upon which the federal government through its Centers for Medicare & Medicaid Services (CMS) will undoubtedly benefit. Even now, CMS is sponsoring pilot projects designed to pay physicians based on evidence-driven performance. Advances in medical protocols derived from federally underwritten research will become the backbone for this push to deliver better, more cost-effective patient care.

By investing in medical research now, Congress can help at-risk patients minimize the impact of cardiovascular disease and improve quality of care for more than 70 million heart patients. The ACC encourages the subcommittee to continue its support of federally-funded cardiovascular research by supplying federal agencies with the resources to continue their life-saving work. Thank you for permitting the ACC to share its views on this important topic.

#### PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

The American Dental Hygienists' Association (ADHA) appreciates this opportunity to submit written testimony regarding fiscal year 2006 appropriations for the Department of Health and Human Services.

ADHA is the largest national organization representing the professional interests of the more than 120,000 dental hygienists across the country. Dental hygienists are preventive oral health professionals who are licensed in each of the fifty states. As prevention specialists, dental hygienists understand that recognizing the connection between oral health and total health can prevent disease, treat problems while they are still manageable, and conserve critical health care dollars. Dental hygienists are committed to improving the nation's oral health, a fundamental part of total health.

Indeed, in order to improve access to oral health care, ADHA is working to establish a new oral health care provider, the "Advanced Dental Hygiene Practitioner." This new provider would deliver preventive, therapeutic and restorative services directly to underserved Americans. Please visit the ADHA web site at [www.adha.org](http://www.adha.org) for more information.

#### U.S. SURGEON GENERAL REPORT ON ORAL HEALTH IN AMERICA AND THE NATIONAL ORAL HEALTH CALL TO ACTION

In May 2000, the U.S. Surgeon General issued *Oral Health in America: A Report of the Surgeon General*. This landmark report confirms what dental hygienists have long known: that oral health is an integral part of total health and that good oral health can be achieved. The Surgeon General's Report on Oral Health challenges all of us—in both the public and private sectors—to address the compelling evidence that not all Americans have achieved the same level of oral health and well-being. The Report describes a "silent epidemic" of oral diseases, which affect our most vulnerable citizens—poor children, the elderly and many members of racial and ethnic minority groups.

ADHA suggests that one step that needs to be taken is to improve access to the preventive oral health care services provided by dental hygienists. This is important because unlike most medical conditions, the three most common oral diseases—dental caries (tooth decay), gingivitis (gum disease) and periodontitis (advanced gum and bone disease)—are proven to be preventable with the provision of regular oral health care. Despite this prevention capability, tooth decay—which is an infectious

transmissible disease—still affects more than half of all children by second grade. Clearly, more must be done to increase children’s access to oral health care services.

While the profession of dental hygiene was founded in 1923 as a school-based profession, today the provision of dental hygiene services is largely tied to the private dental office. Increased utilization of dental hygienists in schools, nursing homes, and other sites—with appropriate referral mechanisms in place to dentists—will improve access to needed preventive oral health services. This increased access to preventive oral health services will likely result in decreased oral health care costs per capita and, more importantly, improvements in oral and total health.

As the General Accounting Office (GAO) confirmed in two recent separate reports to Congress, “dental disease is a chronic problem among many low-income and vulnerable populations” and “poor children have five times more untreated dental caries (cavities) than children in higher-income families.” The GAO further found that the major factor contributing to the low use of dental services among low-income persons who have coverage for dental services is “finding dentists to treat them.” Increased utilization of dental hygiene services—appropriately linked to the services of dentists—is critical to addressing the nation’s crisis in access to oral health care for vulnerable populations. Indeed, ADHA is committed to working with the Congress to improve access to oral health care services, particularly for children eligible for Medicaid and the State Children’s Health Insurance Program (SCHIP). ADHA urges this Subcommittee and all members of Congress to support the Medicaid and SCHIP programs. ADHA strongly supports the Smith-Bingaman amendment in the fiscal year 2006 Senate Budget Resolution that strikes cuts to the Medicaid program and calls for a Medicaid Commission to carefully study and recommend changes to the program.

#### NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

As the Surgeon General’s Report on Oral Health so clearly demonstrates, the nation’s oral health can and must be further improved. The National Institute of Dental and Craniofacial Research (NIDCR) is the nation’s focal point for oral health research and NIDCR’s work has yielded significant advancements in oral health.

Over the past 50 years, our nation’s investment in dental and craniofacial research has yielded tremendous advances in American public health. Some of the often-cited examples include a sharp reduction in the once rampant rate of dental caries and tooth loss, improved care of all aspects of gum (periodontal) diseases, and the effective management of oral pain. In its ongoing quest to improve the nation’s oral health, a fundamental part of overall health and general well-being, NIDCR is, for example, working to realize the potential of salivary diagnostics. As NIDCR Director Lawrence A. Tabak, DDS, PhD explains, “scientists have long recognized that our saliva serves as a mirror’ of the body’s health, in that it contains the full repertoire of proteins, hormones, antibodies, and other molecular analytes that are frequently measured in standard blood tests.”

NIDCR’s work in dental research has not only resulted in better oral health for the nation, it has also helped curb increases in oral health care costs. Americans save nearly \$4 billion annually in dental bills because of advances in dental research and an increased emphasis on preventive oral health care. To enable NIDCR to continue and to build upon its important research mission, ADHA joins with other groups in the oral health community to recommend that NIDCR be funded at \$420 million for fiscal year 2006. ADHA further urges that NIDCR be preserved as an independent institute in any future NIH reorganization.

#### DENTAL HEALTH IMPROVEMENT ACT, A COMPONENT OF THE HEALTH CARE SAFETY NET AMENDMENTS ACT OF 2002

ADHA is pleased to see the increasing recognition among federal policymakers of the importance of oral health to overall health and well-being. A primary illustration of this appreciation for the link between oral health and general health is the Dental Health Improvement Act, which was passed by Congress as part of the Health Care Safety Net Amendments Act of 2002 (Public Law 107–261). This important legislation will assist states in addressing the crisis in access to oral health services. ADHA joins with others in the oral health community to recommend \$10 million to fund the oral health programs and initiatives contained within the Act.

#### CENTERS FOR DISEASE CONTROL ORAL HEALTH PROGRAM

ADHA would also like to lend its support to the Centers for Disease Control and Prevention (CDC) Oral Health Program. ADHA joins with other dental groups in urging a budget of \$18 million for the CDC Oral Health Program. This funding level will enable the Oral Health Program to continue its vital work to control and pre-

vent oral disease, including its important work in the area of community water fluoridation and school-based dental sealant programs. ADHA also requests \$130 million for the CDC prevention block grant. Last year, approximately \$3.5 million in block grant monies flowed to the states for critical oral health projects such as replacement of fluoridation equipment.

#### RYAN WHITE HIV/AIDS DENTAL REIMBURSEMENT PROGRAM

Included in the Ryan White CARE Act is a dental reimbursement program that assists in meeting the oral health needs of people living with HIV/AIDS, most of whose care is not covered under existing federal and state assistance programs. The dental reimbursement program provides participating institutions with partial reimbursement for the cost of providing oral health care services to low income people living with HIV and AIDS. In 1999, oral health care was provided to more than 65,000 patients under the program.

The "Ryan White CARE Act Amendments of 2000" rendered—for the first time—dental hygiene programs eligible for the dental reimbursement program. While there are only 55 dental schools in the United States, there are presently 279 accredited dental hygiene education programs in the United States. In fact, all states have at least one dental hygiene education program.

ADHA joins with the American Dental Education Association in recommending \$19 million for this important program. ADHA further urges this Subcommittee to direct HRSA to work to actively encourage and facilitate the participation of dental hygiene programs in the Ryan White HIV/AIDS reimbursement effort.

#### MATERNAL AND CHILD HEALTH PROGRAM

The Maternal and Child Health Block Grant Program provides vital support and services that improve the health of women and children. It is critical that the oral health component of this program be strengthened. This is important because, for example, research increasingly recognizes the link between severe periodontal disease in pregnant women and pre-term low birth weight babies. ADHA strongly supports the MCH programs and urges full funding for fiscal year 2006.

#### HEALTH PROFESSIONS EDUCATION

ADHA supports the important work of Title VII of the Public Health Service Act, in particular, the Allied Health Project Grants and the Scholarships for Disadvantaged Students Program. Allied health disciplines constitute fully 60 percent of the health care work force. The Scholarships Program seeks to recruit and retain minority and disadvantaged students.

ADHA joins the Association of Schools of Allied Health Professions in recommending \$20 million for Allied Health Project Grants and full funding for the Scholarships for Disadvantaged Students program. With the acknowledged need for cost-effective health care providers, it is time to augment funding for and recognition of these important allied health programs. ADHA further urges full funding for the Centers for Excellence Program, the Faculty Loan Repayment Program and the Health Careers Opportunity Program.

#### NATIONAL HEALTH SERVICE CORPS

ADHA strongly supports the National Health Service Corps (NHSC) and its Scholarship and Loan Forgiveness Programs. Scholarships and loan forgiveness provide vital assistance to students entering the health professions. ADHA urges that the committee again direct the NHSC to increase the participation of dental health providers, dentists and dental hygienists alike. This is important because too few Americans—particularly low-income Americans—regularly access needed oral health services. ADHA supports \$213 million for this important effort.

#### INDIAN HEALTH SERVICE DENTAL PROGRAMS

American Indians and Alaska Natives suffer disproportionately from poor oral health. Indeed, 75 percent of American Indian and Alaska Native children aged 2–5 years old experience untreated dental decay (caries). The prevalence of dental disease only increases with age. A staggering 91 percent of American Indian and Alaska Native children aged 15–19 years old experience tooth decay. In fiscal year 2004, the proportion of American Indian and Alaska Natives with access to dental care was only 24 percent. Presently, there are 109 vacancies in the IHS dental program. Clearly, there is much to be done to improve access to oral health services for Alaska Natives and American Indians. Accordingly, ADHA strongly supports the Community Health Aide Program, including the use of dental health aide therapists.

ADHA joins with the American Academy of Pediatrics and the American Dental Association in recommending \$124 million for IHS dental programs.

CONCLUSION

In closing, the American Dental Hygienists' Association appreciates the important contributions this Subcommittee has made in improving the quality and availability of oral health services throughout the country. ADHA is committed to working with this Subcommittee—and all Members of Congress—to improve the nation's oral health which, as *Oral Health in America: A Report of the Surgeon General* so rightly recognizes, is a vital part of overall health and well-being.

Please contact our Washington Counsel, Karen Sealander of McDermott Will & Emery (202/756-8024 or [ksealander@mwe.com](mailto:ksealander@mwe.com)), with questions or for further information. Thank you for this opportunity to submit the views of the American Dental Hygienists' Association.

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on the importance of federal funding for diabetes programs at the Centers for Disease Control and Prevention (CDC) and diabetes research at the National Institutes of Health (NIH).

As the nation's leading nonprofit health organization providing diabetes research, information and advocacy, the American Diabetes Association feels strongly that federal funding for diabetes prevention and research efforts is critical not only for the 18.2 million Americans who currently have diabetes, but also for the more than 40 million who have a condition known as "pre-diabetes."

Diabetes is a serious disease, and is a contributing and underlying cause of many of the diseases on which the federal government spends the most health care dollars. In addition to the \$132 billion in 2002 dollars in direct and indirect costs spent solely on diabetes each year, diabetes is a significant cause of heart disease (which costs our nation \$183.1 billion each year), a significant cause of stroke (\$43.3 billion each year), and the leading cause of kidney disease (\$40.3 billion). Diabetes is also the leading cause of adult-onset blindness and lower limb amputations.

Approximately 42,000 people suffering from diabetes live in each congressional district and the number of people living with diabetes in this country is growing at a shocking rate. Between 1990 and 2001, diabetes prevalence in the United States has increased by more than 60 percent. The number of Americans with diabetes is now growing at a rate of 8 percent per year and is the single most prevalent chronic illness among children. Because the systemic damage diabetes imposes throughout the body, it is no surprise that the life expectancy of a person with the disease averages 10–15 years less than that of the general population.

As the statistics listed above illustrate, we are facing an epidemic of diabetes in this country, which if left unchecked could have significant implications for many future generations. The picture, however, is not without hope. We can stem the tide of this disease, but to do so requires a renewed federal commitment not only to research, but also to prevention.

The Association appreciates the increased attention by Congress to diabetes research at the National Institutes of Health (NIH) in recent years. While there is not yet a cure for diabetes, researchers at NIH are working on a variety of projects that represent hope for the millions of individuals with type 1 and type 2 diabetes. The Association strongly encourages you to provide a 6 percent increase to the NIH to fulfill this promise. Unfortunately, while the death rate due to diabetes has increased by more than 40 percent in recent years, diabetes research funding has not kept pace. Indeed, from 1987–2001, appropriated diabetes funding as a share of the overall NIH budget has dropped by more than 20 percent (from 3.9 percent to 2.9 percent). Over the last 4 years, Congress has begun to address this discrepancy. We respectfully ask you to continue this commitment.

While the NIH continues to work towards finding a cure, we must also adequately fund the diabetes prevention and outreach work being done at the Centers for Disease Control and Prevention. Therefore, we are requesting:

—At least a 10 percent increase over fiscal year 2005 levels for the CDC's Center on Chronic Disease Prevention and Health, including an additional \$10 million increase for the CDC's Division of Diabetes Translation (DDT); and

—Restoration of the Preventive Health & Health Services Block Grant.

The CDC's Division of Diabetes Translation is critical to our national efforts to prevent and manage diabetes because they translate the research that has already been done to real programs at the community level. Currently, for every \$1 that diabetes costs this country, the federal government invests less than \$.01 to help Amer-

icans prevent and manage this deadly disease. This dynamic must be changed. While the Association strongly believes that significant funding is needed to fully fund programs in all 50 states, our request of \$10 million recognizes the current budget realities.

In 2004 DDT provided support for more than 50 state- and territorial-based Diabetes Prevention and Control Programs (DPCPs) to increase outreach and education, and reduce the complications associated with diabetes. However, funding constraints required DDT to provide severely limited support to 24 states, 8 territories, and D.C. This level of funding, referred to as “capacity building,” allows a state to do surveillance, but is not enough for the state to do much—or anything—in the way of intervention.

DDT was able to provide the higher level of support, “basic implementation,” to the other 26 states. At the basic implementation level, states are able to devise and execute community-level programs. With an additional \$10 million over fiscal year 2005 funding levels, an additional 7 states could start to receive the substantial benefits of basic implementation programs.

The basic implementation programs undoubtedly make a major impact on local communities. For example, Daviess County in Kentucky is using their DPCP funding to support a community-based program that has trained more than 500 health professionals through professional education programs, screened and referred more than 1,500 people for diabetes through innovative events designed to reach the neediest individuals, provides test strips and emergency medications to more than 150 individuals annually, and lead comprehensive media and outreach campaigns to educate the public to recognize the risk factors for diabetes. While this example highlights the accomplishments from only one county in one state; it demonstrates the broad approach enabled by the basic implementation programs. Our goal is to make this a reality for the rest of the country, so that communities have the ability to invest in their future by investing in diabetes prevention and education.

Without fully-funded diabetes programs and projects in all parts of the country, it will be exceedingly difficult—if not impossible—to control the escalating costs associated with diabetic complications and to stem the epidemic rise in diabetes rates. State DPCPs, when provided with enough funding, are proven programs that have been extremely successful in helping Americans prevent and manage their diabetes. In the Division of Diabetes Translation Program Review fiscal year 2004, the CDC stated, “The Basic Implementation DPCPs serve as the backbone for our growing primary prevention efforts. These state programs are the key elements to our success in meeting the challenges of controlling and preventing diabetes.” For example, in Minnesota, the DPCP initiated a unified, statewide strategic plan for combating diabetes which resulted in more than 800,000 Minnesotans getting educational messages through television, radio, print, and web coverage. In Utah, innovative messaging such as bus wraps on public transportation are being used to inform hard-to-reach, at-risk populations of the NDEP messages, “You are the Heart of Your Family” and “Control Your Diabetes. For Life.” Americans in every state should have access to such quality programs. Unfortunately, the Division’s fiscal year 2005 budget of just over \$63 million, and the President’s request for near flat-funding in fiscal year 2006, will prevent more counties from implementing programs such as the one described above.

In addition to DPCP, the CDC’s Division of Diabetes Translation also conducts other activities to help people currently living with diabetes. For example, CDC works with NIH to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. The CDC is also currently working to develop a National Public Health Vision Loss Prevention Program that will investigate the economic burden and strength the surveillance and research of this all-to-common complication of diabetes. In addition, CDC funds work at the National Diabetes Laboratory to support scientific studies that will improve the lives of people with diabetes. In fiscal year 2004, the Division of Diabetes Translation alone published 46 manuscripts on the care, prevention, and science of diabetes.

The Association is also supportive of restoration of the CDC’s Preventive Health & Health Services Block Grant (PBG). The PBG, which allows states to develop innovative health programs at the community level, received \$132 million in FY05, but is currently slated for no funding for fiscal year 2006. These programs have been very successful. For example, New York State uses theirs to help fund state-wide regional partnerships that provide much needed diabetes prevention and control activities for medically underserved individuals and communities. Currently, about \$2.2 million goes toward diabetes-related programs. While this is a relatively

small amount, it is nonetheless important to the communities it is currently helping.

The Association, and the millions of individuals with diabetes we represent, firmly believes that we could rapidly move toward curing, preventing, and managing this disease by increasing funding for diabetes programs and research both at CDC and NIH. Your leadership is essential to accomplishing this goal. As you are considering fiscal year 2006 funding, we ask you to remember that chronic diseases, including diabetes, account for nearly 70 percent of all health care costs as well as 70 percent of all deaths annually. Unfortunately, less than \$1.25 per person is directed toward public health interventions focused on preventing the debilitating effects associated with chronic diseases, demonstrating that federal investment in chronic disease prevention remains grossly inadequate. We cannot ignore those Americans who are currently living with diabetes and other diseases.

In closing, the American Diabetes Association strongly urges the Subcommittee and Congress to provide a 10 percent increase for the CDC's Center on Chronic Disease Prevention and Health, including a \$10 million increase for the CDC's Division of Diabetes Translation, and to restore the Preventive Health & Health Services Block Grant. Providing this funding would be an important step towards empowering states to fight diabetes at the community level. Additionally, we urge the Subcommittee to increase NIH funding by 6 percent to allow for an increased commitment to diabetes research.

On behalf of the 18.2 million Americans with diabetes—a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our nation; and a disease that is exploding throughout our nation—thank you for the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

Agency	Amount
National Institutes of Health .....	30.1
National Heart, Lung, and Blood Institute .....	3,117.4
National Institute of Allergy and Infectious Disease .....	4,667.1
National Institute of Environmental Health Sciences .....	680.0
National Institute of Nursing Research .....	146.2
Fogarty International Center .....	71.0
Centers for Disease Control and Prevention .....	8,500.0
National Institute for Occupational Safety and Health .....	326.0
Office on Smoking and Health .....	130.0
Environmental Health: Asthma Activities .....	70.0
Tuberculosis Control Programs .....	215.0

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

American Lung Association (ALA) is pleased to present our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Lung Association is the oldest voluntary health organization in the United States, with a National Office, constituent, and affiliate associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms, with special emphasis on asthma, tobacco control and environmental health. The Lung Association is funded by contributions from the public, along with gifts and grants from corporations, foundations and government agencies. The American Lung Association achieves its many successes through the work of thousands of committed volunteers and staff.

MAGNITUDE OF LUNG DISEASE

Each year, an estimated 341,500 Americans die of lung disease. Lung disease is America's number three killer, responsible for 1 in every 7 deaths. More than 25 million Americans suffer from a chronic lung disease. This year, lung diseases cost the U.S. economy an estimated \$94.9 billion.



Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include: chronic obstructive pulmonary disease, lung cancer, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis and asthma.

Mr. Chairman, while our comments today will focus on selected parts of the Public Health Service; the American Lung Association is firmly committed to appropriate funding for all sectors of our nation's public health infrastructure.

#### COPD

Chronic Obstructive Pulmonary Disease, or COPD, is a growing health problem. Yet it remains relatively unknown to most Americans and much of the research community. COPD is an umbrella term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis. COPD is the fourth leading cause of death in the United States and worldwide.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It has been estimated that 16 million patients have been diagnosed with some form of COPD and as many as 16 million more are undiagnosed. New government data based on a 1998 prevalence survey suggest that 3 million Americans have been diagnosed with emphysema and 9 million are diagnosed with chronic bronchitis. Emphysema affects more men than women, while chronic bronchitis affects more women than men. In 1999, 119,524 people in the United States died of COPD. During the period 1979–1998, the number of deaths from COPD rose almost 126 percent. COPD costs the U.S. economy an estimated \$30.4 billion a year.

Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research in the genetic susceptibility underlying COPD is making progress. Research is also showing promise for reversing the damage to lung tissue caused by COPD.

Despite these promising research leads, the American Lung Association feels that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. The American Lung Association strongly recommends that the NIH and other federal research programs commit additional resources to COPD research programs.

#### ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes of the lungs become swollen and narrowed, preventing air from getting into or out of the lung. A broad range of environmental triggers that vary from one asthma-sufferer to another causes these obstructive spasms of the bronchi.

Asthma is on the rise. A 1998 survey found that an estimated 26 million Americans (including 8.6 million children under the age of 18) have at some point in their lifetime been told by their doctor that they have asthma. Rates are increasing for all ethnic groups and especially for African American and Hispanic children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition.

Asthma is expensive. The growth in the prevalence of asthma will have a significant impact on our nation's health expenditures, especially Medicaid. Currently, asthma costs the United States \$12.7 billion annually, including \$8.1 billion in direct medical expenditures. Asthma attacks bring nearly two million people to the emergency room each year. Asthma also kills. In 1998, 5,438 people in the United States died as a result of an asthma attack. That is a 109 percent increase from 1979. A disproportionate share of these deaths occurred in African American families.

#### *Federal Response to Asthma*

The federal response to asthma has three components: research, programs and planning. We are pleased to report that, with support from the subcommittee, we are making progress on all three fronts.

#### *Asthma Research*

As the prevalence of asthma has grown, so has asthma research. Researchers are developing better ways to treat and manage chronic asthma. Research supported by National Heart, Lung and Blood Institute (NHLBI) has shown that using corticosteroids to treat children with mild to moderate asthma is safe and effective. For several years there had been concern that corticosteroids would stunt the growth of children who used them. This five-year study showed that children had

a one-year small reduction in their growth rate. But they had normal growth rates compared with children who did not use corticosteroids for the following four years. Children who used corticosteroids did suffer fewer asthma attacks and made fewer trips to the emergency room.

#### *Genetic Research*

Genetic Research is also providing insights into asthma. Physicians have noticed that while most people respond well to inhaled beta-agonists—a commonly prescribed drug to treat asthma—some patients do not respond or have worse asthma using inhaled beta-agonists. Researchers in the NHLBI supported Asthma Clinical Research Network have discovered that a genetic variation in the beta-adrenergic receptor determines how well asthma patients will respond to inhaled beta-agonists. This discovery will enable physicians to better target the drugs they proscribe to treat asthma.

Researchers supported by NHLBI have developed better animal models to allow expression of selected asthmatic genetic traits. This will allow researchers to develop a greater understanding of how genes and environmental triggers influence asthma's onset, severity and long-term consequences.

#### *Asthma Programs*

Last year, Congress provided approximately \$32.7 million for the Centers for Disease Control and Prevention (CDC) to conduct asthma programs. The American Lung Association recommends that CDC be provided \$70 million in fiscal year 2006 to expand its asthma programs.

### TUBERCULOSIS

Mr. Chairman, tuberculosis has been with us since the dawn of time. It is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis* (TB). TB primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine.

TB is spread through coughs, sneezes, speech and close proximity to someone with active tuberculosis. People with active tuberculosis are most likely to spread TB to others they spend a lot of time with, such as family members or coworkers. It cannot be spread by touch or sharing utensils used by an infected person.

There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2001, there were 15,991 cases of active TB reported in the United States.

The Institute of Medicine (IOM) recently published a report, entitled *Ending Neglect: The Elimination of Tuberculosis in the United States*. The report documents the cycles of attention and progress toward TB elimination, the periods of insufficient funding and the re-emergence of TB. The American Lung Association is pleased to note that, for the time being, TB rates in the United States are declining. From a high in 1992 of 26,673 new cases, we have seen 9 straight years of decline. However, the drop in 2001 was reportedly only 2 percent, indicating a leveling off of the overall decline in cases and a cause for concern within the public health community. This is no time to lower our defenses in funding TB programs.

While declining overall TB rates is good news, the emergence and spread of multi-drug resistant TB poses a significant threat to the public health of our nation. Continued support is needed if the United States is going to continue progress toward the elimination of TB.

The IOM report provides the United States with a road map of recommendations on how to eliminate TB in the United States. The IOM report identifies needed detection, treatment, prevention and research activities. The American Lung Association has endorsed the IOM report and its recommendations. We estimate it will cost \$528 million for the CDC Tuberculosis Elimination Program to implement the report recommendations.

The NIH also has a prominent role to play in the elimination of TB. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances has put the goal of an effective TB vaccine within reach. In addition, the American Lung Association encourages the subcommittee to fully fund the tuberculosis vaccine blueprint development effort at the National Institutes of Allergy and Infectious Disease (NIAID).

#### *Fogarty International Center TB Training Programs*

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international phy-

sicians and researchers. The goal is to develop a cadre of health professionals in the developing world who can begin controlling the global AIDS epidemic.

Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area TB treatment and research. This supplemental program has been highly successful in beginning to create the human infrastructure to treat the nearly two billion people who have TB worldwide.

However, we believe TB training grants should not be offered exclusively to institutions that have received AIDS training grants. The TB grants program should be expanded and open to competition from all institutions. The American Lung Association recommends Congress provide \$71 million for FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

#### RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

Protecting the health of our nation's workforce will require research, training, tracking and new technologies. The American Lung Association recommends that the subcommittee provide \$326 million for the National Institute for Occupational Safety and Health (NIOSH) at the Centers for Disease Control and Prevention (CDC), including \$25 million for the NIOSH National Occupational Research Agenda (NORA). NORA represents a partnership research plan for occupational disease. The NORA agenda was developed with input from labor, business and the health community.

#### CONCLUSION

In conclusion, Mr. Chairman, lung disease is a growing problem in the United States. It is America's number three killer, responsible for 1 in 7 deaths. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, tuberculosis kills three million people each year, more people than any other single infectious agent does. Mr. Chairman, the level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

#### PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) is the largest association of psychologists in the world, representing 155,000 members, affiliates and students. APA exists to advance psychology as a science, a profession, and a means of promoting education and human welfare. APA members serve as scientists funded by the National Institutes of Health and Centers for Disease Control and Prevention, as teachers and professors in our nation's high schools, colleges and universities, and as health professionals who treat patients in public and private clinics and programs. APA encourages the committee to strengthen U.S. investment in a continuum of programs on health promotion, disease prevention and care, ranging from basic research to clinical applications that will improve the health and education of all Americans. We appreciate the opportunity to submit testimony for the record.

#### U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

##### *National Institutes of Health*

The Administration's fiscal year 2006 budget proposes an NIH funding increase of 0.5 percent, lower than the biomedical inflation rate. This would not allow NIH to take advantage of many scientific opportunities. The success rate is already falling from one in three grant applications funded, to one in four. APA encourages the Committee to include a six percent funding increase for NIH in this year's legislation.

Funding increases for the NIH Office of Behavioral and Social Sciences Research (OBSSR) have been negligible for the past two years, and the Administration's budget continues the trend (the request is \$26.2 million). The Committee has praised OBSSR for making it easier for NIH institutes to cooperate to fund cross-cutting initiatives. OBSSR has been able to leverage substantive funding initiatives with a small budget. However, its ability to do so is eroding. OBSSR is planning trans-NIH programs to fund behavioral and social research on health disparities in minority populations, and on how gene/environment interactions affect health. It would benefit from a six percent increase. APA supports an appropriation of \$27.66 million for OBSSR.

Critically important behavioral research is being conducted by most NIH institutes. We can list only a few examples here. Epidemiology studies supported by

NIAAA show that alcohol is a drug of choice for youth and that it is associated with a host of consequences in this age group, including death and increased risk of harm and other negative outcomes. Recent data show that 18- to 24-year-olds have the highest prevalence of alcohol dependence of any age group. These and other data make it clear that alcohol has become entrenched in the developmental processes of adolescence, and that the developmental changes of adolescence appear to make this age group particularly vulnerable to alcohol's effects. Research by NIDA and others shows that the human brain does not fully develop until about age 25. Having insight into how the human brain works, and understanding the biological underpinnings of risk taking among young people will help in developing more effective prevention programs. NIAAA and NIDA are to be commended for pursuing research to understand how to extricate alcohol and other addictive drugs from adolescent development and how to change adolescents' behaviors toward addictive substances.

Psychological research supported by the NICHD is providing critical answers to many questions about childhood development, including how children learn to read and how they can overcome learning disabilities. Additional work is needed to improve our understanding of the role of cognition in learning mathematical and scientific concepts. Additional research is also needed to inform the public health community of how best to modify high-risk behaviors in children and families that contribute to the rising incidence of childhood obesity.

As NIMH implements its reorganization, APA is encouraging the institute to maintain its support for a comprehensive research portfolio that includes funding for a broad array of basic behavioral research and continues to support research on the promotion of mental health and the study of psychological, social, and legal factors that influence behavior. Given the increasing burden of mental disorders on children and adolescents, behavioral interventions are especially needed for children and adolescents with eating disorders, attention deficit-hyperactivity disorder, post-traumatic stress disorder and the most common forms of depression. Translational research in the behavioral and social sciences is especially needed to address how basic behavioral processes, such as cognition, emotion, motivation, development and social interaction, inform the diagnosis, treatment and delivery of services for mental disorders.

APA remains concerned that basic behavioral research at NIH—that is, research on the mechanisms that influence and underlie behavior, conducted outside a disease context—is vulnerable to budget pressures and pressures to demonstrate effective interventions. NIH institutes must balance the imperative for translation with the need to continue posing basic questions that will fuel the next generation of interventions. Much basic research is supported at NIH by the National Institute of General Medical Sciences, yet NIGMS funds very little basic behavioral research. APA asks that the committee continue to encourage or direct NIGMS, as it has for the past five years, to fill some of the gaps that now appear in NIH support of basic behavioral research and research training.

#### ADMINISTRATION FOR CHILDREN AND FAMILIES

##### *Prevention of child maltreatment*

Nationwide, an estimated 896,000 children are abused and neglected each year, resulting in an estimated 1,400 child deaths. The negative effects of child maltreatment can persist into adulthood. An increase of \$15 million will enhance prevention activities for child maltreatment by population-based monitoring to capture information about children outside child protective service systems and improve data collection to inform policy, research and public awareness programs. These funds will also advance research to prevent the negative consequences of child maltreatment and to examine risk and protective factors to further the development and implementation of culturally and linguistically appropriate prevention and intervention approaches.

##### *Bullying prevention*

Research indicates that bullying directly affects approximately one in three school children within a school semester. In addition, research confirms that bullying among children poses serious risks for victims and perpetrators and may seriously undermine the climate of schools. APA urges the adoption of research-based comprehensive bullying prevention programs and adequate federal funding to support the implementation of effective, comprehensive bullying prevention programs.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION BUREAU OF HEALTH PROFESSIONS

*Graduate Psychology Education (GPE) Program*

Funding in the amount of \$6 million for fiscal year 2006 is requested to continue the Graduate Psychology Education (GPE) Program, which was established in fiscal year 2002. The GPE Program, administered by the Bureau of Health Professions, is the only federal program dedicated solely to psychology education and training.

Funded in fiscal year 2003 at \$4.5 million and flat-funded for fiscal year 2004 and fiscal year 2005, the funds are now obligated to 27 grants on a three year cycle. As a result there will be no new competition this year. Without a modest increase of \$1.5 million there will not be a new competition in fiscal year 2006. The \$6 million request for fiscal year 2006 will enable hundreds of interested universities and training sites (e.g., veterans hospitals, children's hospitals, academic science centers and public health facilities) to apply for a GPE grant to increase the number of psychologists practicing in underserved rural and urban communities.

The GPE Program provides grants to APA accredited doctoral, internship and post-doctoral programs in support of interdisciplinary training of psychology students for the provision of mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill persons, and victims of abuse and trauma), especially in rural and urban communities. Furthermore, the GPE Program addresses the need for mental health services that was well documented in the New Freedom Commission on Mental Health Report (2003): about 1 in 5 American adults (44 million people) experience a mental disorder in a given year and 28 percent of adults meet the full criteria for a mental or addictive disorder.

## SUBSTANCE ABUSE, MENTAL HEALTH SERVICES ADMINISTRATION CENTER FOR MENTAL HEALTH SERVICES

*Mental and Behavioral Health Services on Campus Program*

Funding in the amount of \$5 million for fiscal year 2006 is requested for the newly established Mental and Behavioral Health Services on Campus Program, which is part of the Garrett-Lee-Smith Memorial Act that provides support for youth suicide early intervention and prevention programs, technical assistance centers for suicide prevention, and mental and behavioral services on campuses. The program also helps identify the best means, strategies and solutions for addressing the mental and behavioral health needs of our college aged youth.

The Mental and Behavioral Health Services on Campus program received \$1.5 million from fiscal year 2005 funds. The requested increased funding for \$5 million in fiscal year 2006 will help ensure that SAMSHA administrators will be able to implement the program in a way that best addresses the needs that exist on college campuses. Academic failure on our college campuses, which is often associated with mental or behavioral problems, not only results in personal loss, but loss in federal investment (student financial assistance), as well. In the most severe cases, unaddressed psychological problems can lead to depression and even suicide—a loss that can never be measured.

*Minority AIDS Initiative*

The estimated number of AIDS cases from 1999 to 2003 has increased for racial and ethnic minorities, including African Americans, Latino/as, Asian Pacific/Islanders and American Indians/Alaska Natives. Many persons with HIV/AIDS have mental and/or substance abuse disorders. While treatment can enhance overall health and well-being, racial and ethnic minorities have less access to, and lower utilization of, mental health and substance abuse services. Accordingly, APA recommends an additional \$5 million, for a total of \$15 million, for the Minority AIDS Initiative to provide culturally competent and accessible mental health and substance abuse services to persons of color living with HIV/AIDS.

## CENTER FOR SUBSTANCE ABUSE PREVENTION

*Rapid HIV Testing*

Each year, 25 to 30 percent of HIV-infected people who come to public clinics for HIV testing do not return a week later to receive their test results. With the rapid HIV test, results are available in about 20 minutes. Greater availability of this test can increase overall HIV testing and reduce the number of people—an estimated 225,000 Americans—who are unaware of their HIV infection. APA strongly supports the Rapid HIV Testing Initiative to train mental health and substance abuse service providers on rapid HIV testing and prevention counseling and urges an additional \$4.8 million, for a total of \$9.6 million, for fiscal year 2006. Mental health treatment

services for individuals testing positive should also be provided as a critical component of rapid HIV testing.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) NATIONAL CENTER FOR INJURY PREVENTION AND CONTROL

*Suicide prevention*

An increase of \$5 million over the fiscal year 2005 appropriation for suicide prevention activities will allow CDC to support the evaluation of suicide prevention planning, programs, and communication efforts to change knowledge and attitudes and to reduce suicidal behavior. These evaluation efforts will support communities to identify promising and effective suicide prevention strategies that follow the public health model and build community resilience.

*National Violent Death Reporting System (NVDRS)*

An increase of \$10 million over the fiscal year 2005 appropriation for the NVDRS will allow approximately 20 additional states to be funded to gather and share state-level data about violent deaths. This state-based system collects data from medical examiners, coroners, police, crime labs, and death certificates to understand the circumstances surrounding violent deaths. The information can be used to develop, inform, and evaluate violence prevention programs.

NATIONAL INSTITUTE FOR OCCUPATIONAL SAFETY AND HEALTH (NIOSH)

APA recommends an overall increase of \$40 million over the fiscal year 2005 appropriation for NIOSH. As the only federal agency for occupational safety and health research and prevention, NIOSH provides national and international leadership to prevent work-related illness, injury, and death by gathering information, conducting scientific research, and translating the knowledge gained into products and services.

U.S. DEPARTMENT OF EDUCATION

*Institute for Education Sciences*

Support for research is particularly critical at the Institute of Education Sciences as it seeks to translate scientifically based research findings into classroom practice. To support the highest quality cognitive, developmental, and educational science, we would encourage IES to hold a field-initiated studies competition in the next fiscal year to encourage innovative research driven by scientific opportunities.

APA appreciates the opportunity to present appropriations recommendations for the written record, and encourages members of the Committee to contact our Public Policy Office at (202) 336-6062 with questions or concerns about this statement.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL SOCIETY

SUMMARY OF RECOMMENDATIONS

- As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30 billion for NIH in fiscal year 2006.
- APS requests Committee support for increased behavioral and social science research and training at NIH in order to: better meet the Nation's health needs, many of which are behavioral in nature; realize the exciting scientific opportunities in behavioral and social science research, and; accommodate the changing nature of science, in which new fields and new frontiers of inquiry are rapidly emerging.
- Committee support is requested for specific behavioral science activities at a number of individual institutes. This statement provides examples to illustrate the exciting and important behavioral and social science work being supported at NIH.

Mr. Chairman, Members of the Committee: The American Psychological Society is a nonprofit organization dedicated to the promotion, protection, and advancement of the interests of scientifically oriented psychology in research, application, teaching, and the improvement of human welfare. Our 16,000 members are scientists and educators at the Nation's universities and colleges.

On behalf of our members, I would like to thank you for your leadership in the bipartisan effort to double NIH budget. As a result, NIH has experienced a period of unparalleled growth in the past 5 years, and the progress achieved as a result of research funded by NIH will lead us into a new era of discovery and innovation. Unfortunately, that progress is threatened by the Administration's request for fiscal

year 2006, which at only .7 percent (or \$196 million) over fiscal year 2005 will not even cover the costs of inflation, never mind sustain and advance the nation's investment in NIH. As a member of the Ad Hoc Group for Medical Research Funding, APS recommends \$30 billion for NIH in fiscal year 2006, an increase of 6 percent over fiscal year 2005 funding levels. This increase would help provide a stable base of funding for the Nation's public health research enterprise and allow NIH to continue its important scientific pursuits.

Within the NIH budget, APS is particularly focused upon the behavioral and social sciences research activities of NIH.

#### THE IMPORTANCE OF BEHAVIORAL RESEARCH IN ADDRESSING THE NATION'S HEALTH

In any realistic picture of our Nation's health, a core finding is that behavior is central to many, maybe to most of our Nation's leading health concerns: heart disease; stroke; lung disease and certain cancers; obesity; AIDS, suicide; teen pregnancy, drug abuse and addiction, depression and other mental illnesses; neurological disorders; alcoholism; violence; injuries and accidents—all have large behavioral components. Further, nearly 40 percent of premature deaths in the United States can be attributed to smoking, physical inactivity, poor diet, or alcohol misuse according to the Centers for Disease Control and Prevention.

None of the conditions or diseases described above can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating and preventing them. For example, before you address how to change attitudes and behaviors around AIDS, you need to know how attitudes develop and change in the first place. Or, before you can change decisions about any risky behavior, you need to know how judgments and decisions are made on a range of topics. Similarly, before you address memory decline in the elderly, you need to know the basics of learning and memory and how that changes with age. And before you address the complexity of the interactions among genetics, the brain, and schizophrenia, you need to know the basics of cognition, emotion, culture, behavioral aspects of neuroscience, and behavioral genetics.

APS members include thousands of scientists who, with NIH support, conduct basic, applied, and clinical research related to physical and mental health at our Nation's leading universities and colleges. Virtually every institute at NIH supports some amount of psychological science. Examples include: The connections between the brain and behavior; research into how children grow and develop; management of debilitating chronic conditions such as diabetes and arthritis as well as mental disorders; and the behavioral aspects of smoking and drug and alcohol abuse, so that science may find ways for people to escape addiction.

NIH Director Dr. Elias Zerhouni, has expressed strong support for behavioral science at NIH, and sees this research as critical to our Nation's health. "We are aware of the challenge in social and behavioral science. It's going to be front and center," he has stated. He went on to add, "The bill for the nation will be unbearable in health and social costs without recognition of the role of behavior." However, to date, behavioral research has not received the recognition or support needed to reverse the effects of behavior-based health problems in this Nation.

APS asks that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, by encouraging NIH to advance a model of health that includes behavior in deciding its scientific priorities, and by encouraging the establishment of a stable infrastructure to support basic behavioral science research at NIH.

#### BASIC BEHAVIORAL SCIENCE RESEARCH NEEDS A STABLE INFRASTRUCTURE

Twenty-four of the 27 institutes at NIH fund behavioral science research, and seven institutes commit over \$100 million to this enterprise. Six institutes commit over 20 percent of their resources to behavioral science research. However, most of these institutes do not fund research into the fundamental behavioral processes that underlie the diseases and conditions that constitute some of the most vexing health problems facing us today. Traditionally, such basic behavioral research has been supported by the National Institute of Mental Health (NIMH). NIMH, for any number of historical reasons, has been the home for far more basic behavioral science than any other institute. Many basic behavioral and social questions were being supported by NIMH, even if their answers also could be applied to other institutes. Recently, NIMH has begun to aggressively reduce its support for many areas of the most basic behavioral research, saying that, like many other Institutes, it too is disease specific and must focus its energy on battling mental illness through

translational and clinical research. This means that previously funded areas now are not being supported.

NIMH is to be commended for promoting the transfer of knowledge into application for mental illness. But this is happening at the expense of critical basic behavioral research. Without progress in our understanding of fundamental behavioral processes, there will not be a sufficient body of knowledge to translate into application. Until other institutes begin to support larger amounts of basic behavioral science research connected to their respective missions, it is essential that NIMH's programs of research in behavioral phenomena such as cognition, emotion, psychopathology, perception, development, and others continue to flourish. APS asks the Committee to encourage NIMH's continued efforts to strengthen the ties between basic and clinical behavioral research, and to encourage NIMH's basic behavioral science portfolio in order to ensure continued progress in our understanding of the causes, treatment and prevention of mental illness and the promotion of mental health.

#### NIGMS SHOULD SUPPORT BASIC BEHAVIORAL SCIENCE RESEARCH AND TRAINING

Answering basic social and behavioral science questions is central to the overall NIH mission. The recent change at NIMH regarding basic behavioral research illustrates the problem of depending too much on non-structural support at any one agency for fundamental behavioral and social science research. Basic behavioral and social science needs a dependable structure of its own.

The most appropriate location is the National Institute of General Medical Sciences (NIGMS), also known as NIH's "basic research institute". NIGMS already has a mandate to support basic behavioral research and training, but that mandate has not been fulfilled in part because NIMH already was serving that function.

Since fiscal year 1999, this Committee has repeatedly issued report language urging NIGMS to fund basic behavioral research and training, saying, for example: "The Committee is concerned that NIGMS does not support behavioral science research training. As the only Institute mandated to support research not targeted to specific diseases or disorders, there is a range of basic behavioral research and training that NIGMS could be supporting. The Committee urges NIGMS, in consultation with the Office of Behavioral and Social Sciences, to develop a plan for pursuing the most promising research topics in this area." [Senate fiscal year 2000 Appropriations Report 106-166, Senate fiscal year 2001 Appropriations Report 107-293, Senate fiscal year 2002 Appropriations Report 107-84, Senate fiscal year 2003 Appropriations Report 107-216, Senate fiscal year 2004 Appropriations Report 108-82]

Two years ago, Senators Specter, Inouye, and Harkin, engaged in a colloquy on the Senate floor expressing the Committee's strong support for basic behavioral research and training, and expressing their concern that NIH had not responded to this matter after many years of report language. Since then, NIH commissioned a task force to study the matter and report back to the Director's Advisory Committee. The panel formally recommended the establishment of a secure and stable home for basic behavioral science research and training at an NIH institute, and, in particular, suggested that an institute such as NIGMS should be that home, as this Committee has recommended for years.

NIGMS is on record saying except for a few fields of inquiry, behavioral studies largely fall outside of its research mission, and are instead deemed to be within the missions of other institutes at the National Institutes of Health. And APS believes this line of thinking may still hold true within NIGMS. However, NIGMS' statutory mandate encompasses "general or basic medical sciences and related natural or behavioral sciences [emphasis added] which have significance for two or more other national research institutes" (TITLE 42, CHAPTER 6A, SUBCHAPTER III, Part C, subpart 11, Sec. 285k).

Basic behavioral research in the cognitive, psychological and social processes underlying substance abuse and addiction (significance for NIDA, NIAAA, NCI and NHLBI), obesity (significance for NIDDK, NHLBI, and NICHD) and the connections between the brain and behavior (significance for NIMH, NINDS, and NHGRI) just to name a few, all are within the NIGMS mission. Given the statutory mandate, the recommendations of a recent Director's advisory council's task force, the strong Congressional interest, the scientific imperative, and most important, the health needs of the Nation, APS asks the Committee to direct NIGMS to develop a plan for establishing a basic behavioral science research and training program at NIGMS.



## NIH NEEDS A COMPREHENSIVE BEHAVIORAL SCIENCE RESEARCH TRAINING STRATEGY

The outcomes of science are unpredictable. Yet there is one aspect of science where the time and money invested is guaranteed to pay off: the training of our future scientists. We know that if we provide support now for a young investigator, we will have a well-trained, highly-qualified scientist as a result. This is a serious issue in behavioral science at NIH, where the demand for behavioral science investigators at NCI, NIMH, and other institutes outpaces the current supply of behavioral science researchers. In order to meet the future needs of research in health and behavior, NIH must have a comprehensive training strategy in place today, one that focuses on training young investigators in the core disciplines of behavioral and social science research as well as in multidisciplinary perspectives.

APS is hopeful that NIH will take a closer look at forthcoming recommendations from a congressionally mandated National Academy of Sciences (NAS) study of research personnel needs with regard to the National Research Service Awards (NRSA). It is anticipated that this study will be transmitted to Congress and NIH in the near future. When NAS conducted this study in 2000, NIH selectively implemented NAS's recommendations and ignored important findings with regard to the need for increased training, if at all. This Committee has taken note of the behavioral science recommendations from this study in the past, and has supported increasing NRSA awards as a mechanism to increase behavioral science research training. APS asks the Committee to developments closely.

More generally, APS asks the Committee to support the development of a comprehensive training strategy for behavioral and social science research at NIH. This strategy should include all training mechanisms, and should be balanced between interdisciplinary research and traditional core disciplines in the behavioral sciences.

## BEHAVIORAL SCIENCE AT KEY INSTITUTES

In the remainder of my testimony, I would like to highlight examples of the cutting edge behavioral science research being supported by individual institutes.

*National Institute of Mental Health (NIMH)*

NIMH is funding behavioral research ranging from neural information processing to social psychology decision-making. Ultimately, this investment will help researchers understand and improve the way people think, plan, and make choices about their future as it relates to everything from chronic mental illness to AIDS. For example, one NIMH study is aimed at identifying how people understand the near future versus the distant future with the hopes of relating study findings to HIV prevention. By investigating how temporal distance from future events influences judgments and decisions regarding those events, researchers hope to identify the advantages and disadvantages of decision-making at different points in time.

An NIMH-funded project is examining the operation of attention at two coarsely defined stages of processing: visual perception and visual working memory. By comparing "memory-intensive" tasks in which working memory is overloaded but the perceptual demands are minimal with "perception-intensive" tasks in which memory is not overloaded but the perceptual demands are great, researchers expect to see attention operate at different stages in these tasks. By developing methods to isolate and assess perceptual-level and working memory-level property mechanisms, researchers will be able to more easily identify attentional mechanisms compromised in a given disorder. This program of research will have important long-term implications for psychological/psychiatric disorders in which attention is compromised, such as attention deficit disorder, many anxiety disorders, even schizophrenia.

Similarly, the NIMH project titled "Executive Processes-Behavioral and Neuroimaging Study" will help scientists better understand the brain mechanisms responsible for so-called "executive" brain functions, such as the ability to stay focused, to multi-task, and to respond with action. Studying these executive processes, which play a central role in cognition, could influence how we look at behavioral and psychological functioning, from the changes that occur over the life span to early diagnosis and treatment of dementia and other conditions involving reduced cognitive capacities.

*National Institute on Drug Abuse (NIDA)*

By supporting a comprehensive research portfolio that stretches across basic neuroscience, behavior, and genetics, the National Institute on Drug Abuse (NIDA) is leading the Nation to a better understanding and treatment of drug abuse. APS applauds NIDA for strengthening its efforts to study adolescent brain development to examine the influence drug exposure has on behavioral, psychological, and physiological development. New research supported by NIDA reveals that drug addiction

is a “developmental disease” that often starts during the early developmental stages in adolescence, an age at which 3 million 12–17 year olds reported using illicit drugs last year. If we can better understand the effects structural brain changes have on functions like thinking, decision-making, sensation and perception we will be able to better develop targeted and more likely effective prevention strategies from the brain development perspective. APS asks this Committee to support this and other critical behavioral science research at NIDA, and to increase NIDA’s budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

*National Institute on Alcohol Abuse and Alcoholism (NIAAA)*

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) works to examine the biological, chemical and behavioral factors associated with alcohol abuse and consumption, the third highest cause of preventable death in the United States according to the Centers for Disease Control and Prevention. Over time, NIAAA has broadened its behavioral science portfolio to understand the underlying psychological and cognitive processes that lead people to drink, and the impact of chronic alcohol abuse on those processes. Today, the institute is stepping up its efforts via its Improving Effectiveness of Treatment initiative to move beyond what we understand about today’s behavior therapies and to further understand the mechanisms that determine how and why alcohol-related behavior changes. And since these changes are influenced by neurobiological, psychological and social factors, this new and exciting research includes multiple levels of research to ensure an integrated understanding to improve behavior strategies. APS asks this Committee to support NIAAA’s behavioral science research efforts, and to increase NIAAA’s budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from alcohol abuse and alcohol dependence.

*National Cancer Institute (NCI)*

The National Cancer Institute (NCI) is an agency that continues to make enormous advances in the behavioral sciences to achieve effective cancer prevention and control. Since its Behavioral Research Program was launched in 1997, NCI has funded comprehensive behavioral science research programs ranging from basic behavioral science to research on the development, testing and dissemination of disease prevention and health promotion interventions in areas such as tobacco use, diet, and even sun protection. APS applauds NCI’s foresight to conduct transdisciplinary research within the program’s five branches of Tobacco Control, Cancer Communications, Health Disparities, Energy Balance, and Cancer Survivorship because it set forward a new path for science—and APS believes disciplines are only made stronger when complimented by others. Take for example the agency’s Centers for Transdisciplinary Research on Energetics and Cancer within the Energy Balance branch. This initiative brings together NCI’s investment in diet, weight and physical activity research priorities by bringing together scientists from multiple disciplines to carry out projects ranging from the biology and genetics of energy balance to behavioral, sociocultural and environmental influences on nutrition, physical activity, weight, energy balance and energy transferred to or expended in life processes. In addition to training established scientists, this investment fosters collaboration among transdisciplinary teams. APS asks Congress to support NCI’s behavioral science research and training initiatives and to encourage other institutes to use these programs as models.

*National Institute on Aging (NIA)*

APS is particularly pleased with NIA’s dedication to behavioral research through the Behavioral and Social Research (BSR) Program—and its 3 branches of individual behavior, population and social processes and research resources and development—that supports basic social and behavioral research and research training by studying the dynamic interplay between individuals’ aging; their changing biomedical, social, and physical environments; and multilevel interactions among psychological, physiological, social, and cultural levels. Agency-conducted research like that of the Behavioral and Imaging Approaches to Implicit Memory in Aging study will ultimately make a major contribution to our understanding of age-related changes in memory. As researchers carefully integrate behavioral and neuroimaging studies to broaden and deepen current understanding of age-related changes in implicit memory, they are evaluating decision accuracy in both young and elderly subjects to assess the neural substrates supporting encoding and retrieval of implicit memory. APS asks the Committee to support NIA’s behavioral science research efforts and to increase NIA’s budget in proportion to the overall increase at NIH in order to continue its high quality research to improve the health and wellbeing of older Americans.

*Office of Behavioral and Social Sciences Research (OBSSR)*

I'm pleased to report that psychological scientist David Abrams, from Brown University, has been appointed as the Director of the Office of Behavioral and Social Sciences Research at NIH. We ask the Committee to join us in welcoming Dr. Abrams to this position, and to support OBSSR in its efforts to achieve a strengthened behavioral science research enterprise at NIH.

It's not possible to highlight all of the worthy behavioral science research programs at NIH. In addition to those reviewed in this statement, many other institutes play a key role in NIH behavioral science research enterprise. These include the National Heart, Lung, and Blood Institute, the National Institute of Neurological Disorders and Stroke, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Nursing Research, and the National Institute for Human Genome Research. Behavioral science is a central part of the mission of these institutes, and their behavioral science programs deserve the Committee's strongest possible support.

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 PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

Chairman Specter and members of the Subcommittee, the American Society of Hematology (ASH) thanks you for the opportunity to submit written testimony on the fiscal year 2006 Departments of Labor, Health and Human Services, and Education Appropriations Bill. In addition, ASH sincerely thanks the Subcommittee for its support of biomedical research.

The Society represents nearly 14,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; non-malignant conditions including anemia, thrombosis, and bleeding disorders; and congenital disorders such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, gene therapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Hematologists treat a diverse group of patients. For example, anemia is a condition that has enormous consequences in the quality-of-life and functioning of the elderly; sickle cell disease is an inherited blood disorder that primarily affects African Americans. The hematological cancers—leukemia, lymphoma, and myeloma—strike men and women of all ages; in 2005, nearly 115,000 Americans will be diagnosed with and more than 53,000 will die from these cancers.

The study of blood and its disorders involves a number of NIH Institutes, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA). The Society supports the leadership of these Institutes and commends them for their vision and responsible research portfolio management.

The Society's requests this year focus on translating basic scientific findings into improved treatments for patients with serious blood diseases. New comprehensive approaches to clinical research funding will advance our understanding of how to treat these and other diseases, enable patients to participate in high quality clinical protocols, and attract and train much-needed clinicians and clinical researchers to the field of hematology.

## FISCAL YEAR 2006 FUNDING REQUESTS

*NIH Funding*

ASH fully supports the Ad Hoc Group for Medical Research Funding recommendation of \$30 billion for NIH in fiscal year 2006. This 6 percent increase represents an important step in maintaining NIH's commitment to medical research funding so that the progress made during the doubling years is not eroded. Research programs are not spigots that you can turn on and off without compromising their effectiveness. Innovative scientific teams working in sophisticated labs cannot be sustained without some stability in medical research funding from year to year. It is critical that the US maintain its commitment to medical research.

For fiscal year 2006, the Bush Administration proposed \$28.845 billion, a \$196 million or 0.7 percent increase over last year. This is the third consecutive year that the President's Budget request for NIH has not kept pace with medical inflation. Only continued, sustained investment in life-saving medical science today will provide cures and therapies for tomorrow. A proposed NIH budget along the lines of

President Bush's recommendation is effectively a cut in funding; it doesn't keep up with the cost of medical inflation.

Moreover, NIH budgets in the range proposed by the Bush Administration will force NIH to drop paylines substantially below the 33rd percentile—where they are generally considered unhealthy for the biomedical research enterprise. Estimated paylines for most NIH Institutes in fiscal year 2006 are less than the 18th percentile. Low paylines create an atmosphere of hopelessness for even established investigators and little incentive for young researchers to take the chance that their grant would receive funding. More funding at NIH would provide the Institutes the opportunity to raise their paylines and fund more qualified and innovative research.

In addition, there needs to be a highly-trained scientific workforce for NIH to meet its research objectives. Training the next generation of biomedical researchers has traditionally been the responsibility of NIH. Under the President's fiscal year 2006 Budget proposal, NIH will support almost 400 fewer full time training positions than last year. Without funding for the next generation of physician scientists, the biomedical research enterprise will not be prepared for future efforts.

The Society is proud that NIH-sponsored research in hematology has led to important discoveries and generated new treatments and pharmaceutical products with broad applicability to human diseases. We have all benefited from past investments in NIH research. Recent advances include the incredibly effective hematologic drug Gleevec—a breakthrough in treating chronic myelogenous leukemia—that is one of the first drugs of its kind to be approved that targets specific molecules in cancer cells, leaving healthy cells unharmed. Moreover, ASH has always emphasized the synergy that is vital to successful scientific work. Basic research on the blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer and AIDS. As a result of this cross-fertilization, the Society remains firmly committed to broad-based support for biomedical research and to the existing peer-review process as the best way to identify and prioritize scientific grants.

In fiscal year 2006, ASH also urges the Subcommittee to recognize the following areas of hematology research that have shown impressive progress and offer the potential of future advances:

*Coordination of the Issues Common to the Hemoglobinopathies*

Sickle cell anemia and thalassemia are inherited blood disorders caused by mutations in the genes for the hemoglobin molecule—the protein in red blood cells that carries oxygen to all parts of the body—and affect the normal functioning of hemoglobin in our blood. These conditions cause many problems including moderate to severe anemia, chronic pain, iron overload with its associated diabetes, liver and heart failure, enlarged spleen, bone weakness, pulmonary hypertension, and stroke. Although these disorders share many common issues, their research programs at NHLBI are organized into two parallel structures that could possibly benefit from the expertise of researchers focused on the other disorder. ASH believes there is an opportunity to determine the science and management issues common to the hemoglobinopathies and identify areas of scientific collaboration and promising new research directions in sickle cell anemia and thalassemia.

*Expansion of Research Activities in the Underlying Causes of Thrombosis at NHLBI and NIA*

Venous and arterial thrombosis (blood clots) are serious conditions that can lead to heart attacks, strokes, limb loss, and respiratory dysfunction. Vascular biology research provides the foundation for understanding the underlying causes of atherosclerosis, angiogenesis, inflammation, and thrombosis. Greater understanding of vascular biology will lead to more knowledge about the prevention of thrombosis, which has implications into the further research of heart disease, stroke, recurrent fetal loss, complications associated with sickle cell anemia and diabetes, as well as the interruption of the blood supply to tumors and cancers.

Recent research disclosed that deep vein thrombosis affects up to 2 million Americans annually. Overall, thrombosis has sharply increased rates in the elderly and causes significant mortality and morbidity. With an expanding elderly population, thrombosis could become an even more serious health care problem. Although age is a known and important risk factor for thrombosis, there are other major research questions that need to be investigated in order to improve its diagnosis and treatment, such as the underlying causes of thrombosis. ASH believes that new research initiatives in the underlying causes of thrombosis will be helpful for improving the diagnosis and treatment of this potentially fatal complication of many diseases.

*Strengthening of Support for Clinical and Translational Blood Cancer Research*

In 2005, nearly 115,000 Americans will be diagnosed with a hematologic malignancy, such as leukemia, lymphoma, and multiple myeloma. Moreover, more than 53,000 Americans will die from these cancers, compared to 40,870 for breast cancer, 30,350 for prostate cancer, and 56,290 for colon and rectum cancer. The blood cancers strike individuals of all ages, races, and each gender, and serve as valuable prototypes for the development of therapies for all types of malignant disorders. The Society hopes to work with NCI to strengthen its support for translational and clinical blood cancer research and use all available mechanisms to support blood cancer research by improving treatments and rapidly moving research advances from the laboratory bench to the patient's bedside.

*Expansion of Research Opportunities in Erythroid Differentiation, Oxidant Injury, and Metabolomics*

High quality hematology research in iron metabolism, gene regulation, and stem cell plasticity is currently being funded by NIDDK. ASH hopes to work with the Institute to continue advancing research in these areas and set new priorities in cutting edge hematology topics, such as erythroid differentiation, oxidant injury, and metabolomics.

*Funding for the Sickle Cell Treatment Act (Public Law 108-357)*

Sickle Cell Disease (SCD) is an inherited blood disorder that is a major health problem in the United States. More than 2.5 million Americans, mostly African-Americans, have the sickle cell trait. SCD occurs in approximately 1 in 300 African-American newborns each year. The average life span for a patient with this devastating disease is 45 years. While we continue to make progress with treatments, patients suffer debilitating pain and dangerous problems such as blood clots and strokes.

As part of fiscal year 2005 Appropriations legislation, Congress provided \$200,000 for the Health Resources and Services Administration to set up a demonstration program for sickle cell disease health centers and establish the National Coordinating Center to collect sickle cell disease-related data as authorized in the Sickle Cell Treatment Act (Public Law 108-357).

For fiscal year 2006, ASH requests \$10 million to continue to build this program by creating 40 Health Centers across the United States that would provide education, treatment (i.e., genetic counseling and testing), and continuity of care for individuals with sickle cell disease. In addition, this support would train health professionals at the 40 centers as well as establish a National Coordinating Center to collect, monitor and distribute information on best practices for the prevention and treatment of sickle cell disease. This recommendation has bipartisan, bicameral support as well as the backing of the Congressional Black Caucus and many other health, children's, church, union and African-American groups.

ASH believes that the centers created through the Sickle Cell Treatment Act will improve the lives of SCD patients through disease management programs to help them live longer, healthier lives while funding research to find a comprehensive cure and providing community education about this disease and its treatment options.

CONGRESSIONAL OVERSIGHT OF THE NIH PUBLIC ACCESS POLICY

The Society remains concerned about the impact of the NIH Public Access Policy on the agency's budget, researchers, and not-for-profit journals. ASH requests that the Subcommittee continue to be engaged in the oversight of the policy's implementation. Moreover, the Society urges the Subcommittee to call for an analysis of the financial impact of the policy on the NIH budget and individual research grants.

CONCLUSION

This is an exciting time to be engaged in biomedical research and the Society is proud that ASH members are participating in so many innovative studies. ASH praises the NIH leadership for the excellent stewardship of the hematology research portfolio at NCI, NHLBI, NIDDK, and NIA. The opportunities in hematology research are immense, particularly in translational research. Partnerships and cooperative ventures involving multiple academic centers are necessary for clinical research projects to succeed and need special attention from NIH. When properly conceived and implemented, ASH believes these studies will lead to improved therapies for patients with debilitating and deadly blood disorders. The Society sincerely

hopes that the Subcommittee will continue its longstanding support of biomedical research and will find the means to fund NIH at \$30 billion in fiscal year 2006.

In addition, ASH requests that the Subcommittee provide \$10 million for the Sickle Cell Treatment Act (Public Law 108-357) in fiscal year 2006. This support will create a network of centers across the United States for the education, treatment, and continuity of care for individuals with sickle cell disease, a major health care problem.

Thank you again for the opportunity to submit testimony. Please contact Jeff Coughlin, ASH Government Affairs Manager, at (202) 776-0544 or [jcoughlin@hematology.org](mailto:jcoughlin@hematology.org) if you have any questions or need further information on hematology research, fiscal year 2006 NIH funding, and support for the Sickle Cell Treatment Act.

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#### PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), representing 43,000 members in the microbiological sciences, is pleased to provide a statement on the fiscal year 2006 funding for the Centers for Disease Control and Prevention (CDC). Although the fiscal year 2006 budget request includes important funding for influenza vaccine, childhood immunizations, global disease detection, and the Strategic National Stockpile, the ASM is concerned about the proposed budget reduction of \$491 million for CDC at a time when new health challenges, including a possible influenza pandemic, threaten public health. The 2003 Institute of Medicine (IOM) report, *Microbial Threats to Health*, warns that the magnitude and urgency of microbial threats demand renewed concern and commitment. The IOM report emphasizes the importance of strong CDC programs including greater global capacity for responding to infectious disease outbreaks, better case reporting by health care providers and laboratories, and expanded efforts related to antimicrobial resistance.

With people at risk from a broad range of health threats, our public health system will not be able to respond adequately without appropriate resources for public health programs. The ASM, therefore, recommends an increase of 8 percent in the fiscal year 2006 budget for the CDC. CDC's importance to safeguarding public health, both nationally and globally, is now unprecedented, but the level of funding for CDC is not keeping pace with its growing responsibilities to address new health threats. Infectious disease public health needs have been and will continue to increase and CDC's funding must remain strong to address them.

#### CDC INFECTIOUS DISEASE PROGRAMS

The CDC recently reorganized programs to better adapt to changing health threats. The Infectious Diseases Coordinating Center oversees three major programs, the National Immunization Program, the National Center for Infectious Diseases, and the National Center for HIV/AIDS, Sexually Transmitted Diseases and Tuberculosis Prevention. The President's budget includes \$1.7 billion related to domestic prevention and control of infectious diseases through these programs.

#### INFLUENZA

The National Center for Infectious Diseases is responsible for measuring progress in global influenza surveillance and detection to prepare for a pandemic influenza outbreak. Funding for pandemic influenza preparedness is appropriated through the Department of Health and Human Service's (DHHS) Public Health and Social Services Emergency Fund (PHSSEF). The budget proposes \$120 million for the expansion of year-round vaccine production capacity, a priority in the DHHS's draft *Pandemic Influenza Response and Preparedness Plan*. A significant investment will be required to enhance vaccine capacity to address the threat of pandemic influenza by developing a newer generation of influenza vaccine that can be quickly produced and deployed to strengthen the public health infrastructure on state and local levels, and to ensure that needed vaccines, antivirals and antibiotics are readily available.

#### HIV/AIDS

Under the CDC reorganization, programs focused on HIV/AIDS, sexually transmitted diseases (STDs), and tuberculosis are managed through the National Center for HIV, STD, and TB Prevention (NCHSTP). The budget proposes \$956 million, \$658 million of which is focused on prevention of these infectious diseases. Despite CDC efforts over the past two decades, the number of new HIV infection cases each year continues to remain high and the number of Americans living with HIV/AIDS is increasing. In fiscal year 2003, CDC launched a different U.S. initiative, based

on new rapid testing techniques for immediate patient results, designed to better prevent infections through earlier notification and to help identify the estimated 180,000 to 280,000 people not aware of their HIV-positive status.

#### GLOBAL HEALTH

The agency's recent reorganization also coordinated programs under the Office of Global Health (OGH) to track and prevent the international spread of diseases like measles, polio, and HIV/AIDS. The overarching goals are to recognize outbreaks faster, wherever in the world they occur, and to better control and prevent further outbreaks. Global disease detection mandates steady expansion of surveillance systems worldwide, as trade and travel allow rapid spread of previously unknown or unanticipated pathogens. Clinical and public health laboratory capacity must be strengthened together with epidemiologic and communications capabilities. The World Health Organization goal of eradicating polio by 2005 has suffered some setbacks recently, with wild poliovirus spreading in some African countries during 2003 and 2004. But last year, cases of the disease declined by nearly 50 percent in India, Pakistan, and Afghanistan. Since the WHO global initiative began in 1988, CDC and others have invested more than \$3 billion in the polio campaign. An estimated 250,000 lives have been saved and 5 million cases of childhood paralysis prevented. The CDC also partners with other federal agencies in the Global AIDS Program and in the President's Emergency Plan for AIDS Relief. In fiscal year 2004, nearly 2 million HIV laboratory tests and 275,000 tuberculosis infection laboratory tests were conducted under auspices of the Global AIDS Program. In addition, antiretroviral drug therapy was provided for nearly 19,000 AIDS patients in nine countries. By the end of 2003, the active spread of measles had been stopped in the Western Hemisphere. That year the CDC and its partners vaccinated more than 115 million children worldwide. Unfortunately measles persists as one of the world's leading child killers with an estimated 30 million cases and 700,000 deaths each year.

#### ANTIMICROBIAL RESISTANCE

Overuse of antimicrobials seriously increases the prevalence of pathogens resistant to commonly prescribed drugs. Antimicrobial resistance is considered one of the pressing issues faced by the CDC and other public health institutions. The 2003 Annual Report of the Antimicrobial Resistance Interagency Task Force reported that the number of cases of invasive pneumococcal disease in children in seven geographic areas declined by 75 percent in 2002 due to widespread use of pneumococcal vaccine, thereby reducing the use of antimicrobials which may become resistant. In fiscal year 2004, the CDC inaugurated a national media campaign about antibiotic resistance, to educate both patients and health care providers about the serious ramifications of overprescribing antibiotics. Also in fiscal year 2004, extramural grants were awarded for applied research in the estimate of economic costs for antimicrobial resistant human pathogens of public health importance. The purpose of the grant program is to obtain information that might impact and improve the current methods of preventing the emergence and spread of antimicrobial resistance. ASM supports sufficient budgetary increases in such prevention programs. The return on investment creates enormous health and economic benefits to the American public.

#### IMMUNIZATIONS

The CDC's immunization program would receive \$2.1 billion under the proposed fiscal year 2006 budget, to support the two primary goals of the program: at least 90 percent of all 2-year-olds to receive the recommended vaccines, and assurances of an adequate annual influenza vaccine supply. Investments in immunization programs are proven cost-savers. For example, every dollar spent on measles-mumps-rubella vaccine saves an estimated \$23 in health-care costs. Fiscal year 2006 funds would flow through the Vaccines for Children program and the Section 317 program, the former to provide vaccinations to children otherwise underserved in the health care system, the latter to subsidize state immunization efforts. As part of the overall CDC immunization focus, \$197 million is requested for influenza-related activities, representing a nine-fold increase over fiscal year 2001 appropriations. Funds would further expand the pediatric vaccine stockpile initiated last year, purchase additional doses of influenza vaccines for the general public, and encourage greater vaccine production for next winter's flu season. The fiscal year 2006 emphasis on immunization activities is a prudent use of federal funds needed to protect the public.

## SURVEILLANCE

DNA technology provides some of the notable cutting-edge science upon which CDC testing and surveillance programs are built and operated. The PulseNet system, which tracks foodborne illness outbreaks, is one particularly extensive use of such technology. These illnesses affect more than 76 million Americans each year; periodic outbreaks often are widely publicized in the national media. One example is the 2004 outbreak of salmonellosis among more than 500 people across five states, which CDC epidemiologists tied to contaminated restaurant tomatoes. Another is a multi-state incident of hepatitis A infecting more than 1,000 people after they ingested imported green onions. Similar surveillance systems now exist in Europe, Pacific Rim countries, and Latin America. The CDC's Tuberculosis Genotyping Program, initiated in fiscal year 2004, also fingerprints the genetic profiles of pathogens, enabling case investigators to assess very quickly how and where the bacterium is spreading. It already has described outbreaks in several states, permitting rapid deployment of preventive measures.

## BIOTERRORISM PREPAREDNESS

Defenses against possible bioterrorist attacks are a collaborative initiative among federal, state, and local agencies and authorities. The CDC is largely responsible for sufficient supplies of countermeasures such as vaccines and portable treatment units. The Administration proposes an increase of \$56 million for bioterrorism preparedness activities at the CDC, for a total of \$1.6 billion in fiscal year 2006. Six hundred million is proposed for further enhancing the Strategic National Stockpile (SNS). Specifically, the Medical Contingency Station project will be enhanced and increased funding will also help to pay for BioShield acquisitions and the purchase of additional anthrax antibiotics for the SNS. The CDC maintains the capacity to transport SNS materials and personnel to any location within the United States within 12 hours. During fiscal year 2004, the CDC nearly tripled the amount of medical countermeasures against anthrax, now capable of treating 30 million people.

Since 2001, the CDC has recognized the importance of anti-bioterrorism capabilities at the state and local levels, where attacks are most likely to occur. About \$4.5 billion has been invested in CDC programs to assure state and local preparedness. The agency's Laboratory Response Network (LRN) now includes 134 reference labs in all states, up from 91 in 2001, nearly all capable of detecting agents of anthrax, tularemia and smallpox. Five veterinary diagnostic laboratories are now part of the system, recognizing the importance of animal-to-human transmission of disease pathogens. More than 8,800 laboratory personnel have been trained for bioterrorism emergencies under CDC auspices. During fiscal year 2004, CDC invested about \$846 million to improve the ability of 62 state, local, and territorial health departments to respond to terrorism, infectious disease outbreaks, and other public health crises. The CDC funded the Cities Readiness Initiative, to boost delivery of medicines and other supplies during large-scale emergencies. The current proposed budget for fiscal year 2006 however, decreases support for state and local capacity. A report released this March by New York University concludes that bioterrorism-related training and equipping of local response personnel like paramedics have been seriously neglected, an example of yet unmet needs.

## BUILDINGS AND FACILITIES

Since 2001, the CDC has initiated or completed construction of more than 2.7 million square feet of laboratory and administrative space, replacing badly deteriorating buildings that were unsafe and inadequate. This year will mark the completion in Atlanta of a new Infectious Disease Laboratory, the Scientific Communications Center, the headquarters building with an Emergency Operations Center to coordinate quick responses, and the Environmental Toxicology Laboratory. The fiscal year 2006 request includes \$22.5 million to complete a replacement Vector Borne Infectious Diseases lab in Fort Collins, Colorado and an additional \$7.5 million to fund miscellaneous repairs and improvements. CDC's master plan for its buildings and facilities includes additional building renovations that are currently on hold, with hope to be funded in the near future. ASM applauds expenditures in recent years to replace the former CDC facilities in such poor condition and supports the completion of the master plan when funds can be allocated.

The ASM appreciates the opportunity to provide written testimony and would be pleased to assist the Subcommittee as it considers its appropriation for the CDC for fiscal year 2006.



## PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), the largest single life science society with over 43,000 members, is pleased to submit a statement on the fiscal year 2006 appropriation for the National Institutes of Health (NIH). The ASM appreciates the strong support that the Congress has provided for NIH supported biomedical research. Congress's investment in NIH has paid tremendous dividends in terms of human health improvements. We can expect progress against disease to continue because of recent scientific advances and new opportunities for applications of research knowledge gained from basic research discoveries. The challenge of infectious diseases, cancer, diabetes and other chronic diseases will continue to increase, thus, strong support for NIH is needed.

The ASM recommends a 6 percent increase in the budget for NIH in fiscal year 2006 and believes this increase would improve the pace of scientific investigation and the translation of science into new and better approaches to prevent, diagnose and treat diseases. A funding increase of this magnitude would allow NIH to take fuller advantage of innovative tools and technologies and the many extraordinary research achievements that have been made during the recent past. It would help to respond to urgent disease threats and realize more of the important medical treatment and public health goals that loom on the near horizon.

The ASM considers a 6 percent increase justified for NIH if it is to continue current programs and deal with new and pressing needs, including the threat from pandemic influenza, other emerging infectious diseases such as the recent and unexpected outbreak of SARS, the AIDS pandemic, a myriad of infectious and chronic diseases that continue to take a human toll worldwide and biodefense initiatives.

Since fiscal year 2003, the NIH budget has flattened, and at less than 1 percent, the proposed fiscal year 2006 budget increase will result in difficult funding decisions for research programs. Because the budget request for NIH falls below the current biomedical rate of inflation, which is about 3.5 percent, biomedical research will face a slowdown in the pace of scientific progress. This static state in funding comes at a rare time with unprecedented opportunities for major advances in human health and also at the very time that our nation's competitors are significantly increasing their investments in research. Their investments are based on the demonstrated positive impact of biotechnology and biomedical research on economic development. The European Union has set a goal of becoming the most competitive knowledge based economy in the world by 2010. Without increased investment in federally funded research in the United States, we stand to diminish the growth of U.S. technology.

## BASIC RESEARCH AND TRAINING

The ASM emphasizes the importance of providing increased support for basic research and the training and participation of young investigators in biomedical fields. Basic research and human ingenuity provide the underpinning of new knowledge that is necessary for successful medical breakthroughs. Basic research drives scientific creativity and productivity, making increased funding for investigator initiated research project grants a particularly critical issue when making funding decisions. Under the proposed fiscal year 2006 budget for NIH, the total number of research project grants (RPGs) supported falls below that of fiscal year 2005 by over 400 and no inflationary increases are provided for direct, recurring costs in non-competing RPGs. The ASM recommends increased funding for NIH to ensure a continuum of high quality research project grants and scientist training programs to keep biomedical research in the future as vigorous as it is today.

Specifically, ASM draws attention to the fact that scientific knowledge of microbes and their role in life and in the environment is key to new discoveries that will benefit human health. For example, the study of microbes resulted in the discovery that DNA is the genetic material of life and was responsible for the molecular revolution that has transformed biology. Research into basic life processes of bacteria is a critical underpinning of cellular studies that contribute to progress in the life sciences. Research on bacteria is urgent because more bacteria are becoming resistant to antibiotics, raising the specter of untreatable diseases. NIH should increase support for basic microbiology research and training and review research portfolios of the National Institute of General Medical Sciences (NIGMS), which provides support for fundamental research, and coordinate with other agencies such as the National Science Foundation (NSF) and the Department of Energy (DOE) to ensure that scientific opportunities in important areas of basic bacteriology physiology and genetics research are receiving adequate attention. The ASM recommends that NIH take steps such as workshops, requests for proposals and training grants to increase the infrastructure in this important area of science.

## INFECTIOUS DISEASES

Over the past 10 years, new and emerging microbial threats have continued to challenge the research community as well as the public health infrastructure. Despite scientific and medical advances, infectious diseases persist as the third leading cause of death in the United States and the second leading cause of death worldwide. A recent report from the Institute of Medicine on microbial threats to public health concluded that a comprehensive infectious disease research agenda is essential for successful anti-disease campaigns. The basic and applied research supported by the National Institute of Allergy and Infectious Diseases (NIAID) is essential to responding to infectious disease public health challenges. Unfortunately, the budget for the NIAID would increase by only 1.3 percent in the request for fiscal year 2006, far less than the amount needed to maintain or accelerate NIAID supported work to combat a myriad of infectious diseases.

Influenza is a familiar infectious disease threat with the proven potential for decimating pandemics. Influenza develops in about 20 percent of U.S. citizens each year and an estimated 36,000 die annually from complications of influenza in the United States, with 250,000 to 500,000 deaths worldwide. In the United States influenza and pneumonia remain the leading infectious cause of mortality and are ranked seventh among all causes of death. Influenza viruses steadily mutate and new strains periodically move from animal hosts to humans. World attention is drawn to outbreaks of avian influenza in Southeast Asia with about 55 infected persons and 42 deaths since January 2004. The current strain of H5N1 influenza could acquire characteristics that permit transmission among humans which could lead to a worldwide influenza pandemic. The 1918 influenza pandemic killed at least 20 million people and pandemic avian influenza could kill millions of people. The NIH Influenza Genomics Project conducts rapid sequencing of the complete genomes of thousands of avian and human influenza viruses and newly emerging ones and will study the molecular basis of how new strains of influenza virus emerge and characteristics that contribute to virulence. Research is being done to develop a live attenuated vaccine candidate against each of 15 isolated hemagglutinin proteins that may speed the development of a vaccine against a potential pandemic strain. Using reverse genetics technology, a genetically engineered vaccine candidate against H5N1 was developed in weeks. This technology was also used to identify a genetic mutation in a H5N1 viral gene that makes the virus more lethal.

In late 2002, Severe Acute Respiratory Syndrome (SARS) became the first severe newly emergent infectious disease of the 21st century, but was rapidly characterized and contained. Because of air travel by its earliest victims, SARS reached five countries within 24 hours and more than 30 countries on 6 continents within 6 months of the initial diagnosed case. Nearly 8,000 persons became ill and international travel and trade were greatly affected. The global cost of SARS has been estimated at about \$80 billion. NIAID funded research in collaboration with the Centers for Disease Control and Prevention (CDC) demonstrated that SARS is a viral disease and a new coronavirus was identified quickly as the causative agent. By May of 2003, an international collaboration of researchers had decoded the genetic sequence of the virus to develop a candidate vaccine that in November 2004 entered early phase tests in humans. Less than 2 years separated the discovery that SARS is a new infectious disease and the beginning of vaccine testing in humans, a process that traditionally can take decades. Results came quickly because of research and public health cooperation, NIAID resources and new molecular biology techniques. Research and technology developed during past disease outbreaks facilitate NIAID responses to unique or sporadic challenges like SARS, West Nile virus, Ebola virus, and bovine spongiform encephalopathy.

Research yields major insights into the pathogenic mechanisms of established diseases such as HIV/AIDS, tuberculosis and malaria. An estimated 40 million people worldwide are living with HIV/AIDS. NIAID research has made possible critical discoveries about the basic biology of HIV and the immune response to HIV infection which has led to the development of therapies that suppress the growth of the virus. Approximately 20 antiretroviral medications that target HIV have been developed and approved by the Food and Drug Administration. More scientific research is needed on the virus to identify additional targets for therapeutic interventions and vaccines. Despite the fact that tuberculosis (TB) is one of the oldest infectious diseases known, the global incidence rate is still increasing. More than one third of the world is latently infected with TB. Every day there are 5,000 deaths due to TB. A big part of the problem is the increasing number of patients with the deadly combination of TB and HIV. The only available medicines to treat and diagnose TB are from another era. Rapid development of new tools is greatly needed to address the growing problems of multi-drug resistant TB. Malaria is one of the major killers of

humans in the world with an estimated 300 million acute illnesses each year and more than 1 million deaths. Both tuberculosis and malaria pathogens are increasingly resistant to commonly used antimicrobial drugs. Genomic and postgenomic techniques are being applied to identify key molecular pathways that could be exploited to develop TB interventions and vaccines. The complete genomic sequence of the malaria vector and parasite were completed in 2002, providing powerful tools to further characterize the genes and proteins involved in the life cycle of the malaria parasite. NIAID supported programs in basic and applied areas are contributing to knowledge that is needed to design new vaccines, therapeutics and diagnostics against these formidable infectious diseases that exact a terrible social, economic and human toll globally.

The NIAID research portfolio is challenged as never before to address new and emerging infectious diseases and those that have affected humans for thousands of years but are still a public health threat. NIAID supports important research on the hepatitis viruses which cause liver inflammation and tissue damage and can cause chronic infections. There are more than 25 identified sexually transmitted infections (STIs) that affect more than 15 million people in the United States. STIs can lead to infertility, complications in pregnancy, cervical cancer, low birth weight, congenital/perinatal infections and other chronic conditions and are of critical global and national health priority because of their impact on women and infants. NIAID basic and clinical research studies on mechanisms of pathogenesis of STIs and prevention strategies for the control of these infections are essential. Bacterial and viral infections of the gastrointestinal tract often lead to diarrheal disease and to chronic conditions such as ulcers and stomach cancer. In the United States, diarrhea is the second most common infectious illness and diarrheal diseases account for 15 to 34 percent of deaths in some countries. Infection with *Helicobacter pylori* is a major risk factor for developing peptic ulcer disease, stomach cancer and primary gastric B cell lymphoma. NIAID supports research to understand, prevent and treat enteric diseases through a variety of initiatives. NIAID also sponsors research on West Nile Virus, which first emerged in 1999 in New York City, other insect-borne diseases such as Lyme Disease and fungal diseases that can cause severe systemic infections.

#### BIODEFENSE RESEARCH

The NIH is responsible for the implementation of the strategic plan for biodefense research. The NIH biodefense budget, proposed at \$1.7 billion for fiscal year 2006, is part of the budget for NIAID, the lead agency at NIH for infectious diseases and immunology research. Research is the backbone of the NIAID biodefense efforts and includes genomics and studies of pathogenesis and host defense, microbial physiology and animal disease models. Sustained funding by the Administration and Congress over the past few years is making possible significant progress evidenced by over 60 NIAID biodefense initiatives now in place.

Following the September 11, 2001 terrorist attack in the United States and terrorist events using biological agents, awareness about the potential of bioterrorism and the vulnerability of people to a bioterrorism event prompted the U.S. Government to pursue a range of programs and capabilities to prepare for future emergencies (Homeland Security Presidential Directive 10). Among these was increased funding for research and development of medical countermeasures within the Department of Health and Human Services to enable the country to mount a successful medical and public health response to a biological attack on the civilian population should such a terrible event occur. In 2002 the ASM testified before Congress that pathogenic microbes pose a threat to national security whether they occur naturally or are released in a bioterrorism attack. Biodefense research is part of the continuum of biomedical research aimed at protecting the nation and the world against infectious diseases. The ASM supports having federal biomedical and infectious disease research efforts related to civilian human health prioritized and conducted by and at the direction of the DHHS and NIH.

In early 2002, the NIAID convened a panel of experts, the Blue Ribbon Panel on Bioterrorism and Its Implications for Biomedical Research, to provide guidance on the future biodefense research agenda, research resources, facilities and scientific personnel. The NIAID developed research priorities and goals for potential agents of bioterrorism with particular emphasis on the "Category A" agents considered by the CDC and NIH as the worst currently recognized potential bioterror threats. The NIAID developed the NIAID Strategic Plan for Biodefense Research, The NIAID Biodefense Research Agenda for CDC Category A Agents, and the NIAID Biodefense Research Agenda for Category B and C Priority Pathogens. Approximately 60 NIAID initiatives were funded in fiscal years 2002–2004, including funding for a

network of 8 nationwide multidisciplinary Regional Centers of Excellence (RCE) for Biodefense and Emerging Infectious Diseases Research, 2 National Biocontainment Laboratories (NBLs), and 9 Regional Biocontainment Laboratories (RBLs) to provide secure space for the expanded civilian biodefense research program. The genomes of the biological agents listed as posing the most severe threats have been sequenced; new animal models have been developed to test promising drugs and repositories have been established to catalog reagents and specimens. NIAID is sponsoring basic research to understand structure, biology and mechanisms by which potential bioweapons cause disease, studies to elucidate how the human immune system responds to dangerous pathogens and technology to translate basic research into medical countermeasures to detect, prevent and treat diseases caused by potential biological weapons.

Advances in biodefense research are outlined in the NIAID Biodefense Research Agenda for CDC Category A Agents Progress Report and the NIAID Biodefense Research Agenda for Category B and C Priority Pathogens Progress Report. NIAID supported biodefense research is conducted through collaborative efforts with academic institutions and public/private partnerships and scientific communications are open, facilitating scientific and medical progress against infectious diseases. NIAID anticipates that the large investment mandated by the government in civilian biodefense research will advance scientific knowledge that will have positive spin offs for other diseases.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

[In millions of dollars]

Agency	Amount
National Institutes of Health .....	30,000.0
National Heart, Lung and Blood Institute .....	3,117.0
National Institute of Allergy and Infectious Disease .....	4,667.0
National Institute of Environmental Health Sciences .....	680.0
Fogarty International Center .....	71.5
National Institute of Nursing Research .....	146.0
Centers for Disease Control and Prevention .....	8,500.0
National Institute for Occupational Safety and Health .....	326.0
Environmental Health: Asthma Activities .....	70.0
Tuberculosis Control Programs .....	215.0

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society that focuses on respiratory and critical care medicine. For 100 years, the ATS has continued to play a leadership role in scientific and clinical expertise in diagnosis, treatment, cure and prevention of respiratory diseases. With approximately 13,500 members who help prevent and fight respiratory disease around the globe, through research, education, patient care and advocacy, the Society's long-range goal is to decrease morbidity and mortality from respiratory disorders and life-threatening acute illnesses.

LUNG DISEASE IN AMERICA

Lung disease in America is a serious problem. Each year, an estimated 342,000 Americans die of lung disease. Lung disease is responsible for one in every seven deaths, making it America's number three cause of death. More than 35 million Americans suffer from a chronic lung disease. In 2005, lung diseases cost the U.S. economy an estimated \$139.6 billion in direct and indirect costs, a total of 5.9 percent of the U.S. economy.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include chronic obstructive pulmonary disease, lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, asthma and severe acute respiratory syndrome (SARS).

The ATS is pleased that the Subcommittee provided increases in the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) budget last fiscal year. However, we are extremely concerned with the president's fiscal year 2006 budget that proposes a mere 0.5 percent increase for NIH and significant cuts for CDC. We ask that this Subcommittee recommend a 6 percent increase for NIH and an 8.1 percent increase for the CDC. In order to stem the devastating effects of lung disease, research funding must continue to grow to sustain the medical breakthroughs made in recent years. There are three lung diseases that illustrate the need for further investment in research and public health programs: Chronic Obstructive Pulmonary Disease, pediatric lung disease, specifically asthma and tuberculosis.

#### COPD

Chronic Obstructive Pulmonary Disease (COPD) is the fourth leading cause of death in the United States and the third leading cause of death worldwide. Yet, COPD remains relatively unknown to most Americans. COPD is the term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis and is a growing health problem.

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It is estimated that 11.2 million patients have COPD while an additional 13 million Americans are unaware that they have this life threatening disease.

According to the National Heart, Lung and Blood Institute (NHLBI), COPD cost the U.S. economy an estimated \$37.2 billion in 2004. Unfortunately, NHLBI spends about \$44,000 a year on COPD research. We recommend the Subcommittee encourage NHLBI to devote additional resources to finding improved treatments and a cure for COPD.

Medical treatments exist to relieve symptoms and slow the progression of the disease. Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Despite these leads, the ATS feels that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. Clearly more needs to be done to make Americans aware of COPD, its causes and symptoms. We were pleased to participate in an NHLBI-sponsored workshop to formulate strategies toward implementing a National COPD Education and Prevention Program. As this effort continues, we encourage the NHLBI to maintain its partnership with the patient and physician community in the next stages in the development of the National COPD Education and Prevention Program.

While additional resources are needed at NIH to conduct COPD research, CDC has a role to play as well. The ATS encourages the CDC to add COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES), the National Health Information Survey (NHIS) and the Behavioral Risk Factor Surveillance Survey (BRFSS). By collecting information on the prevalence of COPD, researchers and public health professionals will be better able to understand and control the disease.

#### PEDIATRIC LUNG DISEASE

Lung disease affects people of all ages. The ATS is pleased to report that infant death rates for various lung diseases have declined for the past ten years. However, of the seven leading causes of infant mortality, four are lung diseases or have a lung disease component. In 2002, lung diseases accounted for 21 percent of all deaths under one year of age. It is also widely believed that many of the precursors of adult respiratory disease start in childhood. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

The pediatric origins of chronic lung disease extend back to early childhood factors. For example, many children with respiratory illness are growing into adults with COPD. In addition, it is estimated that close to 20.3 million people suffer from asthma, including an estimated 6.1 million children. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. Asthma is the third leading cause of hospitalization among children under the age of 15 and is the leading cause of chronic illness among children.

The ATS feels that the NIH and the CDC must play a leadership role in the ways to assist those with asthma. National statistical estimates show that asthma is a growing problem in the United States. However, we do not have accurate data that provide regional and local information on the prevalence of asthma. To develop a

targeted public health strategy to respond intelligently to asthma, we need locality-specific data. CDC should take the lead in collecting and analyzing this data.

Last year, Congress provided approximately \$32 million for the CDC to conduct asthma programs. We recommend that CDC be provided \$70 million in fiscal year 2006 to expand programs and establish grants to community organizations for screening, treatment, education and prevention of childhood asthma.

#### TUBERCULOSIS

Tuberculosis (TB) is a global public health crisis that remains a concern for the United States. Tuberculosis is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis*. Tuberculosis primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine. The statistics for TB are alarming. Globally, one-third of the world's population is infected with the TB germ, 8–10 million active cases develop each year and 2–3 million people die of tuberculosis annually. It is estimated that 10–15 million Americans have latent tuberculosis. Tuberculosis is the leading cause of death for people with HIV/AIDS.

While we are pleased that CDC has reported 12 straight years of decline in United States TB rates, we remain concerned that TB rates in African Americans remain high and the TB rates in foreign-born Americans is growing. In addition, there has also been an increase in the number of TB cases among people with HIV/AIDS, prisoners, the homeless and certain immigrant communities.

Upon review of this information, many have concluded that a cycle of neglect has begun, reminiscent of a previous resurgence in the early 1980's. The ATS, in collaboration with the National Coalition for Elimination of Tuberculosis, recommends an increase of \$105 million for TB control in fiscal year 2006 to allow the CDC undertake an unprecedented initiative, Intensified Support and Activities to Accelerate Control (ISAAC), to enhance, maximize and target resources to sustain the momentum of the past decade and accelerate the control and elimination of tuberculosis. ISAAC targets tuberculosis in African Americans, tuberculosis along the United States-Mexico border, allows for universal genotyping of all culture positive TB cases, and expands clinical trials for new tools for the diagnosis and treatment of tuberculosis.

In the efforts to eliminate tuberculosis, it is important to note that in 2004 foreign-born residents accounted for nearly 54 percent of U.S. tuberculosis cases. The CDC is working to enhance screening of immigrants and refugees overseas, test recent arrivals from countries that have high TB rates, and cooperate with authorities to control tuberculosis along the United States-Mexico border.

The NIH also has a prominent role to play in the elimination of tuberculosis. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances have put the goal of an effective TB vaccine within reach. The National Institute of Allergy and Infectious Disease has developed a Blueprint for Tuberculosis Vaccine Development. We encourage the Subcommittee to fully fund the TB vaccine blueprint. We also encourage the NIH to continue efforts to develop drugs to combat multi-drug resistant tuberculosis a serious emerging public health threat.

It is clear that efforts to eliminate tuberculosis must continue. From recent TB outbreaks in Fort Wayne, IN and Chesapeake, VA to the hundreds of people being tested for tuberculosis in Houston, TX and Santa Barbara, CA, tuberculosis is still a problem in the United States today.

#### PHYSICIAN WORKFORCE SUPPLY

As the number of people diagnosed with lung diseases rises, we need to ask, who will be treating lung disease patients in the future? The ATS is concerned about the supply of physicians in the United States. A recent study published in the *Journal of the American Medical Association* predicts that there will be an acute shortage of physicians trained to treat patients with critical care illness and lung disease starting in 2007.<sup>1</sup> While the study focuses on supply of pulmonary/critical care physicians, what is driving the shortage is the predicated increase in demand for physician services caused by the aging of the U.S. population.

We are pleased that the Bureau of Workforce Analysis at Health Resources and Services Administration (HRSA) has taken an interest in this issue and will soon be releasing a study on pulmonary/critical care physician supply in the United

<sup>1</sup>D. Angus, et al. Current and Project Workforce Requirements for Care of the Critically Ill and Patients with Pulmonary Disease: Can We Meet the Requirements of an Aging Population? *JAMA* 2000; 284:2762–2770.

States. We believe the HRSA study will confirm an existing shortage of pulmonary and critical care physicians. Should the HRSA study confirm a shortage of physicians, Congress will then need to take action to address the shortage before it reaches a crisis. Potential steps Congress could take include: increasing existing caps on training positions for pulmonary/critical care, expanding the J-1 visa waiver program, increasing class sizes in medical schools, and expanding loan forgiveness and accelerated deductions of interests on loans for students enrolled in critical care training programs.

#### LUNG-DISEASE OPPORTUNITIES AND ADVANCES

Pulmonary researchers have made significant advances in lung disease research. The following are identified areas of lung disease research that the NHBLI has said it will be exploring in the next year:

- HIV-Related Pulmonary Complications. As mentioned earlier, the rate of persons with HIV who are also contracting TB are steadily growing. We applaud the NHLBI for its research on the roles of co-infections, immune factors and genetic predisposition in the pathogenesis of HIV-related pulmonary disease.
- COPD and lung cancer research. Nearly a quarter of a million Americans die each year of either COPD or lung cancer. NHLBI hopes to address the gap in knowledge that a common pathogenetic mechanism may be involved as a risk factor for COPD and lung cancer. The research will focus on a search for the similarities of the cellular and molecular mechanisms that lead to COPD and lung cancer. This new research could have important implications for the prevention and management of both diseases.
- Sleep Apnea or Sleep Disordered Breathing (SDB). SDB is a medical condition associated with upper airway obstruction and cessation of breathing that leads to repeated episodes of asphyxia during the night. SDB is very prevalent in the U.S. population with conservative estimates set at 2 percent to 3 percent of all children, 5 percent of middle age adults, and in excess of 15 percent of the aged population. The major health-related implications and morbid consequences of SDB include the neurocognitive and cardiovascular morbidities, depression, hypertension, increased frequency of myocardial infarction and stroke, and increased frequency of motor vehicle accidents due to the increased sleepiness induced by the disruption of sleep in SDB patients. Both the frequency of SDB and its consequences are anticipated to increase in the next decades due to the aging of the overall U.S. population and the ongoing epidemic of obesity that afflicts our country. The ATS supports the need for more research into the causes, diagnosis and treatment of SDB.

In conclusion, lung disease is a growing problem in the United States. It is this country's third leading cause of death, responsible for one in seven deaths. The lung disease death rate continues to climb. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, tuberculosis kills 3 million people each year, more people than any other single infectious agent. The level of support this Subcommittee approves for lung disease programs should reflect the urgency illustrated by these numbers.

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#### PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) COALITION

The CDC Coalition is a nonpartisan association of more than 100 groups committed to strengthening our nation's prevention programs. Our mission is to assure that health promotion and disease prevention are given top priority in federal funding, to support a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and to assure an adequate translation of new research into effective state and local programs. Coalition member groups represent millions of public health workers, researchers, educators, and citizens served by CDC programs. We are grateful for the opportunity to present our views to the Subcommittee.

It is time to support CDC as an agency—not just the individual programs that it funds. In the best professional judgment of the CDC Coalition—given the challenges and burdens of chronic disease, terrorism and disaster preparedness, new and re-emerging infectious diseases and our many unmet public health needs and missed prevention opportunities—the agency will require funding of \$8.65 billion to support its mission for fiscal year 2006.

The CDC Coalition is pleased with the support the Subcommittee has given to CDC programs over the years, including your recognition of the need to fund chronic disease prevention, infectious disease preparedness, and environmental health pro-

grams. By translating research findings into effective intervention efforts in the field, the agency has been a key source of funding for many of our state and local programs that aim to improve the health of communities. Perhaps more importantly, federal funding through CDC provides the foundation for our state and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our nation's public health defense system against emerging and reemerging infectious diseases. From anthrax to West Nile to smallpox to SARS, the Centers for Disease Control and Prevention is the nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

In fiscal year 2002, Congress appropriated \$7.7 billion for CDC. In fiscal years 2003, 2004 and 2005, Congress appropriated \$7.1 billion, \$7.2 billion, and \$8.0 billion, respectively. Now the President's proposed budget for the agency in fiscal year 2006 is \$7.5 billion—a \$500 million cut from last year's funding, and \$200 million below the fiscal year 2002 funding level. We are moving in the wrong direction. Public health is being asked to do more, not less. As far as we can tell, in light of the current workload placed on the public health service—in addition to the threat of emerging diseases such as the avian flu—it simply does not make any sense to cut the budget for CDC at a time when the threats to public health are so great. Funding public health outbreak by outbreak is not an effective way to ensure either preparedness or accountability.

Until we are committed to a strong public health system, every crisis will force trade offs. For instance, the Administration's recent reprogramming request to make up for the vaccine shortage with money originally appropriated by Congress for chronic disease prevention programs (COPP and the Preventive Health and Health Services Block Grant) and bioterror preparedness funds is the most recent concrete example of attention to one disease coming at the expense of another.

CDC serves as the lead agency for bioterrorism preparedness and must receive sustained support for its preparedness programs in order for our nation to meet future challenges. In the best professional judgment of CDC Coalition members, given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities, the agency will require at least level funding to adequately fulfill its mission for fiscal year 2006.

We are concerned that the President's budget proposes cutting the state and local capacity grants for terrorism by almost \$130 million, and eliminating the anthrax preparedness program. We encourage the Subcommittee to restore these cuts to ensure that our local communities can be prepared in the event of an act of terrorism.

Heart disease remains the nation's number one killer. In 2002, 696,947 people died of heart disease (51 percent of them women), accounting for 29 percent of all U.S. deaths. Stroke is the third leading cause of death after heart disease and cancer and a leading cause of serious, long-term disability. In 2002, stroke killed 162,672 people (62 percent of them women), accounting for about 1 of every 15 deaths. In 1998, the U.S. Congress provided funding for CDC to initiate a national, state-based heart disease and stroke prevention program with funding for eight states. Currently, 32 states and the District of Columbia are funded, 21 as capacity building programs and 12 as basic implementation programs. The CDC Coalition recommends \$55.6 million for the Heart Disease and Stroke Prevention Program.

The CDC carries out crucial work to reduce the incidence, morbidity and mortality of cancer through prevention, early detection, treatment, rehabilitation, and palliation. Cancer is the second leading cause of death in the United States. In 2004, about 1.4 million new cases of cancer will be diagnosed, and more than 563,700 Americans—about 1,500 people a day—will die of the disease. The financial cost of cancer is also significant. According to the National Institutes of Health, in 2003, the overall cost for cancer in the United States was \$189.5 billion: \$64.2 billion for direct medical expenses, \$16.3 billion for lost worker productivity due to illness, and \$109 billion for lost worker productivity due to premature death. Among the ways they are fighting cancer, the CDC funds programs to detect colorectal, ovarian, prostate, skin, breast and cervical cancers, as well as maintain a cancer registry to track cancer incidence. The CDC coalition recommends \$385 million for the Cancer Prevention and Control activities of the CDC.

Nearly 16 million Americans have diabetes, including over 5 million who don't know it. During 1980–2002, the number of people with diabetes in the United States more than doubled, from 5.8 million to 13.3 million. Although more than 18 million Americans have diabetes, 5.2 million cases are undiagnosed. Each year, 12,000–24,000 people with diabetes become blind, more than 42,800 develop kidney failure,



and about 82,000 have leg, foot, or toe amputations. Preventive care such as routine eye and foot examinations, self-monitoring of blood glucose, and glycemic control could reduce these numbers. Without additional funds, most states will not be able to create programs based on these new data. States also will continue to need CDC funding for diabetes control programs that seek to reduce the complications associated with diabetes. The CDC Coalition recommends \$150 million for CDC's diabetes prevention efforts.

Over the last 25 years, obesity rates have doubled among United States adults and children, and tripled in teens. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. The CDC funds programs to encourage the consumption of fruits and vegetables, to get sufficient exercise, and to develop other habits of healthy nutrition and activity. The CDC Coalition recommends \$70 million for CDC's Division of Nutrition and Physical Activity.

Arthritis and chronic joint symptoms affect nearly 70 million Americans, or about one of every three adults, making it one of the most prevalent diseases in the United States. As the population ages, this number will increase dramatically. The CDC Coalition recommends \$25 million for the arthritis programs of the CDC.

More than 400,000 people die prematurely every year due to tobacco use. The CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit with ways to do so. The CDC Coalition recommends \$145 million for the CDC's tobacco control programs.

Each day 4,400 young people try their first cigarette. At the same time, daily participation in high school physical education classes dropped from 42 percent in 1991 to 32 percent in 2001. Almost 80 percent of young people do not eat the recommended number of servings of fruits and vegetables, while nearly 30 percent of young people are overweight or at risk of becoming overweight. And every year, almost 800,000 adolescents become pregnant and about 3 million become infected with a sexually transmitted disease. School health programs are one of the most efficient means of correcting these problems, shaping our nation's future health, education, and social well-being. CDC's Adolescent and School Health program supports coordinated school health programs that reduce disease risk factors. In 2003, CDC supported 22 state-coordinated school health programs. The CDC Coalition recommends \$82.4 million for school health programs.

The President's budget proposes the elimination of the Childhood Obesity Prevention Program (COPP), also referred to as the VERB or CDC Youth Media campaign. The success of the COPP program shows that over 30 percent of the target audience, children ages 9 to 10 years old, increased their physical activity as a direct result of the VERB media campaign. This type of success warrants continued funding to empower our children to respond to the growing concerns of the obesity epidemic and improve the health of this nation. We encourage the Subcommittee to restore the cuts and fund the COPP program at \$70 million.

Public health programs delivered at the local level should be flexible to respond to local needs. Within an otherwise-categorical funding construct, the Preventive Health and Health Services Block Grant is the only source of flexible dollars for states and localities to address their unique public health needs. The track record of positive public health outcomes from Prevention Block Grant programs is strong, yet so many requests go unfunded. However, the President's budget proposes the elimination of the Preventive Health and Health Services Block Grant. As states use their Prevention Block Grant dollars to address high priority needs such as emerging and chronic diseases, child safety seat programs, suicide prevention, smoke detector distribution and fire safety programs, adult immunization, oral health, work-site wellness, infectious disease outbreaks, food safety, emergency medical services, safe drinking water, and surveillance needs—we can scarcely understand why the Prevention Block Grant should be eliminated. In fact, the Prevention Block Grant has been flat funded since fiscal year 2000. We encourage the Subcommittee to restore the cuts and fund the Prevention Block Grant at \$132 million.

Much of CDC's work in chronic disease prevention and health promotion, and in other programs areas, is guided by its prevention research activities. Prevention research considers the factors associated with illness, disability, and injury, such as lifestyles or exposure to environmental toxins, and the best ways to address these factors and thereby promote health. By answering these questions, prevention research links biomedical research, which focuses on human physiology and disease treatment, to policies and public health interventions that promote wellness and reduce the need for treatment.

CDC provides national leadership in helping control the HIV epidemic by working with community, state, national, and international partners in surveillance, research, prevention and evaluation activities. These activities are critically impor-

tant, as CDC estimates that between 800,000 and 900,000 Americans currently are living with HIV. Also, the number of people living with AIDS is increasing, as effective new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is our best defense against the AIDS epidemic that has already killed over 400,000 U.S. citizens and is devastating the populations of nations around the globe, and CDC's HIV prevention efforts must be expanded.

Elimination of tuberculosis and sexually transmitted diseases (STDs), especially syphilis, is now within our grasp. These welcome opportunities, if adequately funded now, will save millions in annual health care costs in the future. Untreated STDs contribute to infant mortality, infertility, and cervical cancer. State and local STD control programs depend heavily on CDC funding for their operational support.

CDC conducts the National Health and Nutrition Examination Survey (NHANES), the only national source of objective health data to provide accurate estimates of diagnosed and undiagnosed medical conditions in the population. NHANES is a unique collaboration between CDC, the National Institutes of Health (NIH), and others to obtain data for biomedical research, public health, tracking of health indicators, and policy development. Through physical examinations, clinical and laboratory tests, and interviews, NHANES assesses the health status of adults and children in the United States. Mobile exam centers travel throughout the country to collect data on chronic conditions, nutritional status, medical risk factors (e.g., high cholesterol level, obesity, high blood pressure), dental health, vision, illicit drug use, blood lead levels, food safety, and other factors that are not possible to assess by use of interviews alone. Findings from this survey are essential for determining rates of major diseases and health conditions and developing public health policies and prevention interventions.

We must address the growing disparity in the health of racial and ethnic minorities. CDC's REACH 2010 Demonstration Program, Racial and Ethnic Approaches to Community Health (REACH), helps states address these serious disparities in infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, HIV/AIDS and immunizations. The CDC Coalition recommends \$50 million for the REACH program.

The CDC Coalition is requesting a \$5 million increase, for an appropriation of \$46 million for Steps to a HealthierUS (STEPS) program. Additional resources will allow for the creation of programs in more states. Furthermore, while the President's budget request includes \$1.5 million to support the YMCA Pioneering Healthier Communities initiative, \$3 million is needed to fully fund and continue to expand this important effort. This would enable the funding 20 NEW Pioneering Healthier Community projects with one-time start up grants; provide funding for a conference in 2005 to train these community leadership teams, and establish an office within the Centers for Disease Control and Prevention that would assist YMCAs, non-profits and local/state health departments in initiating, evaluating and sustaining healthy community change efforts.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. The value of adult immunization programs to improve length and quality of life, and to save health care costs, is realized through a number of CDC programs, but there is much work to be done and a need for sound funding to achieve our goals. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination. Significant racial and ethnic disparities in vaccination levels persist among the elderly. Childhood immunization programs at CDC also need a funding boost, to ensure sufficient purchase and delivery of the recently-approved varicella and pneumococcal vaccines. In addition, developing functional immunization registries in all states will be less costly in the long run than maintaining the incomplete systems currently in place.

Injury at work remains a leading cause of death and disability among U.S. workers. During the period from 1980 through 1995, at least 93,338 workers in the United States died as a result of injuries suffered on the job, for an average of about 16 deaths per day. The Bureau of Labor Statistics (Department of Labor) has identified 5,915 workplace deaths from acute traumatic injury in 2000. BLS also estimates that 5.7 million injuries to workers occurred in 1997 alone; while NIOSH estimates that about 3.6 million occupational injuries were serious enough to be treated in hospital emergency rooms in 1998. The injury prevention and workforce protection initiatives of NIOSH need continued support.

Of the 4 million babies born each year in the United States, 3 percent are born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20 percent of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. An es-

estimated 54 million people in the United States currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. Direct and indirect costs associated with disability exceed \$300 billion.

Created by the Children's Health Act of 2000 (Public Law 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. We encourage the Subcommittee to provide at least \$135 million in fiscal year 2006 funding for the NCBDDD. This would be a modest increase of \$10 million and would further surveillance, research and prevention activities related to birth defects and developmental disabilities and improve the lives of those living with disabilities.

We also encourage the Subcommittee to provide \$10 million for CDC's Environmental Public Health Services Branch to revitalize environmental public health services at the national, state and local level. As with the public health workforce, the environmental health workforce is declining. Furthermore, the agencies that carry out these services are fragmented and their resources are stretched. These services are the backbone of public health and are essential to protecting and ensuring the health and well being of the American public from threats associated with West Nile virus, terrorism, *E. coli* and lead in drinking water.

We appreciate the Subcommittee's hard work in advocating for CDC programs in a climate of competing priorities. We encourage you to consider our request for \$8.65 billion for CDC in fiscal year 2006. Members of the CDC Coalition are grateful for this opportunity to present our views to the Subcommittee.

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#### PREPARED STATEMENT OF THE CHARCOT-MARIE-TOOTH ASSOCIATION (CMTA)

I want to thank the Subcommittee for this opportunity to share information about Charcot-Marie-Tooth (CMT) disorder and to express support for expanded CMT research funded by the National Institutes of Health (NIH).

#### BACKGROUND ON CMT

CMT is the most common inherited neurological disorder, affecting approximately 125,000 Americans. The disease affects people across their lifespan and is found world wide in all races and ethnic groups. Unlike muscular dystrophy, which strikes the muscles, CMT adversely affects the nerves that control the muscles. Individuals afflicted with CMT slowly lose normal use of their feet and legs and hands and arms as nerves to the extremities degenerate. The muscles in the extremities weaken due to the loss of stimulation by the affected nerves, and there is often a loss of sensory nerve function.

Even though there are different types of CMT, CMT is largely inherited in an autosomal pattern, meaning when one parent has the disease (either the father or the mother), there is a 50 percent chance it will be passed onto each child. The degree of severity can vary greatly from patient to patient, even within the same family. A child may or may not be more severely disabled than his or her parent. In most cases, CMT does not affect life expectancy; however, in certain forms the disease is more severe: debilitating children so that they require wheelchairs and even resulting in premature death. There are currently no effective treatments—although physical therapy, occupational therapy, and moderate physical activity are beneficial.

#### STATUS OF CMT RESEARCH

CMT was described over 100 years ago; yet, it has only been in the last 10 years that rapid advances in our understanding of CMT have occurred. We now know there are at least 30 different genetic causes of CMT, and the genetic location of many more types are known. Identification of the known CMT genes has led to the development of diagnostic tests, enabling many people to receive a firm diagnosis and evaluate risk to other family members. Despite identifying more genes associated with CMT, we are just beginning to understand how the genes, when abnormal, cause CMT.

To elucidate the complexities surrounding CMT, the CMTA funded the CMT North American Database, which is housed at Indiana University. Simply put, the database is a standardized collection of data about a large number of people with all types of CMT that includes detailed information about a person's medical, genetic, and family histories. Having a central repository of standardized information of CMT patients will accelerate the pace of CMT research, by providing detailed in-

formation about large numbers of uniformly evaluated patients to qualified researchers. Information contained in the database should provide a more accurate picture of the range of disability caused by the various types and sub-types of CMT. The database will also be a rich resource to tap when drugs or other CMT treatments become available for testing.

In addition to the database, for several years, CMTA has funded a quality research program including the sponsorship of many fellowships and national and international meetings. Ongoing studies are investigating the molecular basis of various forms of CMT, the molecular biology of molecules known to cause CMT, relationships between CMT and other neurodegenerative diseases such as ALS, and the development of rational clinical therapies to potentially treat CMT. The National Institutes of Health (NIH), in particular, the National Institute of Neurological Disorders and Stroke (NINDS), has co-funded several of these activities.

#### CMT RESEARCH AND THE NATIONAL INSTITUTES OF HEALTH

Despite providing modest support for a handful of successfully competed applications, NIH has not launched a coordinated effort to stimulate more CMT research opportunities nor invested sufficient resources. In fact, according to the NINDS, from fiscal year 2002 to fiscal year 2005, funding for CMT research at NINDS declined in real terms, even as total NIH dollars and funding of neuropathy research increased.

We are pleased the report that the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education requested on CMT research at NIH last year has contributed to the understanding of relevant trans-NIH activities. Moreover, we are encouraged by NIH's announcement that it is beginning to plan a workshop on peripheral neuropathies, but believe that such a workshop should focus intensively on CMT so that it will result in outcomes which will be directly relevant to CMT research and could lead to a relevant program announcement or request for applications on CMT, specifically.

We are confident the Subcommittee's continued interest in CMT research will help the NIH and CMT field work together to identify potential future research opportunities that could be incorporated into existing trans-NIH initiatives, such as the Blueprint for Neurosciences, or developed from the upcoming scientific workshop into a request for applications or program announcement.

Unlike many other areas of research, CMT did not experience a largess of funding during the NIH doubling period. In spite of this fact, in recent years, researchers made substantial progress towards understanding CMT. Yet, additional advances in the field will be hampered without additional resources from the NIH. This support would not only benefit CMT. Data from CMT research has the potential to translate into direct benefits for research into other neurodegenerative disorders, such as ALS and MS, which devastate hundreds of thousands of Americans. Therefore, by increasing its support for CMT, NIH will also be facilitating research into other neurodegenerative diseases.

#### FISCAL YEAR 2006 REQUEST

CMTA believes the Administration's request for the NIH in fiscal year 2006 is inadequate. Providing NIH with less than a one percent increase, as proposed, would fund the agency well below the rate of biomedical research inflation index (3.5 percent) and limit the agency's ability to invest in emerging areas of sciences, such as CMT, that are in dire need of an infusion of federal support. We urge the Subcommittee to increase funding for the NIH in fiscal year 2006. Moreover, we urge the Subcommittee to continue to express an interest in CMT and work with NIH to ensure that any workshop on peripheral neuropathies is intensively focused on CMT so that it will result in outcomes which will be directly relevant to CMT research and could lead to a relevant program announcement or request for applications on CMT, specifically. We encourage and strongly support any such program announcement or request for applications on CMT.

Once again, I thank the Subcommittee for expressing its interest in CMT and for this opportunity to testify.

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#### PREPARED STATEMENT OF THE COALITION FOR AMERICAN TRAUMA CARE

The Coalition for American Trauma Care is pleased to provide you with its recommendations for fiscal year 2006 appropriations for public health programs that support trauma care, trauma care research, and injury prevention.

The Coalition for American Trauma Care is a nonprofit association of national health and professional organizations that seeks to improve care for the seriously injured patient through improved delivery of trauma care services, research and rehabilitation activities. The Coalition also supports efforts to prevent injury from occurring.

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 United States 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.

Attention to injury was never more important in the wake of the September 11, 2001 attacks. Particularly concerning is our failure, as a nation, to fully implement organized systems of trauma care in every state and region which numerous studies have demonstrated are essential to saving the lives of those who are severely injured. The Health Resources and Services Administration's (HRSA) completed analysis of a 2002 survey of the states that shows only eight states had comprehensive trauma systems, 12 states did not have even rudimentary elements of a trauma system and the remaining states are were in various stages of incomplete development. And yet a new Harris Poll, commissioned in November, 2004 to learn about the American public's views of and support for trauma systems found that:

- Almost everyone recognizes the importance of having a trauma system in their state.
- Large majorities feel that having a trauma system in place is as important as, or more important than, having State police or HAZMAT teams.
- About two in three Americans would be extremely or very concerned if they learned that the trauma system in their state did not meet recognized standards.
- Americans are willing to spend their own money to have trauma centers and trauma systems in place in their states.
- Generally, Americans have high expectations of their states' trauma centers and systems when it comes to handling natural disasters or terrorist attacks.

*Trauma Care Systems.*—The Coalition is opposed to the elimination of this program in the President's fiscal year 2006 budget request and urges you to provide \$12 million in fiscal year 2006 for HRSA's Trauma-EMS systems program. This is the amount provided in Senate authorizing legislation (S. 265) adopted unanimously by the Senate HELP Committee on February 9. The Trauma-EMS program was funded at \$3.0 million in fiscal year 2001, and \$3.5 million for fiscal year 2002–2005. Fully 80 percent of the appropriated dollars, as authorized, is provided for state grants to further trauma system development. States receive 100 percent federal funding in the first grant year and must provide a 2:1 state to federal match in Year 2, and a 3:1 match in Year 3. States may do this through in-kind assets. Thus, this seriously under-funded program provides both critical federal leadership and leverages scarce state resources.

The program has been making steady progress toward the goal of extending and strengthening organized systems of trauma care across the nation. In receiving grants from fiscal year 2002–2004 states had to assure:

1. A lead agency for the state trauma system.
2. Identification of a state-level trauma system manager.
3. A multidisciplinary statewide trauma stakeholder group.
4. Completion of the 2002 National Assessment (with fiscal year 2001 funding).
5. A statewide trauma system plan.

After these components were in place (or for those states with advanced trauma systems), the program funded additional state-specific trauma system projects.

A follow-up assessment of state progress in trauma system development is being planned for fiscal year 2005.

*National Center for Injury Prevention and Control.*—The Coalition supports \$168 million in funding in fiscal year 2006 for the National Center for Injury Prevention and Control which is currently funded at \$138 million. While the Coalition remains a strong supporter of the National Center for Injury Prevention and Control, members would like to see more balance in support for unintentional injuries. Significant increases in the NCIPC in recent years have largely been earmarked for violence prevention—an important focus for NCIPC after disturbing incidents in public

schools around the country. However, unintentional injury remains the leading killer of children and young adults and NCIPC's efforts to translate what works into communities should receive increased funding. These efforts help prevent, for example, the 20,000 head injuries that occur every year by encouraging the use of bicycle helmets, and reduce burn-related injuries through smoke detector implementation programs. The Coalition is also disappointed that as the funding base for the National Center for Injury Control and Prevention has grown, the relative amount of funding for acute care research and demonstration has diminished.

*Traumatic Brain Injury (TBI).*—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 is opposed to the proposed elimination of this important program in the President's fiscal year 2006 budget request and urges you to provide a total of \$30 million for the Traumatic Brain Injury (TBI) Act, reauthorized as part of the Children's Health Act of 2000 (Public Law 106-310), as follows: \$8.715 million for CDC for surveillance—the legislation directs the CDC to build upon its work with state registries to collect information to help improve service delivery to people who have sustained a TBI and to expand monitoring of the incidence and prevalence of TBI to include all age groups and individuals in institutional settings. In 2003, the CDC launched the first phase of the National Information Center for TBI (NCITBI)—a “one call” national information center that provides persons with brain injury and their circles of support toll-free information on State-specific resources and linkage to services. The CDC has also been directed to monitor the incidence, outcomes and services needs of people who sustain injuries, including TBI, during mass casualty events. The Coalition also supports \$15.193 million for the HRSA TBI State Grant Program—this Program was established to improve access to health and other services for individuals with TBI and their families by awarding competitive grants to States and Territories; and \$6 million for HRSA Protection and Advocacy Services for persons with TBI. In addition, the Coalition requests that you include report language to ensure that the National Institutes on Neurological Disorders and Stroke (NINDS) within NIH increases core funding to \$2 million for each of its six Centers and that NINDS dedicate \$1.0 million for funding a new coordinating and administrative network for the six Centers. We also request that NINDS dedicate funding to establish a new category of training grants to incentivize individuals to pursue careers in TBI bench science research. NINDS currently funds six bench science research centers at \$1.0 million each. These six Centers represent groups of renowned basic and clinical physician-scientists working collaboratively on translational research programs who have developed the clinically-relevant laboratory models that will serve as the foundation for future research—it is imperative that we invest in the infrastructure that is now in place.

*Children's EMS.*—The Coalition is opposed to the proposed elimination of this program in the President's fiscal year 2006 budget request and urges you to provide \$20 million in fiscal year 2006, which maintains the fiscal year 2005 funding level. While children currently account for up to 30 percent of all emergency department visits and 10 percent of ambulance runs annually, many facilities lack the specialized equipment needed to care for children. Moreover, many emergency personnel do not have the necessary education or training to provide optimal care to children. In order to assist local communities in providing the best emergency care to children the Children's EMS program needs to continue and continue at the fiscal year 2005 funding level.

*Preventive Health/Health Services Block Grant (PHHS).*—The Coalition is opposed to the proposed elimination of this program in the President's fiscal year 2006 budget supports an fiscal year 2006 funding level of \$132 million, which maintains the same funding level as provided in fiscal year 2005. The Coalition rejects the President's request to eliminate this program because it is duplicative of other activities within the CDC. The PHHS Block Grant provides flexible funding to states to allow them to address specific health problems identified under the Healthy People 2010 assessment process. The funding allows states to take innovative approaches to address significant health issues and complements, not duplicates, some of CDC's other program activities. In addition, the PHHS Block Grant is the largest single source of federal funding for support basic state Emergency Medical Services' (EMS) infrastructure—the first line of defense against death and disability resulting from severe injury.

The Coalition for American Trauma Care is disappointed by the President's fiscal year 2006 budget which proposes elimination of all funding for four programs specifically designed to build infrastructure to ensure that trauma and emergency medical services are available and appropriate to need: HRSA's Trauma-EMS systems program; HRSA's Traumatic Brain Injury program; HRSA's Children's EMS pro-

gram and CDC's Preventive Health and Health Services Block Grant. If these cuts were enacted, the results would be devastating for emergency care in the United States for everyone and particularly for children and those who have suffered head injury. The burden of injury in America has been well documented by numerous IOM reports and injury facts speak for themselves: injury is the leading cause of death and disability for children and adults up to age 44. While much more can and needs to be done to prevent injury from occurring at all, we will never be able to eliminate it entirely. Cutting these programs will not lessen the injury burden in America; on the contrary, it will significantly increase the burden of death, disability and direct and indirect health care costs. We need to increase our investment in these program areas, not reduce our commitment.

The Coalition greatly appreciates the support the Subcommittee has provided to trauma related programs in the past and looks forward to working with the Subcommittee in the coming weeks and months.

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PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

The Coalition for Health Funding is pleased to provide the Subcommittee with testimony recommending fiscal year 2006 funding levels for the agencies and programs of the U.S. Public Health Service. Since 1970, the Coalition's member organizations, representing 40 million health care professionals, researchers, lay volunteers, patients and families, have been advocating for sufficient resources for PHS agencies and programs to meet the changing health challenges confronting the American people. The Coalition for Health Funding is the nation's oldest, most broadly based alliance focused on the breadth of discretionary health spending. One of the important principles that unites the Coalition's members is that the health needs of the nation's population must be addressed by strong, sustained support for a continuum of activities that includes biomedical, behavioral and health services research; community-based disease prevention and health promotion; health care services for vulnerable and medically underserved populations; ensuring a safe and effective food and drug supply; and education of a health professions workforce in adequate numbers to address the breadth of need.

The Coalition for Health Funding believes the Bush Administration, and Congress, are missing an important opportunity to improve the health of all Americans by not making a stronger investment in the agencies and programs of the U.S. Public Health Service. Federal spending for public health is low compared to other health spending, amounting to three percent of total health care spending according to the Centers for Medicare and Medicaid, and yet an investment in public health has the potential to slow unsustainable growth in mandatory costs, reduce lost productivity at work, school and home, and strengthen every citizen's contribution for a healthy, economically strong America. Mounting evidence-based studies ([www.thecommunityguide.org](http://www.thecommunityguide.org); [www.aspe.hhs.gov/health/prevention/prevention.pdf](http://www.aspe.hhs.gov/health/prevention/prevention.pdf); [www.modelprograms.samhsa.gov](http://www.modelprograms.samhsa.gov)) demonstrating the effectiveness of prevention, early intervention, access to basic health care services and associated cost-savings support investing in public health programs and activities. Instead, over the past two fiscal years we have seen an erosion of resources, beginning with the budget phase, with flat-funding, or cuts in funding, effected for many programs during the Committee phase of the appropriations process followed by across-the-board cuts in the omnibus bills for all health programs. The President's fiscal year 2006 budget request takes these reductions considerably further by proposing to cut funding for the seven major public health agencies by \$1.1 billion below fiscal year 2005 levels, a cut of 2.2 percent as the accompanying table shows.

The Coalition for Health Funding urges the Subcommittee on Labor, Health and Human Services and Education to reject the President's proposal to reduce the nation's investment in public health and instead join 425 health organizations that, in letter dated February 1, 2005, urged the President and Congress to make an investment in public health of \$3.5 billion over fiscal year 2005 levels. As that letter states:

"The health of all Americans is at risk from an unprecedented range of threats, including: chronic diseases and disabilities, infectious and food borne illnesses, biological and chemical terrorism, mental disorders and substance abuse, catastrophic injuries, and a shortage of healthcare providers and trained public health workers. Our nation's public health system will not be able to respond adequately to these threats without additional resources for the continuum of medical research, prevention, treatment and training programs. We urge you to increase discretionary funding for public health through the Function 550 budget allocation in fiscal year 2006

by \$3.5 billion. This investment is critical to improving the health, safety and security of our nation.”

The following is a partial list of the Coalition’s fiscal year 2006 recommendations for specific U.S. Public Health Service agencies. The Coalition developed these recommendations working with eight other health coalitions with a more targeted focus on one agency, or major activities within a particular agency. The table that follows provides the Coalition’s recommendations for all the major public health agencies.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

The Coalition supports \$30.1 billion in fiscal year 2006 for the National Institutes of Health, a 6 percent increase over the fiscal year 2005 funding level, to provide sufficient resources to sustain the momentum of the recently completed campaign to double the nation’s investment in the promising research supported and conducted by the NIH. The President’s request to provide \$28.6 billion, or a .5 percent increase over fiscal year 2005, is inadequate to fully reap the research opportunities that the doubling campaign have made available. NIH is engaging the next generation of biomedical research to integrate and aggregate basic research, computational capabilities, and clinical evidence into new cures. Transforming America’s health for the 21st century will require a longstanding commitment from our country and its leaders. The pace and intensity of this transformation is critical. Health improvements will only be possible if the medical research enterprise runs smoothly. Recent discoveries NIH supported research has made possible include: lifestyle intervention can reduce the onset of Type II diabetes as occurred in 58 percent of those at risk in a recent trial; islet cell transplantation has reduced the need for insulin for 250 individuals with juvenile diabetes; low-cost diuretics are as effective as newer, costlier drugs in lowering high blood pressure that affects one in four Americans, potentially saving money and enhancing compliance; newer antidepressant medications are more targeted to specific brain function resulting in fewer side effects and enhanced compliance; great advances in understanding the genetic factors in Alzheimer’s Disease holds promise for treatment for the growing number of Americans afflicted with this devastating disease; new vaccines have been developed against Haemophilus influenzae type b, pneumococcal disease, Hepatitis A and B and a new Ebola vaccine is currently in trial.

Scientific discoveries are the result of a series of incremental steps that pave the way for future breakthroughs. This process needs sustained support. A funding increase of only .5 percent will delay important initiatives leading to earlier, more targeted diagnoses; more targeted, effective treatment options; and more comprehensive, cost-effective prevention strategies.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Coalition for Health Funding recommends an overall funding level of \$8.65 billion for CDC in fiscal year 2006. This amount is \$616 million more than the fiscal year 2005 funding level and \$1.1 billion more the President’s request for fiscal year 2006. The Coalition believes this is the amount needed to enable CDC to carry out its vital mission of disease prevention and health promotion.

The Coalition opposes the President’s request to cut \$130 million from State and Local Preparedness grants and shift the funds to the Strategic National Stockpile (SNS) to purchase vaccines and terrorism countermeasures and fund a new \$50 million Mass Casualty Initiative. Any SNS purchases and new federal terrorism initiatives, if deemed warranted, should be funded from new resources and not at the expense of State and Local Preparedness. State and Local health departments are in the third year of expanded funding for terrorism preparedness. The effect of a 14 percent cut will seriously jeopardize momentum in addressing critical capacity needs. Funding should be restored, at least, to fiscal year 2005 levels and the commitment to rebuilding the nation’s neglected public health infrastructure resumed and sustained.

The Coalition also opposes the proposed elimination of funding for the Preventive Health and Health Services Block Grant. This funding provides the only source of flexible funding to state health departments to help them meet Healthy People 2010 goals. The funding is often used in innovative ways which complement, not duplicate, other disease-specific categorical programs. It is also the only source of funding for many states to monitor well-contamination in poor rural areas. And it helps states cope with unexpected challenges such as emerging infectious diseases like West Nile Virus and the health consequences of disasters. Taken together, the proposed cut in the State and Local Bioterrorism grant program coupled with the elimination of the Preventive Block Grant seriously undermines funding for building State and Local public health capacity, a major Congressional goal expressed in leg-



isolation the year before (Public Law 106–505) and the year after (Public Law 107–188) the attacks of September 11, 2001.

The Coalition is displeased that most of the rest of the programs and activities conducted by the CDC are proposed for flat funding in the President's budget. This is especially egregious for chronic disease programs at a time when the nation faces an epidemic of obesity and the ensuing increase in diabetes, heart disease, kidney disease, cancer, arthritis and other costly diseases. There should be a major national investment in finding ways to address this problem. The VERB program, eliminated in the President's budget, provides a model for reaching young adolescents; it should be replicated.

Similarly, there is insufficient funding provided for infectious disease programs, most of which are flat-funded. The United States is still only partially prepared for diseases such as West Nile virus and pandemic flu, and has not committed funds to combat antimicrobial resistance commensurate with the scope and severity this problem presents in the United States. There are 40,000 new HIV infections each year which means the United States burden of HIV/AIDS is growing, not stagnant. The President's budget request does include increases for the National Immunization Program (+ \$50 million), but the Coalition supports an increase of \$282 million in order to meet the national goal of vaccinating 90 percent of children and adults.

Finally, the Coalition is, overall, deeply disappointed that the President's budget request cuts funding for the CDC, the nation's leading disease prevention/health promotion agency, by more than 6 percent, instead of investing in this agency's potential for saving health care costs.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$7.5 billion for HRSA in fiscal year 2006. This amount is \$691 million, or 10 percent, more than the fiscal year 2005 funding level, and is \$1.5 billion more than the President's request. This is the amount that the Coalition believes is needed to provide adequate resources for the important programs that HRSA administers that address access to needed medical and health care services for medically underserved populations.

The Coalition is pleased that the President has requested a significant 17 percent increase for Community Health Centers (CHC) for a total of \$2.038 billion. These centers provide basic health care services for those who are medically underserved in both rural and inner city communities across the nation. With the number of uninsured rising, CHCs are more important than ever.

There are many other areas in the HRSA budget that the President proposes to cut deeply that the Coalition opposes. Chief among these is the elimination of the Title VII Health Professions Education programs. These programs are beginning to document formally what their supporters have long known: that they have a solid track record in recruiting and training the kind of health professionals that practice in, and stay in, medically underserved areas. Graduates of these programs are 3–10 times more likely to practice in underserved areas and are 2–5 times more likely to be minorities. The Title VII programs also have a solid track record in training needed health professionals in short supply including pharmacists, allied health professionals, dentists, a range of public health practitioners, psychologists, and physician assistants. These shortages will become worse as increasing numbers of the nation's healthcare workforce begin to retire and the babyboom generation requires increased care as it ages.

The Coalition also opposes the elimination of five other programs: Community Access Program, an innovative program of coordinated service delivery to the uninsured that does not duplicate other available programs; the Trauma-EMS program which fosters statewide trauma system development to provide appropriate emergency response for seriously injured individuals—an important terrorism readiness component; the Children's EMS program which builds appropriate emergency response capacity for children; the Traumatic Brain Injury program which helps brain-injured individuals become successful community participants; the universal newborn screening program which ensures that all states screen infants for a core set of screening tests for genetic, metabolic, hormonal, or functional conditions many of which can be treated if detected and disability averted. The Coalition also opposes the \$115 million cut to a number of rural programs, and the \$101 million cut to the Children's Hospitals Graduate Medical Education program.

Also disturbing is the proposed level funding for many other programs. This includes the Nursing Education programs despite considerable documentation of the nursing shortage crisis. It also includes the Ryan White CARE Act programs at a time when the United States is experiencing 40,000 new HIV infections per year.

The President's request for Ryan White programs, when compared to fiscal year 2005 levels, provides level funding for all titles except for the AIDS Drug Assistance Program which receives a \$10 million increase—not enough to eliminate waiting lists for the life-saving drugs. The Maternal and Child Health Block Grant is a critical safety net program for poor women and special needs children. Flat-funding actually cuts services at a time when there is an upsurge in the number of families needing TANF assistance. Family Planning services, which support 4,600 clinics across the United States that provide comprehensive services including screening for cancer, HIV, and other diseases as well as contraception and teen pregnancy prevention, are another critical safety net service that needs increased resources.

Overall, the President proposes to cut existing HRSA programs by \$838 million, or over 12 percent, at a time when the numbers of uninsured individuals and families is rising and they are turning to federally funded programs for assistance and care.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

The Coalition for Health Funding recommends an overall funding level of \$3.5 billion for SAMHSA in fiscal year 2006. This amount is \$262 million, or 8 percent, more than the fiscal year 2005 funding level, and \$316 million more than the President's budget request, which includes a 54 million cut for SAMHSA programs.

The Coalition is pleased that, for the third year, the President requests an increase for substance abuse treatment, although substantially less at \$25 million than the last two years. However, once again, the increase comes at the expense of prevention which is slated for a \$15 million cut. Substance abuse is a significant and very costly national problem involving an estimated 21.6 million Americans—over 9 percent of the population—and needs investment in both treatment and prevention. SAMHSA has developed a set of evidence-based model prevention programs that community-based organizations need help in implementing. On the treatment side, of the 1 million Americans who express a need for substance abuse treatment in a regularly conducted household survey, 273,000 (26 percent) report they made an effort to obtain treatment, but were unable to do so. Clearly, a stronger investment—which the President has championed—needs to be made to provide treatment when it is sought.

The Coalition is very disappointed that the President's budget cuts mental health program funding at SAMHSA by \$64 million. There is no additional investment made in response to the findings and recommendations of the President's New Freedom Commission on Mental Health, the first such commission in over 25 years. The Commission advised the President that youth with mental and emotional problems face enormous access barriers and that an alarming 80 percent of youth in juvenile detention facilities have mental disorders. Yet the President's budget cuts the Jail Diversion program in half and the successful Youth Violence Prevention program by \$27 million. These cuts should not be accepted in the aftermath of the Red Lake school massacre in Minnesota.

The Coalition sincerely appreciates this opportunity to provide its fiscal year 2006 funding recommendations to the Subcommittee for the agencies and programs of the U.S. Public Health Service. The Coalition's recommendations for all of the public health agencies are provided in the accompanying table. The Coalition, and its member organizations, look forward to working with the Subcommittee in the weeks ahead to improve the health of all Americans.

#### COALITION FOR HEALTH FUNDING 2006 RECOMMENDATIONS

[Dollars in millions]

Agency	Fiscal year 2005	President's request fiscal year 2006	President's dollar request fiscal year 2006—fiscal year 2005	Percent President's request fiscal year 2006—fiscal year 2005	CHF recommendation fiscal year 2006	Dollar difference CHF recommendation fiscal year 2006—fiscal year 2005	Percent difference CHF recommendation fiscal year 2006—fiscal year 2005
NIH <sup>1</sup>	\$28,444	\$28,590	+\$146	+0.5	\$30,150	+\$1,706	+6.0
CDC <sup>2</sup>	8,034	7,543	-491	-6.1	8,650	+616	+7.7
HRSA <sup>1</sup>	6,809	5,972	-837	-12.3	7,500	+691	+10.0
SAMHSA <sup>1</sup>	3,269	3,215	-54	-1.6	3,531	+262	+8.0
AHRQ	319	319	.....	.....	443	+124	+38.0
FDA <sup>1</sup>	1,450	1,500	+50	+3.4	1,566	+116	+8.0
IHS <sup>1</sup>	2,985	3,048	+63	+2.1	3,218	+232	+7.8

## COALITION FOR HEALTH FUNDING 2006 RECOMMENDATIONS—Continued

[Dollars in millions]

Agency	Fiscal year 2005	President's request fiscal year 2006	President's dollar request fiscal year 2006—fiscal year 2005	Percent President's request fiscal year 2006—fiscal year 2005	CHF recommendation fiscal year 2006	Dollar difference CHF recommendation fiscal year 2006—fiscal year 2005	Percent difference CHF recommendation fiscal year 2006—fiscal year 2005
Totals .....	51,310	50,187	-1,123	-2.2	55,058	+3,747	+6.8

<sup>1</sup> Reflects Total Budget Authority.<sup>2</sup> Reflects Total Program Level.

## PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA

## SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

(1) A 6 percent increase for the National Institute of Diabetes, and Digestive and Kidney Diseases, and the National Institute of Allergy and Infectious Diseases and a corresponding increase for Inflammatory Bowel Disease Research at both institutes.

(2) \$1.5 Million for the National Inflammatory Bowel Disease Epidemiological Program at the Centers for Disease Control and Prevention.

(3) \$25 million for CDC's National Colorectal Cancer Screening Awareness Program.

## INTRODUCTION

Mr. Chairman, thank you very much for the opportunity to present the views of the Crohn's and Colitis Foundation of America (CCFA). I am Rodger DeRose, President and Chief Executive Officer of CCFA and I am honored to represent the people of this country who suffer from Crohn's disease and ulcerative colitis.

Crohn's disease and ulcerative colitis are chronic disorders of the gastrointestinal tract which represent a leading cause of morbidity from digestive illness. Because they behave similarly, these disorders are collectively known as inflammatory bowel disease (IBD). IBD can cause severe diarrhea, abdominal pain, fever, and rectal bleeding. Moreover, IBD related complications can include; arthritis, osteoporosis, anemia, liver disease, and colon cancer. Crohn's disease and ulcerative colitis are not fatal, but they can be devastating. We do not know their cause, and there is no medical cure.

CCFA is a non-profit, voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis. Throughout its 38-year history, CCFA has sponsored basic and clinical research of the highest quality. The Foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides support services to assist people in coping with these chronic intestinal diseases.

We are extremely grateful Mr. Chairman, for your support of IBD related programs in the fiscal year 2005 Labor-HHS bill. Your leadership is making a tremendous difference in the lives of the patients and families that we serve.

## RECOMMENDATIONS FOR FISCAL YEAR 2005

*(1) National Institutes of Health*

CCFA has developed highly successful research partnerships with the NIH. We are particularly proud of our longstanding collaborations with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) which sponsors the majority of IBD research at NIH, and the National Institute of Allergy and Infectious Diseases (NIAID).

In 2001, a team of investigators from NIDDK, CCFA, and the private industry announced that they had identified the first gene for Crohn's disease. This historic breakthrough opens up exciting new pathways of research focused on the development of improved therapies for Crohn's disease patients. The research which led to the discovery of the gene would not have been possible without the strong support that Congress has provided to the NIDDK in recent years.

Some of the most promising IBD research supported by the NIH has focused on translating findings from studies conducted on animal models to humans with IBD. These animal models have enabled researchers to form the current hypothesis that

Crohn's disease and ulcerative colitis are caused by a malfunctioning immune system, wherein components of the patient's immune system overreact to normal intestinal bacteria. We know that people are susceptible to this malfunction because of their genetic makeup but further research is necessary to determine which bacteria are responsible, how these bacteria interact with the intestine's immune system, and which immune system components are involved.

Mr. Chairman, IBD patients and their families are pinning their hopes for a better life on medical advancements made through NIH sponsored research. For this reason, CCFA recommends a 6 percent increase for NIDDK, NIAID, and NIH overall in fiscal year 2006. Moreover, CCFA encourages the subcommittee to increase IBD research funding within NIDDK and NIAID at the same rate as NIH overall.

*(2) Centers for Disease Control and Prevention*

*IBD Epidemiology Program*

Mr. Chairman, CCFA estimates that "up to one million" people in the United States suffer from IBD. Unfortunately, we do not have an exact number; due to the complicated nature of those diseases, patients may remain undiagnosed or misdiagnosed for several years.

One of CCFA's main public policy objectives has been the establishment of a nationwide IBD epidemiological program in partnership with the Centers for Disease Control and Prevention.

We are extremely grateful for your leadership in providing \$750,000 within CDC's National Center for Chronic Disease Prevention and Health Promotion for this much needed project in the fiscal year 2005 Labor-HHS bill. This program, which was initially funded through private support provided to CDC from our Foundation, will further our understanding of both the prevalence of IBD in the United States, and the demographic characteristics of this unique patient population.

The cultivation of patient demographic information is critically important to our biomedical research efforts given that environmental factors are believed to play a major role in the development and progression of IBD. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

CDC, in partnership with our scientific experts, are making significant progress on the epidemiology study. Phase one of the study has been completed and is being prepared for publication this summer. Plans are currently underway to expand the study to other key areas of investigation. For fiscal year 2006, CCFA respectfully requests an appropriation of \$1.5 million for the continuation of the epidemiology study within the National Center for Chronic Disease Prevention and Health Promotion.

*Colorectal Cancer Prevention*

Finally Mr. Chairman, in addition to coping with either Crohn's disease or ulcerative colitis, many IBD patients are at high risk for developing colorectal cancer. As you may know, colorectal cancer is the third most commonly diagnosed cancer for both men and women in the United States and the second leading cause of cancer-related deaths. Because people who have suffered from IBD for more than 8 years are susceptible to this disease, CCFA has a long history of actively promoting the benefits of colorectal cancer screening.

Although colorectal cancer is almost entirely curable when detected early, studies have shown a tremendous need to: (1) inform the public about the availability and advisability of screening and (2) educate healthcare providers about screening guidelines. CDC's National Colorectal Cancer Roundtable is actively working to address these challenges by partnering with organizations like CCFA to implement a national public awareness campaign emphasizing the importance of screening and early detection. Moreover, CDC's "Screen for Life" awareness campaign is actively promoting the importance of colorectal cancer screening via television, radio and print media. CCFA encourages the subcommittee to provide CDC with \$25 million in fiscal year 2006 to support its colorectal cancer prevention activities.

Once again, Mr. Chairman, thank you for the opportunity to present the views of Crohn's and Colitis Foundation of America. We look forward to continuing to work with you on these important issues.

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PREPARED STATEMENT OF THE DEVELOPMENTAL DISABILITIES RESEARCH CENTERS  
ASSOCIATION

Mr. Chairman, on behalf of the Developmental Disabilities Research Centers Association (DDRCA), I thank you for this opportunity to share with you and your

Committee, some of the exciting achievements that are happening in the world of developmental disabilities and mental retardation research. I am Steven F. Warren, Director of the Kansas Mental Retardation and Developmental Disabilities Research Center at the University of Kansas and Chair of the Developmental Disabilities Research Centers Association. First, let me tell you a little about our Association.

The DDRCA is a national resource that grew out of Congress' mandate in 1963 to establish "centers of excellence" in mental retardation and developmental disabilities research. With funding from the National Institute of Child Health and Human Development, our 20 member Centers represent the nation's first sustained and integrated effort to prevent and treat disabilities through biomedical and behavioral research. Today, we are the world's largest concentration of scientific expertise in the fields of intellectual and developmental disabilities. We believe that our Centers, and the network they form, substantially foster communication, innovation, and excellence in research. We work collaboratively on a number of research projects, and together with the Society for Developmental Pediatrics, produce the quarterly publication, "Mental Retardation and Developmental Disabilities Research Reviews." Each edition highlights the exciting new research on a developmental disability.

Our research Centers are located within premier research intensive universities and often are affiliated with major medical centers which provide academic, scientific and often clinical expertise as well as institutional support. Collectively, our work represents a multidisciplinary, vigorous, and innovative research program directed at understanding, treating and eventually substantially reducing the incidence of developmental disabilities including mental retardation. Additionally, our investigators are engaged in a very important mission—training the next generation of scientific investigators and clinicians in this area of great importance to America's children and families.

Although a significant portion of the research portfolios at the Centers consists of fundamental studies that are directed at understanding the biological and behavioral processes in animal models and human subjects, each Center directs considerable attention toward seeking solutions to practical issues and problems. Our connection to the University Centers for Excellence in Developmental Disabilities (UCEDDs) is critical in relating our research to practice. The scope of the research conducted at the Centers encompasses every known major dimension of mental retardation.

Over the last three decades there has been a huge payoff in the federal investment in the Developmental Disabilities Research Centers. Many disorders that cause intellectual disabilities can be prevented or treated to improve developmental outcomes. The Centers' scientific achievements have helped improve quality of life for individuals and families affected by disabilities. Among the most exciting aspects of this research is the work that is getting close to understanding the fundamental biological mechanisms that contribute to many of these disabilities with development of interventional strategies. I am pleased to share some examples with you.

*Brain Imaging Technologies.*—We are all familiar now with magnetic resonance imaging or MRI technology. Many of us have experienced this technology as it has been used increasingly over the past 12 years as a way for physicians to see increasingly higher resolution images of the brain as well as to measure local brain activity and metabolism. Functional magnetic resonance imaging (fMRI) provides a way to examine brain processing during complex behavior such as thinking and reading. Signal abnormalities associated with several diseases and syndromes that dramatically affect behavior and cognition have been characterized, including fragile X syndrome, Rett syndrome, Turner syndrome, Tourette syndrome and neurofibromatosis.

At the Kennedy Krieger Institute (KKI), the Mental Retardation Developmental Disability Research Center at Johns Hopkins University in Baltimore, MD., they have utilized functional brain imaging to establish a link between the lowering of vocabulary in children with neurofibromatosis (NF-1) and enlargement of the cerebrum. More detailed imaging techniques called spectroscopy imaging was then used to locate the specific regions of the brain that linked with the loss of vocabulary and cognitive functioning. A similar type of cerebral enlargement was discovered in autistic children by investigators at the University of North Carolina Mental Retardation Research Center. Understanding the processes of increased rates of brain growth will help lead researchers to finding preventive measures to stop the results of loss of IQ or vocabulary in these children.

*Brain Growth and Development.*—We are aware that the brain develops complex circuitry both under the guidance of internal genetic cues and in response to the brain's interaction with the outside world through activity and experiences ranging from simple sensation to complex behavioral interaction between the child and others. Developmental problems result when genetic errors occur either through the expression of an inherited copy of a deleterious gene, through chromosomal abnormali-

ties or when environmental factors may modify the expression pattern of genes. In addition, the developing brain is particularly sensitive to exposure to environmental toxins such as alcohol or lead. These insights into brain development provide a foundation for prevention through biomedical and behavioral intervention. During the initial formation of the brain in the fetus and in early postnatal life of the child, new nerve cells are forming and each one must extend fine processes that migrate through the brain to their correct targets and then they must establish the right connections (synapses) and assemble those synapses into the functional networks of communication sites whereby each cell in our brain talks to the next and communicates with the outside world. Many developmental disorders such as neonatal seizures that occur due to the mislocation of the brain's nerve cells to abnormal sites (heterotopia) or due to the failure of synapses to form their proper structural arrangements through a refinement process such as fragile X syndrome, result from the failure of synaptic connections to properly form in the developing brain. In order to understand a brain that has developed abnormally, leading to mental retardation or other developmental disabilities, it is necessary to understand the normal processes that guide this development.

At the Civitan International Research Center and Mental Retardation Research Center at the University of Alabama at Birmingham, investigators have discovered a new particle that forms in nerve cells during their earliest stages of development that brings together all of the necessary molecules to allow formation of a newborn synapse. At the University of North Carolina Mental Retardation research Center, investigators have determined the chemical pathways for regulating the migration of newborn neurons' in the developing brain. Several groups of investigators have determined how the fragile X gene product protein plays a role in the normal refinement of synapses in the normal developing brain and the consequences of interference with this protein's production in humans with fragile X syndrome and animal models. The functional consequences of this abnormal development include abnormally strong responses to sensory stimuli as determined by investigators from the University of Colorado Mental Retardation/Developmental Disabilities Research Center. This work is providing the scaffolding for designing strategies for specifically targeting early molecular events in the formation of the brain that may go awry in order to prevent or correct disorders of synaptic development.

*Language and Communication.*—Language and communication are key aspects in a human's ability to function in society. Researchers now know that the first 48 months of life is an optimal period in brain development for language acquisition and therefore is a period when intervention can have the greatest impact on a child's overall communication ability. With this in mind, researchers are asking the question, "Are there linkages between language impairments and various developmental disabilities or syndromes?"

The Kansas Mental Retardation Developmental Disability Research Center asked a more specific question. "Do some children with Specific Language Impairment (SLI) and children with some forms of autism share a genetic relationship?" Research conducted in Kansas suggests that this may be the case. Children with SLI often show a particular grammar deficit, an inability to accurately mark tense in the sentences they produce. Research reveals that this deficit may even be inherited. Collaboration with researchers at the Shriver Center Mental Retardation Research Center in Massachusetts shows that children with autism were also found to exhibit this tense-marking deficit. On the other hand, collaboration with researchers at the University of Louisville in Kentucky demonstrated that children with William's syndrome do not show this deficit. Researchers at the University of Texas Health Sciences Center in Houston have found that in dyslexic children, remedial training is helpful and that this training results in changes in patterns of brain activation similar to those seen in proficient readers. This work will ultimately lead to better identification and effective interventions to limit the disability caused by these disorders.

*Early Identification and Intervention.*—Researchers are learning that early intervention as well as early identification of a problem can lead to dramatically different life outcomes for a child and his/her family. At the Civitan International Research Center at the University of Alabama at Birmingham MRRC, investigators have begun using a dramatic new training regimen in children with cerebral palsy. This therapy termed pediatric constraint induced intensive therapy (PCIIT) involves limiting the child's use of the most affected limb with intensive training of the other limb over several weeks. Similar to its beneficial effect in adults who have experienced stroke, this therapy results in improved use of the trained limb. Investigators will evaluate whether this therapy in children results in similar massive functional reorganization of the brain as occurs in adult stroke patients. The Mental Retardation Research Center at the University of Washington in Seattle, has devoted a

great deal of its research to early intervention studies. Behavioral scientists there have enhanced the ability to recognize autism in the first two years of life. The new neuropsychological and brain-imaging findings in autism indicate that the severity observed reflects different underlying neurobiological bases that can be readily identified; these findings may now help focus early intervention programs. Other investigators in this field have identified and characterized the unique peer interaction deficits experienced by a vast majority of young children with developmental disabilities. Researchers who study early intervention developed a methodology to evaluate parent/child interactions using feeding and teaching scales, a methodology that has been extremely useful in identifying problem areas for children who are at risk. Researchers at the Waisman Mental Retardation Research Center at the University of Wisconsin in Madison, Wisconsin, have developed a method using gene sequencing technology to determine if children suffer from a rare but progressive disorder in children that has profound effects on cognitive development, Alexander's disease. By comparing their results with gene analysis to those obtained with more conventional clinical and fMRI analysis, these investigators have determined that a more definitive early diagnosis can be made with modern genetic tests. This work is contributing to our ability to identify and treat developmental disorders earlier and more effectively.

*Genetics.*—About 40 to 60 percent of known causes of moderate to severe mental retardation have genetic origins. Researchers are working on DNA probes designed to identify specific genes, to distinguish abnormal genes, and to identify genes responsible for specific disabilities such as Duchenne muscular dystrophy. Investigators have succeeded in mapping genes responsible for disabilities caused by enzyme defects, storage diseases, and other inborn errors of metabolism. Researchers have identified genes located on chromosome 21 known to be associated with Down syndrome and Alzheimer's disease. Researchers at the Baylor College of Medicine Mental Retardation Research Center in Houston, TX have discovered an X chromosome-linked gene that is associated with a large percentage of patients with Rett syndrome a neurodevelopmental disorder that primarily affects infant girls (the leading cause of mental retardation in girls) causing loss of speech, purposeful hand movements, seizures, ataxia and apraxia, episodes of apnea (breath holding) and sometimes death. Utilizing a mouse model, investigators at Baylor are investigating which genes are silenced in Rett and the underlying biological consequences of this process on neural development and synaptic function. Mutations in the same gene that causes Rett syndrome can also lead to other developmental disorders including autism and mild mental retardation as well as bipolar disorders and schizophrenia. Researchers at the University of Kansas Institute for Child Development have determined that children with Prader-Willi syndrome (the most common known form of genetically caused obesity) who have a life threatening eating disorder also display obsessive compulsive disorder (OCD). Both of these disorders may be caused by a gene defect on chromosome 15 causing lack of inhibition of brain centers involved with OCD and other brain centers that regulate growth hormone. This work is giving investigators a rich source of animal models to precisely identify the mechanisms whereby genetic defects cause developmental disorders and is providing the potential therapeutic targets for correcting the consequences of these disorders in humans.

While we have come a long way over the last 30 years, we still have far to go. With knowledge generated by the DDRCs, we will be able to:

- Use brain imaging and genetic methods to better understand the causes of specific disabilities and design strategies for treatment.
- Develop new therapies to prevent or reverse some of the symptoms of specific disabilities.
- Better understand the process of brain cell development and enrichment through studying the interplay of the brain's own chemistry with a child's experiences.
- Prevent many types of developmental disabilities by treating maternal infections and viruses transmitted to their infants.
- Capitalize on the brain's natural "plasticity" to optimize brain development in children born with developmental disabilities through early intervention or by extending the period of brain development.
- Design learning environments so all children have improved academic outcomes, including those with learning and intellectual disabilities.
- Determine which child with a disability will respond best to which speech or communication learning approach.
- Develop culturally competent psychological and medical assessment and treatment procedures for children born into minority families.

- Prevent and treat atypical behavior among children and adults with disabilities who are especially prone to such difficulties, such as children with autism, fragile X syndrome, or Rett's syndrome.
- Assist families in preparing their adult sons and daughters with disabilities for successful lives of their own and prepare older people with developmental disabilities for coping with the normal process of aging.

To address our concerns, we respectfully ask the Committee to increase NIH funding to \$30.067 billion for fiscal year 2006. Additionally, we ask that you increase funding for NICHD to the level of \$1.34 billion for fiscal year 2006.

Again, I thank you Mr. Chairman for taking time to learn about the DDRC network and the scope of work being conducted at these Centers across the nation. Together we believe that we are making strong headway in finding solutions to the many diseases and disabilities, which affect the children and adults of our society. With your continued support, and that of the Subcommittee, we can make great strides into the future.

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PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide increased funding for the National Institutes of Health (NIH) at 6 percent for fiscal year 2006. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases by 6 percent.
- Continue focus on digestive disease research and education at NIH, including the areas of Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, Celiac Disease, and Hemochromatosis.
- \$30 million for the Centers for Disease Control and Prevention's (CDC) Hepatitis Prevention and Control activities.
- \$25 million for the Center for Disease Control and Prevention's (CDC) Colorectal Cancer Screening and Prevention Program.

Chairman Specter, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 27 professional societies and patient organizations concerned with the many diseases of the digestive tract. The Coalition has as its goal a desire to improve the health and the quality of life of the millions of Americans suffering from both acute and chronic digestive diseases.

The DDNC promotes a strong federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, Celiac Disease, and Hemochromatosis.

Mr. Chairman, the social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). With respect to the coming fiscal year the DDNC is recommending an increase of 6 percent (\$1.7 billion) to \$30.1 billion for the National Institutes of Health (NIH) and all of its Institutes.

Specifically the DDNC recommends:

- \$5.1 billion for the National Cancer Institute (NCI).
- \$1.9 million for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).
- \$4.66 billion for the National Institute of Allergy and Infectious Diseases (NIAID).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies.

With the completed and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.



## INFLAMMATORY BOWEL DISEASE

In the United States today about 1 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. Crohn's disease and ulcerative colitis are not usually fatal but can be devastating. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. In 1998, the FDA approved the first drug ever specifically to fight Crohn's disease, a remarkable milestone. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium will continue its work in IBD research. Given the recent advancements in treatment for these diseases and the increased risk that IBD patients have for developing colorectal cancer, the DDNC strongly believes that generating improved epidemiological information on the IBD population is essential if we are to provide patients with the best possible care. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to initiate a nationwide IBD surveillance and epidemiological program in fiscal year 2006.

## HEPATITIS C: A LOOMING THREAT TO HEALTH

It is estimated that there are over 4 million Americans who have been infected with Hepatitis C of which over 2.7 million remain chronically infected. About 10,000 die each year and the Centers for Disease Control and Prevention (CDC) estimates that the death rate will more than triple by 2010 unless there is additional research, education, and more effective treatments and public health interventions. Hepatitis C infection is the largest single cause for liver transplantation and one of the principal causes of liver cancer and cirrhosis. There is currently no vaccine for hepatitis C, and treatment has limited success, making the infection among the most costly diseases in terms of health care costs, lost wages, and reduced productivity. Patients who are older at the time of infection, those who continually ingest alcohol, and those co-infected with HIV demonstrate accelerated progression to more advanced liver disease.

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of state health departments, particularly to enhance resources available to the hepatitis C state coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health, education, communication and training materials about prevention, diagnosis and medical management for hepatitis A, B, and C.

The DDNC supports \$30 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

## COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally. Although colorectal cancer is preventable and curable when polyps are detected early, a General Accounting Office report issued in March 2000 documented that less than 10 percent of Medicare beneficiaries have been screened for colorectal cancer. This report revealed a tremendous need to inform the public about the availability of screening and educate health care providers about colorectal cancer screening guidelines. In 2003, the New York City Department of Health has recommended colonoscopy for everyone over age 50 to prevent colorectal cancer.

The DDNC recommends a funding level of \$25 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports en-

hanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

#### PANCREATIC CANCER

In 2002, an estimated 28,300 people in the United States were found to have pancreatic cancer and approximately 28,200 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 2 out of 10 patients will live 1 year after the cancer is found and only a very few will survive after 5 years. Although we do not know exactly what causes pancreatic cancer, several risk factors linked to the disease have been identified:

- (1) Age: Most people are over 60 years old when the cancer is found;
- (2) Sex: Men have pancreatic cancer more often than women
- (3) Race: African Americans are more likely to develop pancreatic cancer than are white or Asian Americans
- (4) Smoking
- (5) Diet: Increased red meats and fats
- (6) Diabetes

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

#### IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable and fickle disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The unpredictable bowel symptoms may make it next to impossible to leave your home. It is difficult to ease the pain than may repeatedly occur periodically throughout the day. A patient can become reluctant to eat for fear that just eating a meal will trigger symptoms all over again. IBS has a broad and significant impact on a person's quality of life. It strikes individuals from all walks of life and results in a significant toll of human suffering and disability.

While there is much we don't understand about the causes and treatment of IBS, we do know that IBS is a chronic complex of systems affecting as many as 1 in 5 adults. In addition:

- (1) It is reported more by women than men
- (2) It is the most common gastrointestinal diagnosis among gastroenterology practices in the United States
- (3) It is a leading cause of worker absenteeism in the United States
- (4) It costs the U.S. Health Care System an estimated \$8 billion annually.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders.

#### CELIAC DISEASE

Celiac Disease is a life-long condition in which the body develops an allergy to gluten, a protein found in wheat, barley, and rye, which can result in damage to the small intestine. Celiac disease affects as many as two million Americans. Onset of the disease can occur at any age. The common symptoms of Celiac Disease include fatigue, anemia, chronic diarrhea or constipation, weight loss, and bone pain. The only treatment for celiac disease is strict adherence to a gluten-free diet. Undiagnosed and untreated celiac disease can lead to other disorders such as

osteoporosis, infertility, neurological conditions, and in rare cases cancer. Persons with Celiac Disease often have other associated autoimmune disorders as well.

#### DIGESTIVE DISEASE COMMISSION

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the United States, identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases. The Commission's subsequent report in 1979 laid the groundwork for significant progress in the area of digestive disease research.

After almost 25 years, however, the burden of digestive diseases among the U.S. population remains substantial. The DDNC, therefore, calls upon Congress to establish a contemporary Digestive Diseases Commission to address the numerous digestive disorders that remain in today's diverse population.

The Commission should be comprised of the nation's leading non-governmental scientists, physicians, and health professionals, including practicing clinical gastroenterologists and researchers studying in the field of digestive diseases. Congress should charge the Commission with the following:

(1) Conducting a comprehensive study of the present state of knowledge of the incidence, duration, and morbidity of, and mortality rates resulting from, digestive diseases and of the social and economic impact of such diseases;

(2) Evaluating the public and private facilities and resources (including trained personnel and research activities) for the diagnosis, prevention, and treatment of, and research in, such diseases; and

(3) Identifying programs (including biological, behavioral, nutritional, environmental, and social programs) in which, and the means by which, improvement in the management of digestive diseases can be accomplished.

The Commission also should develop and recommend a long-range plan for the use and organization of national resources to effectively deal with digestive diseases, related nutritional disorders and basic biological processes and mechanisms in nutrition which are related to digestive diseases. Finally, the Commission should recommend for each of the Institutes of the NIH whose activities are to be affected by the long-range plan estimates of the expenditures needed to carry out each Institute's part of the overall program.

#### CONCLUSION

The DDNC understand the challenging budgetary constraints and times we live in that is subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health.

Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

#### DIGESTIVE DISEASE NATIONAL COALITION

The Digestive Disease National Coalition was founded 25 years ago. Since its inception, the goals of the coalition have remained the same: to work cooperatively to improve access to and the quality of digestive disease health care in order to promote the best possible medical outcome and quality of life for current and future patients with digestive diseases.

#### PREPARED STATEMENT OF THE DORIS DAY ANIMAL LEAGUE

The Doris Day Animal League represents 350,000 members and supporters nationwide who support a strong commitment by the federal government to research, development, standardization, validation and acceptance of non-animal and other alternative test methods. We are also submitting our testimony on behalf of People for the Ethical Treatment of Animals and the Animal Welfare Institute and their 800,000 members and supporters. Thank you for the opportunity to present testimony relevant to the fiscal year 2006 budget request for the National Institute of Environmental Health Sciences for the Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for the Interagency Coordinating Committee for the Validation of Alternative Test Methods (ICCVAM) activities for fiscal year 2006.

In 2000, the passage of the ICCVAM Authorization Act into Public Law 106-545, created a new paradigm for the field of toxicology. It requires federal regulatory agencies to ensure that new and revised animal and alternative test methods be scientifically validated prior to recommending or requiring use by industry. An internationally agreed upon definition of validation is supported by the 15 federal regulatory and research agencies that compose the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM), including the EPA. The definition is: "the process by which the reliability and relevance of a procedure are established for a specific use."

#### FUNCTION OF THE ICCVAM

The ICCVAM performs an invaluable function for regulatory agencies, industry, public health and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulated the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test methods as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulator burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test methods. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

#### HISTORY OF ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97-3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report, and subsequent revisions, has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, several methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. In addition, the ICCVAM is working to streamline assessment of methods from the European Union (EU) that have already been validated for use within the EU. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

#### REQUEST FOR APPROPRIATIONS

On December 19, 2000, the "ICCVAM Authorization Act" which makes the entity a permanent standing committee, was signed into Public Law No. 106-545. For several years, the NIEHS has provided between \$1 and \$2.6 million per fiscal year to the NICEATM for ICCVAM's activities. In order to ensure that federal regulatory agencies and their stakeholders benefit from the work of the ICCVAM, it is important to fund it at an appropriate level. I respectfully urge the Subcommittee to support increasing appropriations from within NIEHS' existing budget request for NICEATM for ICCVAM's activities to \$3.6 million for fiscal year 2006. This appro-

priation request includes all FTEs, funding for independent peer review assessment of test methods and meetings of the ICCVAM and other activities as deemed appropriate by the Director of the NIEHS.

REQUEST FOR COMMITTEE REPORT LANGUAGE

The NIEHS should support the NICEATM/ICCVAM in creating a five-year roadmap for assertively setting goals to prioritize ending the use of antiquated animal tests for specific endpoints. While the stream of methods forwarded to the ICCVAM for assessment has remained relatively steady, it is imperative that the ICCVAM take a more proactive role in isolating areas where new methods development is on the verge of replacing animal tests. These areas should form a collective call by the federal agencies that compose ICCVAM to fund any necessary additional research, development, validation and validation assessment that is required to eliminate the animal methods. We also strongly urge the NICEATM/ICCVAM to closely coordinate research, development and validation efforts with its European counterpart, the European Centre for the Validation of Alternative Methods (ECVAM) to ensure the best use of available funds and sound science. This coordination should also reflect a willingness by the federal agencies comprising ICCVAM to more readily accept validated test methods proposed by the ECVAM to ensure industry has a uniform approach to worldwide chemical regulation.

We also respectfully request the Subcommittee consider the following report language for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

“In order for the Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) to carry out its responsibilities under the ICCVAM Authorization Act of 2000, the Committee strongly urges the National Institute of Environmental Health Sciences (NIEHS) to strengthen the resources provided to ICCVAM for methods validation reviews in fiscal year 2006. ICCVAM and NIEHS activities must include up-front validation study design, execution and review to ensure that new and revised test methods, non-animal test methods, and alternative test methods (such as QSARs, mechanistic screens, high throughput assays, and toxicogenomics) are deemed scientifically valid before they are recommended or adopted for use by federal agencies or used in implementing the National Toxicology Program’s (NTP) Road Map and Vision for NTP’s toxicology program in the 21st century.”

Thank you for the opportunity to submit this request on behalf of our more than 1.1 million members and supporters.

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

Provide increased funding for the National Institute of Health at 6 percent for fiscal year 2006. Increase funding for the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Deafness and other Communication Disorders (NIDCD), and the National Eye Institute (NEI) by 6 percent.

FISCAL YEAR 2006 RECOMMENDATIONS FOR NIH

- NIH: \$30.1 billion
- NINDS: \$1.63 billion
- NEI: \$709 million
- NIDCD: \$417.6 million

Continue to accelerate funding for intramural and extramural dystonia research at NINDS.

Provide funding for NINDS to conduct an epidemiological study and to increase public and professional awareness of dystonia.

Continue to expand NIDCD’s intramural and extramural research on dysphonia. Continue to expand NEI’s intramural and extramural research on dystonia.

Chairman Specter, thank you for the opportunity to submit testimony to the Subcommittee on behalf of the Dystonia Medical Research Foundation (DMRF). Dystonia has affected the lives of many Americans and we are thankful to be able to provide for you our recommendations for fiscal year 2006 federal funding with regards to dystonia research.

Dystonia is a neurological disorder characterized by powerful and painful involuntary muscle spasms that causes the body to twist, repetitive jerking movements, and sustained postural deformities. There are several different variations of dystonia, in-

cluding: focal dystonias which affect specific parts of the body, such as the arms, legs, neck, jaw, eyes, vocal cords; and generalized dystonia, affecting many parts of the body at the same time. Some forms of dystonia are genetic and others are caused by injury or illness. Dystonia does not affect a person's consciousness or intellect, but is a chronic and progressive movement disorder for which, at this time, there is no known cure. The Foundation estimates that some form of dystonia affects about 300,000 people in North America.

Even though there is no known cure for dystonia, there are treatments to lessen the severity of the symptoms of the disease such as oral medications, botulinum toxin injections, and in some cases surgery. Having increased access to these medical therapies is becoming an increasing larger issue for the community as a whole.

In the past few decades, dystonia researchers have made several exciting scientific advancements and have been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures, directly benefiting those affected. Genetics, in particular, is opening up a new understanding into the cause and pathophysiology of the disorder. Thus far, 13 dystonia related genes or gene loci have been identified. In 1997, the DYT1 gene for childhood early onset dystonia was identified, and we now have a genetic test available to confirm diagnosis of this particular type of dystonia. Most recently, in 2002, the gene for myoclonus dystonia was identified. However the community is still without a diagnostic test and misdiagnosis still occurs too frequently.

Deep brain stimulation is a surgical procedure that was originally developed to treat Parkinson's disease but is now being applied to severe cases of dystonia. Deep brain stimulation has drastically improved the lives of dozens of dystonia patients during the past few years. Individuals who were previously bedridden by muscle spasms and pain are able to walk without assistance, to speak clearly, to dress themselves, to get a driver's license, to date, to travel, and to live the life of an able-bodied person. Deep brain stimulation is currently used primarily to treat severe cases of generalized dystonia but its promising role in treating focal dystonias is being explored. Surgical interventions are a crucial and active area of dystonia research.

#### RESEARCH, AWARENESS, AND SUPPORT

Now is an exciting time to be involved in dystonia research and awareness. Researchers are becoming more interested in movement disorders and dystonia at the National Institutes of Health (NIH), and research is yielding promising clues for better understanding and management of this disorder.

One way the Dystonia Medical Research Foundation has advocated for more research on dystonia, is by funding "seed" grants to researchers. Thus far, the Dystonia Foundation has funded over 370 grants, and 5 fellowships, totaling more than \$18 million. Due to our advocacy there are a growing number of talented researchers dedicated to understanding the biochemistry of dystonia, genetic causes, new therapeutics and the necessity of an epidemiology study.

Another primary goal of the Dystonia Foundation is education of both lay and medical audiences. The Foundation conducts regular medical workshops and patient symposiums to present, discuss, and disseminate comprehensive medical and research data on dystonia. In January 2001, NINDS co-sponsored a genetics and animal models meeting, designed to involve not only prominent researchers but inviting junior investigators to participate in the discussions. Additionally, in October 1996, the NIH was one of our co-sponsors for an international medical symposium, which featured 60 papers on dystonia and 125 representatives from 24 countries. The Young Investigators Award Program and the Residency Program are in place to entice emerging medical professionals into the field of dystonia research and cultivate future dystonia experts.

Since 1995, over 3,000 educational medical videos have been distributed to hospitals, medical and nursing schools, and at medical conventions. In addition to medical and coping publications, we have a children's video to educate families and increase public awareness of this devastating disorder in younger populations. Media awareness is conducted throughout the year, and especially during Dystonia Awareness Week, observed nationwide from October 14 through 20. Local volunteers have been successful in securing news stories on dystonia in local venues as well as national media shows such as Good Morning America, The Oprah Winfrey Show, and Maury Povich. Through his friendship with the mother of a dystonia patient, screen star Kirk Cameron has taken an interest in promoting dystonia awareness, and the Dystonia Foundation is in the process of investigating the possibility of a public service announcement and several appearances at fundraising events.

The Dystonia Foundation has over 200 chapters, support groups, and area contacts across North America. In addition, there are 15 international chairpersons whose mission is to promote awareness, children's advocacy, development, extension, Internet resources, leadership, medical education, and symposiums. Furthermore, patient symposiums are held internationally and regionally to provide the latest medical and coping information to dystonia patients and others interested in the disorder.

#### DYSTONIA AND THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation recommends an increase to \$30.1 billion or 6 percent for NIH overall, and a 6 percent increase for NINDS, and NIDCD. We at DMRF request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We also urge the Subcommittee to recommend that NINDS provide the necessary funding for additional extramural research and a large-scale dystonia epidemiological study. There is also an imperative need for NINDS to increase its efforts to educate the public and medical community about dystonia through co-sponsorship of workshops and seminars. We also encourage the Subcommittee to support NIDCD in its efforts to revamp its strategic planning process by implementing a Strategic Planning Group which will help NIDCD as they: consider applications for high program priority; develop program announcements and requests for applications; and develop new research areas in the Intramural Research Program.

The National Institute of Neurological Disorders and Stroke (NINDS) awarded seven grants in fiscal year 2004 for dystonia research in response to the Program Announcement, "Studies into the Causes and Mechanisms of Dystonia" (August 2002). In addition, the National Institute on Deafness and Other Communication Disorders (NIDCD) funded an eighth study on brainstem systems and their role in spasmodic dysphonia.

DMRF also supports the many intramural researchers studying dystonia. Research includes: exploring improved clinical rating scales for dystonia, elevations of sensory motor training, utilizing botox as a possible treatment for focal hand dystonia, characterization of abnormalities in sensory regions of the brain, treatments for spasmodic dysphonia, anatomy imaging of the affect of dystonia on brain activity, and exploring the link between laryngitis and spasmodic dysphonia. The public awareness impact of pianist Leon Fleisher's treatment through the NIH intramural research program has had a tremendously positive impact.

NINDS continues to work with dystonia research and voluntary disease groups in the community. In January 2004, NINDS sponsored a workshop at Emory University on the Pathology of Dystonia, and in October 2004, NINDS participated in a workshop to develop a strategic plan for a series of studies on the epidemiology of dystonia. NINDS also provided funding in September 2004 to a researcher affiliated with the Dystonia Medical Research Foundation (DMRF) to provide partial support for a multi-year series of workshops focused on evolving areas of research that are critical for the development of therapeutics.

Dystonia is the third most common movement disorder after Parkinson's Disease and tremor, and affects many times more people than better known disorders such as Huntington's Disease, muscular dystrophy and ALS or Lou Gehrig's Disease. We ask that NINDS fund dystonia-specific extramural research at the same level that it supports research for other neurological movement disorders.

#### CONCLUSION

The ultimate goal of the Dystonia Foundation is a cure for dystonia. Until that goal is realized, we are hungry for knowledge about the nature of dystonia and for more effective treatments with fewer side effects. We have amassed many exceptional and diligent researchers; who are committed to our goal, and our top priority is funding their very important research. But the Foundation cannot do it alone. We need federal support through NIH, NINDS, NIDCD and NEI to continue to fund quality scientific research and eliminate this debilitating disease.

Combine the thwarting of scientific progress with the decreased access to therapies and all the progress of the last few years could be wiped away. We ask that you aggressively support medical research, specifically for movement disorders and brain research. By doing so, you are doing a tremendous service for my family and myself and to the hundreds of thousands of people and families affected by dystonia.

Thank you very much.

## THE DYSTONIA MEDICAL RESEARCH FOUNDATION

The Dystonia Medical Research Foundation was founded 25 years ago and has been a membership-driven organization since 1993. Since its inception, the goals of the Foundation have remained the same: to advance research for more effective treatments of dystonia and ultimately a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

PREPARED STATEMENT OF THE FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY SOCIETY, INCORPORATED (FSH SOCIETY, INC.)

Mr. Chairman, it is a pleasure to submit this testimony to you today.

My name is Daniel Paul Perez, of Lexington, Massachusetts, and I am testifying as President & CEO, of the FacioScapuloHumeral Muscular Dystrophy Society (FSH Society, Inc.) and as an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for nearly 43 years. FSHD is the third most prevalent form of muscle disease. It affects 1/20,000 people. For men, women, and children the major consequence of inheriting FSHD is a lifelong progressive and severe loss of all skeletal muscles. Most people are familiar with Duchenne muscular dystrophy (DMD) that affects boys. What they are not aware of is, that in any given moment, there are probably more individuals with FSHD alive than with Duchenne MD (14,800 vs. 11,000). Recently, the NIH identified significant gaps in FSHD and a preponderance of DMD research grants and reported that it only has five (5) active projects on facioscapulohumeral muscular dystrophy in its entire NIH wide portfolio.

We have given testimony before the U.S. Congress every year since 1994. We have submitted 26 written testimonies and 5 oral testimonies to the U.S. Senate and U.S. House Appropriations Subcommittees on Labor, Health, Human Services and Education and Related Agencies. We have had considerable report language written in the appropriations budget from the committees directed to the National Institutes of Health (NIH) with regard to improving the portfolio at the NIH in FSHD in nearly every year that we have come before you. In April 2000, prior to the passage of the "Muscular Dystrophy CARE Act 2001" law, we testified that Congressional directive on FSHD has been and is repeatedly ignored by the NIH. Since 2001, we have been working closely with the NIH on the MD CARE ACT 2001 law mandated research plan. Prior to all of the activity around the MD CARE Act 2001, we noted then that the NIH is seriously out of compliance with the previous four years of Congressional Directives. Incredibly, today in the calendar year 2005 heading into the fiscal year 2006 the NIH still is out of compliance and has an anemic portfolio on FSHD. Going back in time, in 2000 we reported the NIH had not responded to the past and prior years of Report Language.

The Report Language for 2000 has been responded to in an untimely manner and mainly ignored. The 2000 Report Language is as follows: "The Committee is concerned that NIH has not responded to a previous request to develop a plan for enhancing NIH research into Facioscapulohumeral (FSH) disease. The Committee urges NIH to promptly convene a research planning conference and to establish a comprehensive portfolio into the causes, prevention, and treatment of FSH disease through all available mechanisms, as appropriate. The Director is requested to be prepared to testify on the status of this initiative at the fiscal year 2001 appropriations hearing." (House Report 3037, p. 81 for NINDS, p. 97 for NIAMS.) The status of fiscal year 2000 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

The Report Language for 1999 has been ignored and the status of the Report language for fiscal year 1999 is not done. The 1999 Report Language is as follows: "The Committee encourages the Institute to continue and expand research efforts focused on aiding in the diagnosis and treatment of FSHD." (House Report, NINDS Section, p. 103), and, "The Committee was pleased with the Institute's 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 NIH to conduct a research planning conference in the near future in order to explore scientific opportunities in FSHD research, both intramurally and extramurally." (House Report, NIAMS Section, p. 120-121.) The status of 1999 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

The Report Language for 1998 has been ignored and the status of Report language for fiscal year 1998 is not done. The 1998 Report Language is as follows: "The Committee has heard compelling testimony about facioscapulohumeral (FSH) dis-



ease, which causes progressive and severe loss of skeletal muscle. FSHD 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 (FSHD), including an assessment of whether an intramural research program in this area would be beneficial." (House Report, p. 101.) In 2005, the status of 1998 Report Language is as follows: FSHD extramural research is almost non-existent. Intramural research on FSHD is non-existent at NIH.

We have worked hard to be sure that our constituency understands and supports the doubling of the NIH budget and have been very successful in helping to grow the NIH budget from \$10.326 billion to \$28.649 billion. In the same period, we saw FSHD funding increase by about \$1.3 million. This year we will spare you the heartache of our personal story and the pain and suffering our disease brings in its train. This year we simply would like you to ask the NIH "Where did the money that Congress appropriated and further directed through appropriations report language go?"

We formerly request a congressional investigation, hearing or some other Congressional action regarding the absolute failure of the NIH to increase funding in facioscapulohumeral muscular dystrophy (FSHD). We have been testifying and generating report language and laws for a dozen years and have done the yeoman's share in building the base for FSHD. Despite the specific directions from the Congress in report language as shown above and with a public law and a federal advisory committee on muscular dystrophy, the NIH has failed to follow through on improving FSHD research. Despite our active involvement with the NIH, the NIH has made the grant review process very secretive, has turned down opportunities to shed light on the grant decision making process and still has not responded to congressional letters and inquiries on the lack of facioscapulohumeral muscular dystrophy (FSHD) research in the NIH portfolio.

I would like to illustrate what we have done at the FSH Society, Inc. to improve the funding and portfolio of muscular dystrophy (MD) and FSHD. The FSH Society (Society) has represented the FSHD community of researchers and clinicians by the following activities on the Hill, in the districts, and at the NIH. The FSH Society was the first on the Hill and at the NIH and before Parent Project Duchenne Muscular Dystrophy (PPDMD) and MDAUSA for many years since 1993. The Society has given nearly three dozen Congressional testimonies, in writing and in person, before the committee to support the doubling of the NIH budget and to encourage spending on muscular dystrophy. The Society has succeeded in achieving nearly a dozen sections of report language in appropriations reports. I have served on numerous NIH research and planning task forces. The Society has had countless hundreds of meetings with the Directors, Staff and program officers of the NIH NINDS, NIAMS, NICHD, NHGRI, ORD and the OD. I served on the five year long range planning meeting for the NIH NIAMS July 1999. I rewrote the MD CARE Act 2001 bills to include all muscular dystrophies, ages and genders, and to establish the Muscular Dystrophy Coordinating Committee (MDCC) federal advisory committee with public members, and to establish five national centers for MD not at the exclusion of the basic research, and much more. The Society has contributed to supporting two NIH funded FSHD research planning conferences (1997, 2000). I work closely and collaboratively with NIH program directors. I serve on the MDCC at the request of Secretary Tommy G. Thompson and Dr. Elias Zerhouni. I helped write the MDCC NIH research plan submitted to Congress in summer 2004. I continually encourage FSHD researchers to submit NIH grant applications for R01, R21, R03, P01, U54, K, T, F training and mentoring awards and Director's Pioneer Awards. The Society has given testimony before the Institute of Medicine (IOM) on improving the Center for Scientific Review (CSR) grant review process for FSHD. The FSH Society itself has funded \$1.1 million in \$30,000 a year fellowships to more than 2 dozen researchers in 5 years, leading to nearly 7 dozen publications in top tier journals. The FSH Society helps the NIH FSHD patient registry and existing Wellstone Cooperative Research Center's as a volunteer health agency.

As a grant agency, the FSH Society has world renowned and leading clinicians and researchers peer reviewing applications, funding research, reviewing progress reports and preliminary data and ideas. We know and have comprehension on the quality of applicants and projects and data being submitted to you in the NIH grant applications for FSHD research. I have first hand knowledge of the research as well as our Nobel quality advisors. I can tell you that researchers of Wellstone, Nobel, and Howard Hughes stature working on FSHD have had applications on FSHD rejected by the NIH. However, their applications on other types of muscular dystrophy have been funded by the very same agency.

Mr. Chairman, as you know, the National Institute of Child Health and Human Development (NICHD), the National Institute of Arthritis and Musculoskeletal Disorders (NIAMS), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Human Genome Research Institute (NHGRI) are four of the National Institutes of Health (NIH) institutes called upon by the Muscular Dystrophy Community Assistance Research and Education Act of 2001 (MD CARE Act 2001) to develop a research plan for muscular dystrophy (MD) research and education conducted through the National Institutes of Health. Certainly, other NIH institutes will be called into action where appropriate such as NHLBI, NEI, NIA, NIMH, NCRR, FIC, and OD.

We rewrote the MD CARE Act 2001 bill from the Muscular Dystrophy Children's Assistance Research and Education Act 2001, covering only the childhood form of Duchenne MD (DMD), to the Muscular Dystrophy Community Assistance Research and Education Act 2001 covering all forms of MD. We rewrote the bill to include all forms of muscular dystrophy affecting men, women, and girls in addition to boys because it was the right thing to do. Oddly, in 2004 Duchenne MD received a commanding portion of the muscular dystrophy funding and seven of the other muscular dystrophy types have little or no funding from the NIH.

An analysis was presented at the December 2004 MD CARE Act mandated Muscular Dystrophy Coordinating Committee (MDCC) meeting of the 164 grants in the NIH portfolio for future planning purposes related to the five sections of the muscular dystrophy research plan. Subsequent to the meeting, I requested the details of the 164 grants used for the December 1, 2004 discussion from Dr. John Porter (DHHS NIH NINDS), the Executive Secretary of the MDCC. It has been communicated that this compilation was done for planning purposes. From discussions with Dr. Porter we understand that this view of grants differs from the muscular dystrophy portfolios as presented by the budget and NIH OCPL offices regarding the various institutes along coding parameters. The 164 grants were assembled with a degree of scientific subjectivity and based on professional expertise and judgment. The December 2004 MDCC meeting yielded an analysis of a subjective grouping of the NIH wide 164 muscular dystrophy grants. Eight were reported related to FSHD. At that time, the NIH identified that 8 out of 164 grants are on FSHD! Only eight out of 164 grants are for research on FSHD the third most prevalent dystrophy that affects men, women and children!

The details of the data of the 164 grants as presented at the December 1, 2004 MDCC for the grants with funding start dates in 2004 shows 35 grants funded for the 2004 year to that date. The count by dystrophy for calendar year 2004 is: 18 for Duchenne muscular dystrophy (DMD), 2 for Limb Girdle muscular dystrophy (LGMD), 1 for Myotonic muscular dystrophy (DM), 1 for facioscapulohumeral muscular dystrophy (FSHD), 7 for stem cell research, and 6 for other research. To reiterate by dystrophy the total grants awarded in 2004 were: 18 for DMD, 2 for LGMD, 1 for DM, and 1 for FSHD! The most recent year of funding data shows that the non-Duchenne muscular dystrophy group is not doing well in terms of numbers of grants and funding. We request a hearing that focuses on this issue with immediacy and attention to ameliorating this unequal growth. Oddly, there is an order of magnitude difference between Duchenne muscular dystrophy (DMD) and the entire complement of all other dystrophies.

What has happened in facioscapulohumeral muscular dystrophy (FSHD) research in the five years since the MD CARE Act was signed and what has happened since the thirteen years since we first started asking NIH to invest and build the facioscapulohumeral muscular dystrophy portfolio? NIH has rejected nearly four dozen grant applications on facioscapulohumeral muscular dystrophy of R03, R21, R01, P01, U54, NIH Director Pioneer Award Nominations mechanisms and more. The funding track record speaks for itself. To date in fiscal year 2005 the NIH has rejected every FSHD application it has received. It is difficult to attract investigators to FSHD when there is no money made available for them and it becomes a downward spiral to attract new and promising investigators.

Incredibly, the NIH NIAMS, NINDS, NICHD, NHGRI FSHD funding is still non-existent. Since 2001, the overall NIH wide muscular dystrophy budget has increased from \$21.0M to \$42.2M in fiscal year 2006 estimated and enacted. Since 2001, the FSHD budget has increased from \$500,000 to \$1.6M in fiscal year 2006 estimated.

NATIONAL INSTITUTES OF HEALTH (NIH) MUSCULAR DYSTROPHY AND FSHD APPROPRIATIONS HISTORY <sup>1</sup>

[In millions of dollars]

Fiscal year	Total NIH dollars on MD	NIAMS dollars on MD	NINDS dollars on MD	NICHD dollars on MD	NHGRI dollars on MD	NIH wide dollars on FSHD
2000 .....	12.6	4.8	4.9	1.2	.....	0.4
2001 .....	21.0	9.2	8.2	0.5	0.3	0.5
2002 .....	27.6	11.1	9.8	0.6	2.3	1.3
2003 .....	39.1	15.5	13.2	4.5	2.1	1.5
2004 .....	38.7	15.0	14.8	3.8	0.3	2.2
2005ES .....	41.0	16.3	13.7	4.8	2.2	1.6
2005EN .....	42.2	15.2	16.6	5.0	0.3	1.6
2006ES .....	42.2	15.2	16.7	5.0	0.3	1.6

<sup>1</sup> Source: NIH/OD Budget Office & NIH OCPL

NIH NIAMS. The NIAMS is ostensibly the lead institute at the NIH on muscular dystrophy. After all of our efforts the NIH National Institute of Arthritis and Musculoskeletal Disorders (NIAMS) now has only one research contract that it is co-funding with NIH NINDS for FSHD for \$186,233 per year? Not one single research grant for FSHD, the third most prevalent dystrophy! The total muscular dystrophy portfolio ending December 15, 2005 was 58 projects, including Wellstone Cooperative Research Centers (CRC) components for a total of \$14,992,725.

NIH NINDS. The NINDS is the second largest NIH contributor towards muscular dystrophy research funding. The NIH National Institute of Neurological Disorders and Stroke (NINDS) now has three research grants, one research contract, and one-quarter of a Wellstone CRC for FSHD for a total of \$1,386,620 in fiscal year 2004. The total muscular dystrophy fiscal year 2004 portfolio reported February 1, 2005 was 39 projects, including Wellstone CRC components for a total of \$14,756,290.

NIH NICHD. The NICHD is third largest NIH contributor towards muscular dystrophy research funding. The NIH National Institute of Child Health and Human Development (NICHD) does not have a single research grant or project directly focused on covering FSHD, which is the third most prevalent dystrophy that affects both boys and girls. The total muscular dystrophy fiscal year 2004 portfolio reported December 1, 2004 was 15 projects, including Wellstone CRC components for a total of \$3,837,633.

NIH NHGRI. The NHGRI is historically the fourth largest NIH contributor towards muscular dystrophy research funding. The NIH National Human Genome Research Institute (NHGRI) does not have a single research grant or project directly focused on covering FSHD. The total muscular dystrophy fiscal year 2004 portfolio reported on December 1, 2004 was 1 project (Z01-HG000215-02), including Wellstone CRC components for a total of \$281,396. The project is Hereditary Inclusion Body Myopathy (HIBM) and HIBM is not a type of muscular dystrophy.

Astonishingly, the total NIH wide spending on muscular dystrophy decreased from \$39.1 million (fiscal year 2003) to \$38.7 million (fiscal year 2004). Something is wrong with this trend given the Appropriations Subcommittee's interest in this area and the efforts of the patient and research communities to shore up and improve muscular dystrophy research.

NATIONAL INSTITUTES OF HEALTH (NIH) APPROPRIATIONS HISTORY <sup>1</sup>

[Dollars in millions]

Fiscal year	NIH overall dollars	MD research dollars	MD percent of NIH	FSH research dollars	FSHD percent of MD	FSHD percent of NIH
2000 .....	\$17,821	\$12.6	0.071	\$0.4	3.18	0.0022
2001 .....	20,458	21.0	0.103	0.5	2.38	0.0024
2002 .....	23,296	27.6	0.118	1.3	4.71	0.0056
2003 .....	27,067	39.1	0.144	1.5	3.83	0.0055
2004 .....	27,887	38.7	0.139	2.2	5.67	0.0079
2005E .....	28,495	41.0	0.144	1.6	3.90	0.0056
2006E .....	28,640	42.2	0.147	1.6	3.79	0.0056

<sup>1</sup> Source: NIH/OD Budget Office & NIH OCPL

The NIH NIAMS, NINDS, NICHD, NHGRI the four lead institutes on muscular dystrophy reported a combined total of 113 projects on muscular dystrophy totaling \$33,869,044 in fiscal year 2004. Of that total amount facioscapulohumeral muscular dystrophy (FSHD) received \$1,572,853 for three grants, one contract and one-quarter of a Wellstone CRC.

Looking at the three existing Wellstone Cooperative Research Centers (CRCs) the NIH NICHD is spending \$1,631,994, the NIH NIAMS is spending \$1,224,971, and the NIH NINDS is spending \$1,462,151. Only one-quarter of the Wellstone CRC funded by the NIH NINDS specifically works on FSHD. One more Wellstone center is currently in the process of being funded and none of the work at the fourth Wellstone pertains to FSHD. Of \$4,319,116 funded to the first three Wellstone CRCs, only \$365,538 is directly titled for FSHD. Only 8.46 percent of the total Wellstone expenditure is being spent on the third most prevalent form of muscular dystrophy that affects both men and women.

Mr. Chairman, we are troubled by the NIH grant review process used for the Wellstone Center applications as NIH uses a review process that deviates from its rigorous adherence to stating that it funds projects of the highest scientific merit. The Wellstone applications are reviewed for scientific merit and then the entire score is adjusted upward or downward based on a "gestalt" or an impression. The NIH NIAMS extramural program director writes that as an "example, one or more of the research projects may have very high scientific merit but lack relevance or contribute little to the Center [Wellstone] as a whole; conversely, research projects with relatively lower scientific merit may provide necessary strengths to the other components of the Center, and make a major contribution to the Center as a whole." This changing of the rules has not worked in the favor of FSHD research and in fact quite the opposite in round two of the Wellstone evaluations. We ask the committee to hold a hearing to more closely examine if scientific quality is abrogated by a more subjective review standard.

Mr. Chairman, we are asking you to inquire about the abysmal performance record in FSHD funding and FSHD oriented Wellstone CRCs by the NIH. Last, at the end of the day, we all recognize that simply not enough grants are being submitted by the extramural research community to the NIH. Note that the NIH has done nothing to date to specifically encourage or targeted to draw in FSHD research applications in five or six years. For most of fiscal year 2004, there was no active program announcement on the street in muscular dystrophy from the NIH giving researchers no obvious avenues or handles to submit basic research grants. Of course, researchers are not restricted from submitting applications and can always submit grants in the absence of a call for proposal but most look for a program announcement or call for applications as a signal of NIH interest. The NIH is certainly not receiving enough grants applications for FSHD, but it also manages to reject almost every one of the scarce few being submitted by the top FSHD researchers in the world. It can be said that the volunteer health agencies and extramural community of researchers have done everything in their power to grow the area of research and to promote new researchers and research projects. We have been very successful as shown above and need the NIH to capitalize on our success and investments. The NIH has recognized that there is a systemic problem and has even self-identified a significant gap as relates to FSHD, but it has not stated what and if anything it intends to do to ameliorate the unequal growth and opportunity for muscular dystrophies other than Duchenne muscular dystrophy.

At the December 2004 MD CARE Act mandated Muscular Dystrophy Coordinating Committee (MDCC) the staff and Director's of the NIH admitted there was a problem in the gap with FSHD research. The follow-up has been deferred to programmatic staff and the implementation details of the pending muscular dystrophy research plan. The NIH did not say exactly when it would follow-up on funding new research in FSHD. The NIH has a history in FSHD of committing to address this issue and never following through. The two prior NIH sponsored research planning conferences on FSHD are an example. Only a minor fraction of the 2000 NIH planning conference research plan developed by the NIH has been implemented. At this point, we are unsure if the lack of FSHD research in the NIH portfolio is a problem of miscommunication or perhaps a more deliberate and calculated on the part of the NIH.

We also ask that Congress request an explanation from the program staff and Directors of the NIH NIAMS, NHGRI, OD and NICHD for the inability to do better in the area of FSHD despite repeated Congressional requests. We implore Congress to request the NIH to specifically build the research portfolio on FSHD through all available means, including re-issuing specific calls for research on FSHD at an accelerated rate, to make up for historical and present neglect.

Mr. Chairman, we trust your judgment on the matter before us. We believe the Committee should explore why muscular dystrophy in general and FSHD in particular has been left behind in the great rise in research support at the NIH. Frankly, we are extremely frustrated that amid a huge increase in funding and strong unambiguous expressions of Congressional support, the NIH commitment in facioscapulohumeral muscular dystrophy (FSHD) is so feeble. Mr. Chairman thanks to your extraordinary efforts, consideration and work in this area I have hope that we will find solutions and that hope keeps me going.

Mr. Chairman, again, thank you for providing this opportunity to testify before your Subcommittee.

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PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR  
EXPERIMENTAL BIOLOGY

INTRODUCTION TO FASEB

The Federation of American Societies for Experimental Biology (FASEB) is a coalition of 22 scientific societies who together represent more than 66,000 biomedical research scientists. The mission of FASEB is to enhance the ability of biomedical and life scientists to improve, through their research, the health, well-being and productivity of all people.

FASEB'S RECOMMENDATION FOR NIH FUNDING IN FISCAL YEAR 2006

As your committee begins deliberations on appropriations for agencies under its jurisdiction, FASEB would like to offer its views on funding for the National Institutes of Health (NIH). FASEB recommends that the National Institutes of Health receive \$30.07 billion in fiscal year 2006, an increase of 6 percent over the level for the previous fiscal year. This level of funding is consistent with our analysis of what is needed to prevent the curtailment of vital research programs.

NIH'S MISSION

The National Institutes of Health (NIH) is the single most important source of funding that drives advances in basic biomedical research and clinical medicine. Over the past 50 years, NIH research has transformed the practice of medicine and made significant improvements in the long-term health of our citizens. Even greater benefits are possible in the next two decades, if we are positioned to capitalize on the many profound advances in fundamental science.

Modern medical research is poised to revolutionize the prevention, diagnosis and treatment of disease. These opportunities coincide with urgent public health needs. The baby boom generation is graying; without more effective strategies against chronic diseases, such as osteoporosis, Parkinson's and Alzheimer's diseases, and heart disease, the health care needs of this generation will place enormous economic and social burdens on their children and our Nation. In addition, new and emerging infectious diseases are a constant threat to our society; without novel and improved methods for predicting, detecting, controlling and preventing emerging and re-emerging diseases, our nation will be ill prepared to respond to the major public health challenges of the twenty-first century. To meet all of these challenges with improvements in patient care depends on continuous scientific discovery that will usher in a new age in the practice of medicine.

NOVEL MEDICAL PRACTICE MADE POSSIBLE BY NIH-FUNDED RESEARCH

The pace of advancement continues to accelerate such that there are new treatments that substantially increase the quality and length of life for a large number of Americans. Most of these successes were only made possible because of basic research and committed clinical development. Below, we have highlighted some major advances in prevention and treatment of heart disease, infectious diseases, cancer, vaccines, obesity and diabetes, and women's diseases. We point out how basic research is benefiting Americans and increasing their longevity and quality of life. At the same time, we indicate some of the many areas of medicine that provide opportunities for important advances in the future.

*Cardiovascular Disease.*—Without doubt, one of the most important advances in human health for an aging population has been the investigation and treatment of cardiovascular disease (CVD). Basic research identified the limiting step in cholesterol biosynthesis, and this led directly to the development of statins. These wonder drugs lower levels of blood lipids, and they are remarkably effective in the reduction of coronary events and death from coronary heart disease. Without the basic re-

search, drug development for the treatment of hypercholesterol would have languished for years.

Although important progress has been made, there is need to understand the causes of CVD, and find new means of prevention. Studies published within the past 2 years affirm that CVD is strongly affected by inflammation, and that the most reliable early predictors of disease are blood proteins that reflect chronic inflammation such as C-reactive protein. Further research into the prevention of dangerous inflammatory responses promises to substantially reduce the major cause of death in Americans.

*Infectious Diseases.*—Like HIV/AIDS, Ebola and West Nile virus, SARS reminds us that emerging and reemerging infectious diseases are constant threats to national and international public health. In 2003, SARS rapidly moved across the globe, becoming a worldwide health emergency that resulted in quarantines, travel warnings, and mounting economic damage. The ability of NIH to marshal its resources to rapidly initiate development of diagnostics, therapeutics and vaccines against SARS has positioned us well in our quest for tools to detect, treat and prevent SARS.

*Cancer.*—Using monoclonal antibodies (mAb), scientists have also identified the cell surface receptors that characterize many different cells of the body. These same mAb can be chemically engineered for use as biologic drugs in the treatment of many different diseases. The mAb reagent that targets a lymphocyte receptor has become a proven therapy for non-Hodgkin's B cell lymphoma; many patients remain disease-free for several years after having failed chemotherapy. Based on more recent clinical trials, this same drug may also be effective in the treatment of several forms of autoimmune disease including rheumatoid arthritis. Many other engineered mAb are being tested in clinical trials for use as biologic drugs, and again, more research is needed to identify new disease targets.

The latest genetic technologies are also beginning to deliver important tools for the treatment of cancer. Recently, NIH-supported research has been used to develop technologies where virtually the entire genome can be studied on a small chip (DNA microarray). A recent example of the promise of this technology comes from the study of chronic lymphocytic leukemia (CLL). CLL patients fall into two categories: those whose tumors progress slowly and those with highly malignant tumors that require aggressive therapy. Microarray analyses identified the expression of a single gene that discriminates these tumor types with a high degree of accuracy. This has now led to a simple blood test to determine tumor prognosis and guide therapy. Microarray analyses will be used in the future to analyze each individual cancer as a way of guiding highly individualized therapies, and this will in turn result in a new generation of highly effective treatments.

*Vaccines.*—Vaccine research and development proceeds at a rapid pace using new tools from a variety of fields. Hemophilus influenza type b is one of the leading causes of invasive bacterial infection in young children worldwide. The development of a vaccine for this disease has dramatically decreased the incidence of pediatric meningitis from approximately 20,000 to 200 cases per year in the United States. The cost for treating this disease and its complications was \$500 million annually, whereas the cost of vaccination is presently no more than fifty cents per patient. The development of this successful vaccine evolved naturally out of NIH-supported research in basic immunology and many additional breakthroughs are anticipated. For example, similar vaccines are being tested to prevent pneumococcal and meningococcal infections that often result in pneumonia or meningitis.

New sequencing techniques made possible from the Human Genome Project allow the rapid decoding of genomes of bioterrorism threats as well as rapidly mutating pathogens. Immunologists have created a malaria vaccine that was made possible by genome sequencing of the malaria parasite and its mosquito host, and recent results in children show that this vaccine can convey a 50 percent decline in infections. The genome sequence of each pathogen facilitates the identification of virulence factors, which in turn, constitute the best targets for vaccination. For example, the creation of a SARS DNA microarray chip, available from NIAID, will aid in the rapid development of vaccines against this recently identified pathogen. The complementary nature of basic and clinical research is no where more apparent than in the advantage that vaccine research takes of chemical structures determined by x-ray crystallography. The recent discovery of the 3-D structure of the anthrax bacterium will speed development of novel antitoxins to protect our populace against bioterrorism. Thus, work on the horizon promises vaccines that will confer resistance to previously uncontrollable infectious agents.

*Obesity and Diabetes.*—The obesity epidemic continues to rise. The projected health care requirements arising from complications associated with excessive weight will substantially expand the costs of Medicare and private health insurance

in an aging population. In response to this crisis, NIH has increased funding in obesity research and this has led to an explosion of new information concerning the regulation of metabolism and the causes of pathogenesis. For example, the 2004 Lasker Prize was shared by two American NIH-funded researchers and a Frenchman for their work on nuclear receptors, and in part for the role these receptors play in insulin resistance and metabolism of fat cells. This work holds great promise for therapeutic intervention since nuclear receptors are easily targeted by modified versions of steroid hormones. Remarkably, some of the most incisive work has come from basic studies using model organisms, such as worms and flies, where genetic screens have identified the essential metabolic pathways.

Over the period of the NIH budget doubling, researchers have discovered previously unknown hormones such as Resistin and Gherlin. Resistin is a fat-cell derived hormone that, in excess, causes problems with carbohydrate metabolism, and this in turn can result in diabetes. Gherlin, along with Leptin, has been found to be important in the modulation of appetite. In another area of metabolic research, we now understand the molecular basis for trans fatty acid and saturated fatty acid effects on LDL cholesterol, and this has important implications both in weight control and in cardiovascular disease.

Health care costs more than twice as much for diabetes patients as for all other individuals. Eliminating or reducing the health problems caused by diabetes could significantly improve the quality of life for people with diabetes and their families while at the same time potentially reducing national expenditures for health care services and increasing productivity in the U.S. economy. These costs will increase dramatically if the epidemic is allowed to worsen. Indeed, it was recently predicted by the Centers for Disease Control that one out of three children born in the United States in the year 2000 will develop diabetes in his or her lifetime.

Obesity affected 44 million Americans as of 2001, an increase of 74 percent from 1991. Obesity is a major risk factor for diabetes and is also associated with cardiovascular disease and cancer. The total cost attributable to obesity amounted to \$99.2 billion in 1995. Approximately \$51.7 billion of those dollars were direct medical costs. The number of restricted-activity days, bed-days, and work-lost days increased substantially between 1988 and 1994, while the number of physician visits attributed to obesity increased 88 percent during the same period.<sup>1</sup> The health-related economic cost of obesity to U.S. business is substantial, representing approximately 5 percent of total medical care costs.<sup>2</sup>

*Women's Health.*—Recent work has demonstrated that estrogen and related compounds reduce brain damage from stroke in experimental animals. With these new findings it is extremely important that support for existing and new research to resolve the controversy of safety and risks of hormone replacement therapy be continued and increased. Such a resolution will have a wide impact on women's health concerns such as osteoporosis, stroke, Alzheimer's disease and memory loss.

#### COMPETITIVE PEER REVIEW

Part of the success of American science derives directly from the system for awarding research grants. The majority of NIH funding comes in response to investigator-initiated research proposals that are evaluated by a committee of experts in each scientific field. Elaborate care is taken to ensure that conflicts of interest are minimized and each research proposal is evaluated on its merit. Over many years this competitive system has promoted the highest quality research, and it is a shining example of a program based on "reward for excellence." No scientist can afford to rest on his or her previous accomplishments. As opposed to the entitlement system of funding found in some other countries, the American system rewards productivity, innovation, and impact. While FASEB welcomes new ideas to make the system function even more efficiently, we support the basic concept of peer review as practiced by NIH.

#### THE IMPORTANCE OF CONTINUING THE MOMENTUM

There has never been greater opportunity for advancing biomedical science and generating more effective practices for clinical medicine. Within our reach are dramatic new breakthroughs that can lessen the economic and human costs of disease.

In response to the massive amounts of new information being generated in every field of biomedical science, the NIH has recently developed a framework of priorities that NIH as a whole must address in order to optimize its entire research portfolio.

<sup>1</sup>Obesity Research 1998; 6 (2): 97–106.

<sup>2</sup>American Journal of Health Promotion 1998; 13 (2): 120–127.

The NIH Roadmap<sup>3</sup> identifies the most compelling opportunities in three main areas and will (1) promote a quantitative understanding of the many interconnected networks of molecules that comprise our cells and tissues, their interactions, and their regulation; (2) explore new organizational models for team science; and (3) foster large-scale epidemiological studies and clinical trials to enhance the state of medical treatment and move new therapies into practice. Specialized core facilities and consortia are being promoted to bring together scientists from different disciplines as a way of accelerating discovery. FASEB supports the goals and vision of this initiative, although we maintain that most novel discovery and innovative research will continue to originate from individual investigators. In order to maintain our rate of discovery and build the infrastructure outlined in the Roadmap, NIH requires adequate support for agency-initiated and investigator-initiated projects.

The momentum generated from doubling the NIH budget has energized biomedical science at every level. We see new young investigators making some of the most important discoveries. Training initiatives have encouraged talented students to choose a career in academic medicine. These highly talented and motivated individuals spend 10 years or more after college in graduate school and postdoctoral appointments. In 2003, only 16.6 percent of new investigators obtained funding within their first 3 years of applying for these critical grants, thereby making it very difficult for these young scientists to establish their new innovative research programs.

It is impossible to predict which cures and therapies might be lost if funds for medical research are curtailed, but it is certain that inconsistent NIH funding sends a chilling message to young scientists in training and those just entering the research field. Scientific competition will always be intense, but exceptionally talented young scientists must be assured that sufficient research funding will be available or they will be forced to pursue alternative careers.

#### RECOMMENDATION

FASEB understands that the fiscal year 2006 budget for discretionary spending is projected to be constrained in light of the large deficit, the expenditures for defense and homeland security and the growth in entitlement obligations. However, FASEB strongly believes that the scientific opportunities for progress in medical research have never been greater. Therefore, FASEB recommends that the National Institutes of Health receive \$30.07 billion in fiscal year 2006, an increase of 6 percent over the level for the previous fiscal year.

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#### PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS)

The Friends of the National Institute of Environmental Health Sciences (NIEHS) group appreciates the opportunity to comment on the fiscal year 2006 appropriation for the institute. The Friends of NIEHS is a coalition committed to expanding the National Institutes of Health's (NIH) environmental health research portfolio through increased appropriations for NIEHS. Comprised of over 50 patient, healthcare provider, children's health, and industry groups, the Friends of NIEHS represents an enormously broad constituency dedicated to improving the nation's knowledge about our health and our environment.

Over the last several years Congress has shown a strong commitment to health research sponsored by NIH. This financial commitment has allowed the nation to dedicate resources to emerging scientific opportunities that will lead to beneficial health outcomes for Americans. We thank Congress for fulfilling its commitment to double the NIH overall budget. However, we remain concerned about how we will fund these opportunities in the upcoming years.

This dilemma is particularly true for the NIEHS. This institute plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Specifically, NIEHS has played an important role in discovering the mechanisms by which DES (diethylstilbestrol) causes damage, through its historical and ongoing work on DES in the animal model. Continuing research of these mechanisms is vital to help determine future health events related to DES, such as the possibility of third generation effects in the grandchildren of women who took DES during pregnancy. Our expanded knowledge, as a result, al-

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<sup>3</sup><http://nihroadmap.nih.gov/>.



lows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

As the nation continues to steel itself from terrorist threats, the Friends of NIEHS applauds Congress's commitment to bolstering research funding in the area of infectious disease as a part of national anti-bioterrorism effort. The coalition, however, feels that an effort that only targets bioterrorism falls short of truly protecting the nation as it leaves the public vulnerable to chemical terrorism. Funding is critical for future initiatives such as research concerning the possible health effects of exposure to low levels of hazardous chemicals and the use of an Environmental Medical Unit (EMU), as previously supported by Congress and underway in Japan, to examine populations affected by toxicant-induced intolerances to determine the biomarkers and mechanisms by which to identify individual susceptibility so as to avoid placing such individuals in hazardous situations.

In an effort to continue the expansion of this knowledge base, the Friends of NIEHS supports a \$35 million increase in funding for NIEHS over fiscal year 2005 levels, bringing the total appropriation for fiscal year 2006 to \$680 million. This additional funding will allow the Institute to continue current projects and pursue promising research in the areas of individual susceptibilities (due to gender, age, racial/ethnic backgrounds, etc.), environmental disease triggers and technologies (such as toxicogenomics and mouse genomics).

While there are many competing interests that must be considered in the fiscal year 2006 budget, a top priority for Americans is medical research that explores the relationship between disease and the environment. The members of the Friends of NIEHS respectfully request a total of \$680 million for fiscal year 2006 for the National Institute of Environmental Health Sciences. Thank you for this opportunity to discuss the importance of these programs as the Congress configures the Labor-HHS fiscal year 2006 budget.

The Friends of NIEHS respectfully requests Congress to appropriate a total of \$680 million for fiscal year 2006.

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PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE COALITION

Mr. Chairman and Members of the Subcommittee: The Friends of the National Institute on Drug Abuse (FoN) a burgeoning coalition of over 50 organizations, is pleased to provide testimony to support the extraordinary work of the NIDA. Although a new coalition, it is comprised of organizations representing scientists, health professionals, and advocates for preventing and treating substance use disorders as well as understanding the causes and public health consequences of addiction. Pursuant to clause 2(g)4 of House Rule XI, the Coalition does not receive any federal funds.

Drug abuse and addiction represent a major health crisis in America, and create an economic burden of over \$484 billion per year. One way we can and should continue to address this problem is through scientific research. Because of the critical importance of drug abuse research for the health and economy of our nation, we write to you today to request your support for a 6 percent increase for NIDA in the Fiscal 2006 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. That would bring total funding for NIDA in Fiscal 2006 to \$1,067,040,300. Recognizing that so many health research issues are inter-related, we also support a 6 percent increase for the National Institutes of Health overall, which would bring its total to \$30 billion for Fiscal 2006.

NIDA is the world's largest supporter of research on the health aspects of drug abuse and addiction. The Institute supports a comprehensive research portfolio that has led to our current understanding of addiction as a preventable developmental disorder and a chronic relapsing disease associated with long-lasting changes in the brain and the body that can affect all aspects of a person's life. NIDA's research portfolio is broad and deep, and spans the continuum of basic neuroscience, behavior and genetics research through applied health services research and epidemiology. This work deserves continuing, strong support from the Congress. Some examples include:

New research supported by NIDA and others reveals that drug addiction is a "developmental disease." That is, it often starts during the early developmental stages in adolescence and sometimes as early as childhood. This is a time when the brain undergoes major changes in both structure and function. We now know that the brain continues to develop throughout childhood and into early adulthood. Exposure to drugs of abuse at an early age may increase a child's vulnerability to the effects

of drugs and may impact brain development. As a result, NIDA has increased its emphasis on adolescent brain development to better understand how developmental processes and outcomes are affected by drug exposure, the environment and genetics. Recent advances in genetic research have enabled researchers to start to investigate which genes make a person more vulnerable, which genes protect a person against addiction, and how genes and environment interact. As part of the prevention portfolio NIDA is also involving pediatricians and other primary care providers to develop tools, skills and knowledge to be able to screen and treat patients as early as possible, including patients with mental disorders who may be at a high risk to develop addiction. We know that if we do not intervene early, drug problems can last a lifetime, making prevention a high research priority.

Treatment research is another priority area for NIDA. Significant effort is underway to develop, test, and ensure the delivery of evidence-based interventions to all practitioners and patients across the country. Building on advances from the Institute's basic neuroscience and behavioral research program NIDA has introduced a number of effective medications and behavioral treatments. The Institute also continues to look for more innovative, efficacious, and cost-effective ways to treat patients for a variety of addictions, including addiction to nicotine. NIDA is also using the National Drug Abuse Treatment Clinical Trials Network (CTN) to help respond to emerging public health needs like prescription drug abuse and the increases in patients who are seeking treatment for both substance abuse and mental disorders.

Another priority area for NIDA is curtailing the spread of HIV/AIDS. Because illicit drug use can impact decision-making and increase the likelihood that an individual will engage in risk-taking behaviors, treatment for drug abuse is, itself, HIV prevention. Drug abuse treatment can reduce activities related to drug use that increase the risk of getting or transmitting HIV. NIDA is especially interested in reducing HIV/AIDS rates in racial and ethnic minority populations, which are disproportionately affected by this disease.

Recognizing substance abuse as a disorder that can affect the course of other diseases, including HIV/AIDS, mental illness, trauma, cancer, cardiovascular disease and even obesity is critical to improving the health of our citizens. NIDA has launched several efforts to reach out to numerous professions within the healthcare community to address these issues.

#### ADDITIONAL SUCCESS STORIES, CHALLENGES AND OPPORTUNITIES

*Adolescent Brain Development—How Understanding the Brain Can Impact Prevention Efforts.*—NIDA maintains a vigorous developmental research portfolio focused on adolescent populations. NIDA working collaboratively with other NIH Institutes has shown that the human brain does not fully develop until about age 25. This adds to the rationale for referring to addiction as a “developmental disease;” it often starts during the early developmental stages in adolescence and sometimes as early as childhood, a time when we know the brain is still developing. Having insight into how the human brain works, and understanding the biological underpinnings of risk taking among young people will help in developing more effective prevention programs. FoN believes NIDA should continue its emphasis on studying adolescent brain development to better understand how developmental processes and outcomes are affected by drug exposure, the environment and genetics.

*Medications Development.*—NIDA has demonstrated leadership in the field of medications development by partnering with private industry to develop anti-addiction medications resulting in a new medication, buprenorphine, for opiate addiction. FoN recommends that NIDA continue its work with the private sector to develop much needed anti-addiction medications, for cocaine, methamphetamine, and marijuana dependence.

*Co-Occurring Disorders.*—NIDA recognizes substance abuse rarely occurs in isolation. And to adequately address co-occurring substance abuse and mental health problems, NIDA has developed robust collaborations with other agencies (such as NIAAA, NIMH and SAMHSA) to stimulate new research to develop effective strategies and to ensure the timely adoption and implementation of evidence-based practices for the prevention and treatment of co-occurring disorders. Through these initiatives, NIDA is supporting research to determine the most effective models of clinically appropriate treatment and how to bring them to communities with limited resources. FoN recognizes the imperative for continued funding of essential research into the nature of and improved treatment for these complex disorders and endorses these efforts.

*Drug Abuse and HIV/AIDS.*—One of the most significant causes of HIV virus acquisition and transmission involves drug taking practices and related risk factors

in different populations (e.g. criminal justice, pregnant women, minorities, and youth). Drug abuse prevention and treatment interventions have been shown to be effective in reducing HIV risk. Therefore, FoN trusts that NIDA will continue its support of research that is focused on the development and testing of drug-abuse related interventions designed to reduce the spread of HIV/AIDS in these populations.

*Emerging Drug Problems.*—NIDA recognizes that drug use patterns are constantly changing and expends considerable effort to monitor drug use trends and to rapidly inform the public of emerging drug problems. FoN believes NIDA should continue supporting research that provides reliable data on emerging drug trends, particularly among youth and in major cities across the country and will continue its leadership role in alerting communities to new trends and creating awareness about these drugs.

*Reducing Prescription Drug Abuse.*—NIDA research has documented recent increases in the numbers of adults and young people who are using prescription drugs for non-medical purposes. Reducing prescription drug abuse, particularly among our Nation's youth will continue to be a priority for NIDA. FoN endorses NIDA's programmatic research designed to further the development of medications that are less likely to have abuse/addiction liability, and to develop prevention and treatment interventions for adolescents and adults who are abusing prescription drugs.

*Reducing Methamphetamine Abuse.*—NIDA continues to recognize the epidemic abuse of methamphetamine across the United States. Methamphetamine abuse not only affects the users, but also the communities in which they live, especially due to the dangers associated with its production. FoN believes NIDA should continue to support research to address the medical consequences of methamphetamine abuse. Topics of particular concern include: understanding the effects of prenatal exposure to methamphetamine and developing pharmacotherapies and behavioral therapies to treat methamphetamine addiction.

*Reducing Inhalant Abuse.*—For the second year in a row, NIDA's Monitoring the Future Survey (MTF) has shown an increase in the use of inhalants by 8th graders. Inhalants pose a particularly significant problem since they are readily accessible, legal, and inexpensive. They also tend to be abused by younger teens and can be highly toxic and even lethal. FoN applauds NIDA's inhalant research portfolio and believes NIDA should continue its support of research on prevention and treatment of inhalant abuse, and to enhance public awareness on this issue as it did recently with the release of a Community Drug Alert Bulletin: Inhalants, as well as its new dedicated web site, [www.inhalants.drugabuse.gov](http://www.inhalants.drugabuse.gov).

*General Medical Consequences of Drug Abuse.*—NIDA recognizes that addiction is a disorder that affects the course of other diseases such as cancer, cardiovascular and infectious diseases. Therefore, FoN believes that NIDA should continue to support research on the medical consequences associated with drug abuse and addiction.

*Long-Term Consequences of Marijuana Use.*—NIDA research shows that marijuana can be detrimental to educational attainment, work performance, and cognitive function. However, more information is needed in order to assess the full impact of long-term marijuana use. Therefore, FoN recommends that NIDA continue to support efforts to assess the long-term consequences of marijuana use on cognitive abilities, achievement, and mental and physical health, as well as work with the private sector to develop medications focusing on marijuana addiction.

*Translating Research Into Practice.*—NIDA has been a leader working with State substance abuse authorities to reduce the current 15- to 20-year lag between the discovery of an effective treatment intervention and its availability at the community level. In particular, NIDA worked with SAMHSA on a recent RFA designed to strengthen State agencies' capacity to support and engage in research that will foster statewide adoption of meritorious science-based policies and practices. FoN believes that NIDA should continue collaborative work with States to ensure that research findings are relevant and adaptable by State Substance Abuse systems. NIDA is also to be congratulated for its broad and varied information dissemination programs as part of an effort to ensure drug abuse research is used in everyday practice. The Institute is focused on stimulating and supporting innovative research to determine the components necessary for adopting, adapting, delivering, and maintaining effective research-supported policies, programs, and practices. As evidence-based strategies are developed, FoN urges NIDA to support research to determine how these practices can be best implemented at the community level.

*Primary Care Settings and Youth.*—NIDA recognizes that primary care settings, such as offices of pediatricians and general practitioners, are potential key points of access to prevent and treat problem drug use among young people; yet primary care and drug abuse services are commonly delivered through separate systems.

FoN encourages NIDA to continue to support health services research on effective ways to educate primary care providers about drug abuse; develop brief behavioral interventions for preventing and treating drug use and related health problems, particularly among adolescents; and develop methods to integrate drug abuse screening, assessment, prevention and treatment into primary health care settings.

*Utilizing Knowledge of Genetics and New Technological Advances to Curtail Addiction.*—NIDA recognizes that not everyone who takes drugs becomes addicted and that this is an important phenomenon worthy of further exploration. Research has shown that genetics plays a critical role in addiction, and that the interplay between genetics and environment is crucial. The science of genetics is at a crucial phase—technological advances are providing the tools to make significant breakthroughs in disease research. For example, FoN believes NIDA should take advantage of new high-resolution genetic technologies which may help to develop new tailored treatments for smoking.

*Combating Nicotine Addiction.*—NIDA understands that the use of tobacco products remains one of the Nation's deadliest addictions and FoN supports NIDA's continuing efforts to address this major public health problem through its comprehensive research portfolio.

*Reducing Health Disparities.*—NIDA research demonstrates that the consequences of drug abuse disproportionately impacts minorities, especially African American populations. FoN was pleased to learn that NIDA formed a Subgroup of its Advisory Council to address this important topic and applauds NIDA for working to strategically reduce the disproportionate burden of HIV/AIDS among the African American population. FoN believes that researchers should be encouraged to conduct more studies in this population and to target their studies in geographic areas where HIV/AIDS is high and or growing among African Americans, including in criminal justice settings.

*The Clinical Trials Network—Using Infrastructure to Improve Health.*—NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN), which was established in 1999 and has grown to include over 17 research centers or nodes spread across the country. The CTN provides an infrastructure to test the effectiveness of new and improved interventions in real-life community settings with diverse populations, enabling an expansion of treatment options for providers and patients. FoN suggests NIDA continue to develop ways to use the CTN as a vehicle to address emerging public health needs.

*Neuroscience Blueprint and Training.*—NIDA is one of the 15 Institutes and Centers involved in the NIH Blueprint activities and FoN recommends that NIDA continue to demonstrate leadership to foster additional training in cross-cutting scientific issues.

*Neuroimaging and the Developing Brain.*—NIDA has also demonstrated leadership in the development and application of neuroimaging technologies to gain a greater understanding of the circuitry of the human brain underlying drug addiction. FoN encourages NIDA to utilize neuroimaging technology to improve its understanding of how the brain of children and adolescents develop.

*Behavioral Science.*—NIDA has long demonstrated a strong commitment to supporting behavioral science research. FoN encourages NIDA to continue to determine the interplay of behavioral, biological, and social factors that affect development and the onset of diseases like drug addiction to understand common pathways that may underlie other compulsive behaviors such as gambling and eating disorders.

*Drug Treatment in Criminal Justice Settings.*—NIDA is very concerned about the well-known connections between drug use and crime. Research continues to demonstrate that providing treatment to individuals involved in the criminal justice system decreases future drug use and criminal behavior, while improving social functioning. Blending the functions of criminal justice supervision and drug abuse treatment and support services create an opportunity to have an optimal impact on behavior by addressing public health concerns while maintaining public safety. FoN strongly supports NIDA's efforts in this area, particularly the Criminal Justice Drug Abuse Treatment Studies (CJ-DATS), a multi-site set of research studies designed to improve outcomes for offenders with substance use disorders by improving the integration of drug abuse treatment with other public health and public safety systems.

#### CONCLUSION

It is true that many challenges remain. However, only the resources available for carrying out its vital mission limit the potential contributions of NIDA-funded research to the lives of countless individuals. This is why the Friends of NIDA ask you to provide an appropriation of \$1,067,040,300 billion to the Institute so that our

nation and the world will continue to benefit from NIDA's commitment to improving health and scientific advancement.

We understand that the fiscal year 2006 budget cycle will involve setting priorities and accepting compromise. However, in the current climate, we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserve to be prioritized accordingly. We look forward to working with you to make this a reality.

Thank you, Mr. Chairman, and the Subcommittee, for your support for the National Institute on Drug Abuse.

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#### PREPARED STATEMENT OF THE HEART RHYTHM SOCIETY

The Heart Rhythm Society (HRS) thanks you and the Subcommittee on Labor, Health and Human Services and Education for your past and continued support of the National Institute of Health, and specifically the National Heart, Lung and Blood Institute (NHLBI). The Heart Rhythm Society is the international leader in science, education and advocacy for cardiac arrhythmia professionals and patients, and the primary information resource on heart rhythm disorders. Its mission is to improve the care of patients by promoting research, education and optimal health care policies and standards. Founded in 1979 to address the scarcity of information about the diagnosis and treatment of cardiac arrhythmias, the Heart Rhythm Society is the preeminent professional group representing more than 3,700 specialists in cardiac pacing and electrophysiology in 64 countries.

The Heart Rhythm Society recommends the Subcommittee continue its commitment to supporting biomedical research in the United States and recommends Congress provide NIH with a 6 percent increase for fiscal year 2006. This translates into an appropriation of \$30 billion for NIH, with \$3.1 billion designated to the National Heart, Lung, and Blood Institute (NHLBI). This increase will enable the NIH and NHLBI to sustain the level of research that leads to research breakthroughs and improved health outcomes.

In particular, the Heart Rhythm Society recommends Congress support research into abnormal rhythms of the heart, known as cardiac arrhythmias. HRS appreciates the actions of Congress to double the budget of the NIH in recent years. The doubling of the NIH budget has served to promote a series of innovations that have improved treatments and cures for a variety of medical problems facing our nation.

#### RESEARCH ACCOMPLISHMENTS

In our field for example, this research has provided critically important insights into the genetic basis of sudden death syndrome, which takes the lives of infants, children and young adults born with inherited defects in the ion channels or contractile proteins of the heart. SIDS (Sudden Infant Death Syndrome) remains the leading cause of death for infants one month to one year of age, continuing to claim the lives of approximately 2,500 babies each year.<sup>1</sup> Our research has led to the recognition that sudden infant death syndrome is due, in part, to abnormal rhythms of the heart. This research is offering these babies a chance at a normal life span.

Major advances have also been realized in our ability to treat atrial fibrillation and to prevent the complications of stroke. Atrial fibrillation is found in about 2.2 million Americans and is an independent risk factor for stroke, increasing the risk about 5-fold. About 15–20 percent of strokes occur in people with atrial fibrillation. Stroke is a leading cause of serious, long-term disability in the United States and people who have strokes caused by AF have been reported as 2–3 times more likely to be bedridden compared to those who have strokes from other causes. Each year about 700,000 people experience a new or recurrent stroke and in 2002 stroke accounted for more than 1 of every 15 deaths in the United States.<sup>2</sup>

Ablation therapy has provided a cure for individuals whose rapid heart rates had previously incapacitated them, giving them a new lease on life. Important advances have been made in identifying patients with heart failure and those who had suffered a heart attack and are at risk for sudden death. The development and implantation of sophisticated internal cardioverter defibrillators (ICD) in such patients has saved the lives of hundreds of thousands and provided peace of mind for families

<sup>1</sup>First Candle/SIDS Alliance, Facts on SIDS, 2005 <http://www.sidsalliance.org/FC-PDF4/Expectant%20Parents/facts%20on%20sids.pdf>.

<sup>2</sup>American Stroke Association and American Heart Association, Heart Disease and Stroke Statistics—2005 Update, 2005 <http://www.americanheart.org/downloadable/heart/1105390918119HDSStats2005Update.pdf>.

everywhere, including that of Vice-President Cheney. A new generation of pacemakers and ICDs is restoring the beat of the heart as we grow older, permitting us to lead more normal lives. Many of these advances are due to the research sponsored by the NHLBI.

#### BUDGET JUSTIFICATION

These impressive strides notwithstanding, cardiac arrhythmias continue to plague our society and take the lives of loved ones at all ages, nearly one every minute of every day. Sudden Cardiac Arrest is a leading cause of death in the United States, claiming an estimated 325,000 lives every year, or one life every two minutes.<sup>3</sup> The burden of morbidity and mortality due to cardiac arrhythmias is predicted to grow dramatically as the baby boomers age. Atrial fibrillation strikes 3–5 percent of people over the age of 65,<sup>4</sup> presenting a skyrocketing economic burden to our society in the form of healthcare treatment and delivery. As previously mentioned one in seven of all strokes are due to atrial fibrillation. It is estimated in 2005 that the direct and indirect cost of stroke will be \$56.8 billion.<sup>5</sup> Cardiac diseases of all forms increase with advancing age, ultimately leading to the development of arrhythmias.

The above progress we have witnessed in recent years is gradually eroding as the resources available to the academic scientific and medical community are diminished. The budgets appropriated by Congress to the NIH in the past two years averaged 2.8 percent and were far below the level of scientific inflation. These vacillations in funding cycles threaten the continuity of the research and the momentum that has been gained over the years.

It is for this reason that we are asking for your support to increase NIH appropriations by 6 percent for a fiscal year 2006 budget of \$30 billion for NIH and \$3.1 billion for NHLBI. The Heart Rhythm Society recommends Congress specifically acknowledge the need for cardiac arrhythmia research to prevent sudden cardiac arrest and other life threatening conditions such as sudden infant death syndrome, definitive therapeutic approaches for atrial fibrillation and the prevention of stroke, and other genetic arrhythmia conditions.

Thank you very much for your consideration of our request. If you have any questions or need additional information, please contact Amy Melnick, Vice-President, Health Policy at the Heart Rhythm Society (amelnick@hrsonline.org or 202-464-3434). Thank you again for the opportunity to submit testimony.

#### PREPARED STATEMENT OF THE HEMOPHILIA FEDERATION OF AMERICA

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Continued support for the completion of Ricky Ray Hemophilia Relief Fund “half-cases”.
- An additional \$10 million for Hemophilia Treatment Centers through the Maternal Child Health Bureau at the Health Resources and Services Administration.
- Continued support for the Centers for Disease Control and Prevention’s hemophilia grant program, including expansion of the program to additional patient-based organizations within the hemophilia community.
- A 6 percent increase overall for the National Institutes of Health, including a 6 percent increase for the National Heart, Lung, and Blood Institute, and the National Institute for Allergy and Infectious Diseases.

##### INTRODUCTION

The Hemophilia Federation of America (HFA) is a national voluntary health organization that both assists and advocates for the blood clotting disorders community. The Federation was founded in 1994 and exists for the purpose of serving its constituents as an advocate for blood safety, best practices treatment for hemophilia, issues involving health insurance, and enhancing the quality of life for those who suffer with hemophilia and other blood clotting disorders. Our mission is to serve the needs of all families with coagulation disorders and mitigate the complications of treatment. Our vision at the Hemophilia Federation of America is that the blood

<sup>3</sup>Heart Rhythm Foundation, The Facts on Sudden Cardiac Arrest, 2004 [http://www.heartrhythmfoundation.org/its\\_about\\_time/pdf/provider\\_fact\\_sheet.pdf](http://www.heartrhythmfoundation.org/its_about_time/pdf/provider_fact_sheet.pdf).

<sup>4</sup>Heart Rhythm Society, Atrial Fibrillation & Flutter, 2005 [http://www.hrspatients.org/patients/heart\\_disorders/atrial\\_fibrillation/default.asp](http://www.hrspatients.org/patients/heart_disorders/atrial_fibrillation/default.asp).

<sup>5</sup>American Stroke Association, Impact of Stroke, 2005 <http://www.strokeassociation.org/presenter.jhtml?identifier=1033>.

clotting disorders community has removed all barriers to both choice of treatment and quality of life.

The Hemophilia Federation of America provides a multitude of programs and services to the bleeding disorder community. These programs include the Emergency Room Triage Program, which educates emergency room physicians and support staff to the sensitivities of patients with hemophilia need in an ER medical setting. The Moms on a Mission and Dads in Action programs work to intimately educate parents of those with hemophilia to be active in the care of their child and understand the care that the disorder needs to lead a healthy, productive life. The Helping Hands Project assists struggling families of hemophilia patients with resources to meet their medical and living expenses, because of the high costs of hemophilia treatment. HFA is proud of the services our organization provides to the hemophilia community and encourages the community to take advantage of them.

#### RICKY RAY HEMOPHILIA RELIEF FUND

Mr. Chairman, we are extremely grateful for your leadership last year in supporting efforts to finalize pending "half-cases" within the Ricky Ray Hemophilia Relief Fund.

The closing of the Ricky Ray fund in November of 2003 marked the completion of the 5-year period that the federal government designated to provide compassionate payments to those in the hemophilia community who were infected with HIV/AIDS due to contaminated anti-hemophilia factor concentrates in the 1980s.

In the closing days of the Fund, the program administrator contacted HFA to ask for our assistance in the completion of many unfinished cases. He brought to our attention 43 cases where the entitled family only received half of the compassionate payment, due to a parent's absence from a patient's life. The Ricky Ray Fund administrator asked the Federation to assist him in the adjudication of those cases that qualified for additional support. HFA would like to thank the subcommittee for its assistance in working with the community to provide the remaining payments and encourage you to continue this support until this process is completed.

#### HEMOPHILIA TREATMENT CENTERS/HEALTH RESOURCES AND SERVICES ADMINISTRATION

In 1974, Congress created a network of Hemophilia Treatment Centers (HTCs) throughout the United States. This treatment centers remain essential to ensuring that comprehensive and specialized care is available for persons with bleeding disorders. There are currently over 130 HTCs in the United States. These centers abide by federal guidelines for the delivery of comprehensive hemophilia services as developed by the Maternal Child Health Bureau and the Centers for Disease Control and Prevention.

Hemophilia Treatment Centers provide family centered, state of the art medical and psychosocial services, as well as education and research to persons with inherited bleeding disorders. The bleeding disorder community utilizes many services through the Hemophilia Treatment Centers. These services include diagnostic evaluations for hemophilia, von Willebrand disease and other bleeding disorders. They also include annual comprehensive evaluations, clinical trials on new blood clotting therapies, coordination with the individual's primary care physician, emergency consultations, hematological management for surgeries, dental procedures and child-birth. Hemophilia Treatment Centers educate patients and family members on infusion training, encourage collaboration with HTC clinicians throughout the United States, participate in CDC research, and collaboration with the hemophilia voluntary health community.

For fiscal year 2006 HFA encourages the subcommittee to increase funding for HTC's at the Maternal and Child Health Bureau by \$10 million.

#### HEMOPHILIA GRANT PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Mr. Chairman, HFA strongly supports the expansion of the Centers for Disease Control and Prevention's hemophilia grant program. This important initiative provides support for education and awareness activities regarding hemophilia, as well as disease management, blood safety, and surveillance projects.

Given the important contributions that all voluntary organizations in the hemophilia community make to patients and families, we are recommending that steps be taken to ensure that additional organizations can participate in the hemophilia program on an annual basis. Based on the current structure of the grant program, only one organization is able to receive funds to support patients. In order to maximize the effectiveness of this important initiative, we believe that additional organizations should be empowered to participate in the CDC program on an annual basis.

We encourage the subcommittee to support our efforts in this area in fiscal year 2006 bill.

NATIONAL INSTITUTES OF HEALTH

HFA applauds the National Heart, Lung and Blood Institute and the National Institute of Allergy and Infectious Diseases for their support of hemophilia research. In addition, we are grateful to the subcommittee for recognizing the growing problem of women and bleeding disorders, which if left untreated, can lead to such dangerous medical conditions as anemia, unnecessary hysterectomies, and complications during menstruation.

Patients and families in the hemophilia community are placing their hopes for a better quality of life on treatment advances made through biomedical research. For fiscal year 2006, we encourage the subcommittee to provide a 6 percent increase overall for NIH, and a 6 percent increase for NHBLI and NIAID.

Mr. Chairman, thank you for the opportunity to present the views of the Hemophilia Federation of America. If you have any questions, please do not hesitate to contact HFA's Washington Representative, Dale Dirks at (202) 544-7499.

PREPARED STATEMENT OF THE HEPATITIS FOUNDATION INTERNATIONAL

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

—Continue the great strides in research and prevention at the National Institutes of Health (NIH) by providing a 6 percent budget increase for fiscal year 2006. Increase funding for the National Institute for Allergy and Infectious Diseases (NIAID), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA) by 6 percent.

—\$41 million in fiscal year 2006 for a hepatitis B vaccination program for high risk adults at CDC as recommended by the National Hepatitis C Prevention Strategy.

—\$40 million in fiscal year 2006 for CDC's Prevention Research Centers.

—Continued support of the National Viral Hepatitis Roundtable.

Mr. Chairman and members of the subcommittee thank you for your continued leadership in promoting better research, prevention, and control of diseases affecting the health of our nation. I am Thelma King Thiel, Chairman and Chief Executive Officer of the Hepatitis Foundation International (HFI), representing members of 425 patient support groups across the nation, the majority of whom suffer from chronic viral hepatitis.

Currently, five types of viral hepatitis have been identified, ranging from type A to type E. All of these viruses cause acute, or short-term, viral hepatitis. Hepatitis B, C, and D viruses can also cause chronic hepatitis, in which the infection is prolonged, sometimes lifelong. While treatment options are available for all types of hepatitis, individuals with chronic viral hepatitis (types B, C, and D) represent the majority of liver failure and transplant patients. Treatment options and immunizations are available for most types of hepatitis (see below). However, all types of viral hepatitis are preventable.

HEPATITIS A

The hepatitis A virus (HAV) is contracted through fecal/oral contact (i.e. fecal contamination of food, or diaper changing tables if not cleaned properly), and sexual contact. In addition, eating raw or partially cooked shellfish contaminated with HAV can spread the virus. Children with HAV usually have no symptoms; however, adults may become quite ill suddenly experiencing jaundice, fatigue, nausea, vomiting, abdominal pain, dark urine/light stool, and fever. There is no treatment for HAV; however, recovery occurs over a 3 to 6 month period. About 1 in 1,000 with HAV suffer from a sudden and severe infection that may require a liver transplant. Luckily, a highly effective vaccine can prevent HAV. This vaccination is recommended for individuals who have chronic liver disease (i.e. HCV or HBV) or clotting factor disorders, in addition to those who travel or work in developing countries.

HEPATITIS B

Hepatitis B (HBV) claims an estimated 5,000 lives every year in the United States, even though we have therapies to both prevent and treat this disease. This disease is spread through contact with the blood and body fluids of an infected indi-



vidual. Unfortunately, due to both a lack in funding to vaccinate adults at high risk of being infected and the absence of an integrated preventive education strategy, transmission of hepatitis B continues to be problematic. Additionally, there are significant disparities in the occurrence of chronic HBV-infections. Asian Americans represent four percent of the population; however, they account for over half of the 1.3 million chronic hepatitis B cases in the United States. Current treatments have limited success in treating the chronically infected and there is no treatment available for those who are considered "HBV carriers". Preventive education and vaccination are the best defense against hepatitis B.

#### HEPATITIS C

Infection rates for hepatitis C (HCV) are at epidemic proportions. Unfortunately, as many are not aware of their infection until several years after infection, we are dealing with an "epidemic of discovery". This creates a vicious cycle, as individuals who are infected continue to spread the disease, unknowingly. Hepatitis C is also spread through contact with an infected individual's blood. The CDC estimates that there are over 4 million Americans who have been infected with hepatitis C, of which over 2.7 million remain chronically infected, with 8,000–10,000 deaths each year. Additionally, the death rate is expected to triple by 2010 unless additional steps are taken to improve outreach and education on the prevention of hepatitis C, new research is undertaken, and case-finding is enhanced and more effective treatments are developed. As there is no vaccine for HCV, prevention education and treatment of those who are infected serve as the most effective approach in halting the spread of this disease.

#### PREVENTION IS THE KEY

Only a major investment in immunization and preventive education will bring these diseases under control. All newborns, young children, young adults, and especially those who participate in high-risk behaviors must be a priority for immunization, outreach initiatives and preventive education. We recommend that the following activities be undertaken to prevent the further spread of all types of hepatitis:

- Provide effective preventive education in our elementary and secondary schools helping children avoid the ravages of health problems resulting from viral hepatitis infection.
- Training educators, health care professionals, and substance abuse counselors in effective communication and counseling techniques.
- Public awareness campaigns to alert individuals to assess their own risk behaviors, motivate them to seek medical advice, encourage immunization against hepatitis A and B, and to stop the consumption of any alcohol if they have participated in risky behaviors that may have exposed them to hepatitis C.
- Expansion of screening, referral services, medical management, counseling, and prevention education for individuals who have HIV/AIDS, many of whom may be co-infected with hepatitis.

HFI recommends an increase of \$41 million in fiscal year 2006 for further implementation of CDC's Hepatitis C Prevention Strategy. This increase will support and expand the development of state-based prevention programs by increasing the number of state health departments with CDC funded hepatitis coordinators. The Strategy will use the most cost-effective way to implement demonstration projects evaluating how to integrate hepatitis C and hepatitis B prevention efforts into existing public health programs. Additionally, HFI recommends that \$10 million be used to train and maintain hepatitis coordinators in every state.

CDC's Prevention Research Centers, an extramural research program, plays a critical role in reducing the human and economic costs of disease. Currently, CDC funds 26 prevention research centers at schools of public health and schools of medicine across the country. HFI encourages the Subcommittee to increase core funding for these prevention centers, as it has been decreasing since this program was first funded in 1986. We recommend the Subcommittee provide \$40 million for the Prevention Research Centers program in fiscal year 2005.

#### INVESTMENTS IN RESEARCH

Investment in the National Institutes of Health (NIH) has led to an explosion of knowledge that has advanced understanding of the biological basis of disease and development of strategies for disease prevention, diagnosis, treatment, and cures. Countless medical advances have directly benefited the lives of all Americans. NIH-supported scientists remain our best hope for sustaining momentum in pursuit of scientific opportunities and new health challenges. For example, research into why

some HCV infected individuals resolve their infection spontaneously may prove to be life saving information for others currently infected. Other areas that need to be addressed are:

- Reasons why African Americans do not respond to antiviral agents in the treatment of chronic hepatitis C.
- Pediatric liver diseases, including viral hepatitis.
- The outcomes and treatment of renal dialysis patients who are infected with HCV.
- Co-infections of HIV/HCV and HIV/HBV positive patients.
- Hemophilia patients who are co-infected with HIV/HCV and HIV/HBV.
- The development of effective treatment programs to prevent recurrence of HCV infection following liver transplantation.
- The development of effective vaccines to prevent HCV infection.

The Hepatitis Foundation International supports a 6 percent increase for NIH in fiscal year 2006. HFI also recommends a comparable increase of 6 percent in hepatitis research funding at the National Institute of Diabetes and Digestive and Kidney Diseases and the National Institute of Allergy and Infectious Diseases.

#### NATIONAL VIRAL HEPATITIS ROUNDTABLE

Victims of hepatitis suffer emotionally as well as physically. They experience discrimination in employment, strained personal relationships and severe depression when treatments fail to control their illness as well as during their treatment. Traditionally, however, there has not been an organized effort to periodically convene all stakeholder organizations that play a role in hepatitis prevention, education, treatment and patient advocacy. Successfully addressing viral hepatitis will require a comprehensive and strategic approach developed by all key stakeholders.

In order to fill this void, HFI and CDC co-founded the “National Viral Hepatitis Roundtable”. HFI believes that a National Viral Hepatitis Roundtable will enhance and assist CDC’s viral hepatitis mission for the prevention, control, and elimination of hepatitis virus infections in the United States, as well as the international public health community. It will provide an infrastructure for the sharing of information and education of all stakeholders.

The “National Viral Hepatitis Roundtable” is a coalition of public, private, and voluntary organizations dedicated to reducing the incidence of infection, morbidity, and mortality from viral hepatitis in the United States through research, strategic planning, coordination, advocacy, and leadership.

HFI is dedicated to the eradication of viral hepatitis, which affects over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle. Thank you for providing this opportunity to present our testimony.

#### THE HEPATITIS FOUNDATION INTERNATIONAL

The Hepatitis Foundation International (HFI) is dedicated to the eradication of viral hepatitis, a disease affecting over 500 million people around the world. We seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle.

Our mission has four distinct parts:

- Teach the public and hepatitis patients how to prevent, diagnose, and treat viral hepatitis.
- Prevent viral hepatitis by promoting liver wellness and healthful lifestyles.
- Serve as advocates for hepatitis patients and the related medical community worldwide.
- Support research into prevention, treatment, and cures for viral hepatitis.

#### PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide a 6 percent increase for fiscal year 2006 to the National Institutes of Health (NIH) budget. Within NIH, provide proportional increases of 6 percent to the various institutes and centers, specifically, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
- Continue to accelerate funding for extramural clinical and basic functional gastrointestinal research at NIDDK.
- Continue to urge NIDDK to develop a strategic plan setting research goals on IBS and functional bowel diseases and disorders.

- Urge NIDDK to develop a standardization of scales to measure incontinence severity and quality of life and to develop strategies for primary prevention of fecal incontinence associated with childbirth.
- Provide funding to NIDDK and the National Cancer Institute (NCI) for more research on the causes of esophageal cancer.

Chairman Specter and members of the Subcommittee, thank you for the opportunity to present this written statement regarding the importance of functional gastrointestinal and motility research.

IFFGD has been serving the digestive disease community for fourteen years. We work to broaden the understanding about functional gastrointestinal and motility disorders in adults and children.

IFFGD speaks about and raises awareness on disorders and diseases that many people are uncomfortable and embarrassed to talk about. The prevalence of fecal incontinence and irritable bowel syndrome, as well as a host of other gastrointestinal disorders affecting both adults and children, is underestimated in the United States. These conditions are truly hidden in our society. Not only are they misunderstood, but the burden of illness and human toll has not been fully recognized.

Given that we have been diligently working for the past thirteen years, it is an exciting time to work for IFFGD, not only are we serving more and more people, but we are beginning to be able to privately fund research. Our first research awards were made on April 6, 2003.

Since its establishment, the IFFGD has been dedicated to increasing awareness of functional gastrointestinal disorders and motility disorders, among the public, health professionals, and researchers. In November of 2002, we hosted a conference on fecal and urinary incontinence, the proceedings of which were published in *Gastroenterology*, the Official Journal of the American Gastroenterological Association. During the first week of April 2003 we also hosted the Fifth International Symposium on Functional Gastrointestinal Disorders, which was a great success in bringing scientists from across the world together to discuss the current science and opportunities on irritable bowel syndrome and other functional gastrointestinal and motility disorders. The IFFGD has become known for our professional symposia. We consistently bring together a unique group of international multidisciplinary investigators to communicate new knowledge in the field of gastroenterology. In 1 week, we will be holding the Sixth International Symposium on Functional Gastrointestinal Disorders.

The majority of the diseases and disorders we address have no cure. We have yet to understand the pathophysiology of the underlying conditions. Patients face a life of learning to manage chronic illness that is accompanied by pain and an unrelenting myriad of gastrointestinal symptoms. The costs associated with these diseases are enormous, conservative estimates range between \$25–\$30 billion annually. The human toll is not only on the individual but also on the family. Economic costs spill over into the workplace. In essence these diseases reflect lost potential for the individual and society. The IFFGD is a resource and provides hope for hundreds of thousands of people as they try to regain as normal a life as possible.

#### FECAL INCONTINENCE

At least 6.5 million Americans suffer from fecal incontinence. Incontinence is neither part of the aging process nor is it something that affects only the elderly. Incontinence crosses all age groups from children to older adults, but is more common among women and in the elderly of both sexes. Often it is a symptom associated with various neurological diseases and many cancer treatments. Yet, as a society, we rarely hear or talk about the bowel disorders associated with multiple sclerosis, diabetes, colon cancer, uterine cancer, and a host of other diseases.

Damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction can cause fecal incontinence. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most try to hide the problem as long as possible, so they withdraw from friends and family. The social isolation is unfortunate but may be reduced because treatment can improve bowel control and make incontinence easier to manage.

In November 2002, the International Foundation for Functional Gastrointestinal Disorders (IFFGD) sponsored a consensus conference—"Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities." Among other outcomes, the conference resulted in six key research recommendations:

1. More comprehensive identification of quality of life issues associated with fecal incontinence and improved assessment and communication of treatment outcomes related to quality of life.
2. Standardization of scales to measure incontinence severity and quality of life.
3. Assessment of the utility of diagnostic tests for affecting management strategies and treatment outcomes.
4. Development of new drug compounds offering new treatment approaches to fecal incontinence.
5. Development and testing of strategies for primary prevention of fecal incontinence associated with childbirth.
6. Further understanding of the process of stigmatization as it applies to the experience of individuals with fecal incontinence.

#### IRRITABLE BOWEL SYNDROME (IBS)

Irritable Bowel Syndrome affects approximately 30 million Americans. This chronic disease is characterized by a group of symptoms, which can include abdominal pain or discomfort associated with a change in bowel pattern, such as loose or more frequent bowel movements, diarrhea, and/or constipation. Although the cause of IBS is unknown, we do know that this disease needs a multidisciplinary approach in research and treatment.

Similar to fecal incontinence and depending on severity, IBS can be emotionally and physically debilitating. Because of persistent bowel irregularity, individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home.

In the House and Senate fiscal year 2003, 2004, and 2005 Labor, Health and Human Services, and Education Appropriations bills, Congress recommended that the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) develop an IBS strategic plan. The development of a strategic plan on IBS would greatly increase the institute's progress toward the needed research on this functional gastrointestinal disorder.

#### GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a very common disorder affecting both adults and children, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. But sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. Periodic heartburn is a symptom that many people experience. There are several treatment options available for individuals suffering from GERD.

Gastroesophageal reflux (GER) affects as many as one third of all full term infants born in America each year. GER results from an immature upper gastrointestinal motor development. The prevalence of GER is increased in premature infants. Many infants require medical therapy in order for their symptoms to be controlled. Up to 25 percent of older children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction. In this population, the natural history of GER is similar to that of adult patients, in whom GER tends to be persistent and may require long-term treatment.

#### ESOPHAGEAL CANCER

Approximately 13,000 new cases of esophageal cancer are diagnosed every year in this country. Although the causes of this cancer are unknown, it is thought that this cancer may be more prevalent in individuals who develop Barrett's esophagus. Diagnosis usually occurs when the disease is in an advanced stage, early screening tools are currently unavailable.

#### CHILDHOOD DEFECATION DISORDERS AND DISEASES

*Chronic Intestinal Pseudo-Obstruction (CIP).*—About 200 new cases of CIP are diagnosed in American Children each year. Often life threatening, the future for children severely affected with CIP is brightened by the evolving promise of cure with intestinal or multi-organ transplantation.

*Hirschsprung's disease.*—A serious childhood and sometimes life-threatening condition that can cause constipation, occurs only once in every 5,000 American children born each year. Approximately 20 percent of children with HD will continue

to have complications following surgery. These complications include infection and/or fecal incontinence.

*Functional constipation.*—Millions of children (1 in every 10) each year will be diagnosed with functional constipation. In fact, it is the chief complaint of 3 percent of pediatric outpatient visits and 10–25 percent of pediatric gastroenterology visits.

FUNCTIONAL GASTROINTESTINAL AND MOTILITY DISORDERS AND THE NATIONAL  
INSTITUTES OF HEALTH

The International Foundation for Functional Gastrointestinal Disorders recommends an increase of 6 percent or 1.7 billion for NIH overall, and a 6 percent increase for NIDDK. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We urge the subcommittee to provide the necessary funding for the expansion of the NIDDK's research program on functional gastrointestinal (FGI) and motility disorders, this increased funding will allow for the growth of new research, a prevalence study and a strategic plan on IBS, and increased public and professional awareness of FGI and motility disorders.

A primary tenant of IFFGD's mission is to ensure that clinical advancements concerning GI disorders result in improvements in the quality of life of those affected. By working together, this goal will be realized and the suffering and pain millions of people face daily will end.

Thank you.

*The International Foundation for Functional Gastrointestinal Disorders*

The International Foundation for Functional Gastrointestinal Disorders is a non-profit education and research organization founded in 1991. IFFGD addresses the issues surrounding life with gastrointestinal (GI) functional and motility disorders and increases the awareness about these disorders among the general public, researchers, and the clinical care community.

PREPARED STATEMENT OF THE LYMPHOMA RESEARCH FOUNDATION

I am Melanie Smith, Director of Public Policy and Advocacy for the Lymphoma Research Foundation (LRF). LRF appreciates the opportunity to submit this statement to the record of the Labor, Health and Human Services and Education Appropriations Subcommittee. The LRF is the nation's largest lymphoma-focused voluntary health organization devoted exclusively to funding lymphoma research and providing patients and healthcare professionals with critical information on the disease. Our ultimate goal is to find a cure for all forms of lymphoma. To that end, we fund some of the world's leading lymphoma researchers at outstanding academic institutions. These researchers are engaged in research aimed at understanding the basic mechanisms of lymphoma and improving the current treatments for the disease. LRF also aims to equip those who are diagnosed with lymphoma with up-to-date information about treatment options. The organization sponsors educational conferences at which the leaders in lymphoma research and treatment address patients and families regarding cutting edge research and the most recent developments in therapies.

BACKGROUND ON LYMPHOMA

Lymphoma is a major health problem. It is the most common form of blood cancer and the third most common form of childhood cancer. In 2005, approximately 56,390 cases of non-Hodgkin's lymphoma (NHL) will be diagnosed in this country, and more than 19,000 Americans will die from NHL. Also this year, 7,350 cases of Hodgkin's lymphoma will be diagnosed, and more than 1,400 Americans will die from the disease. Nearly 500,000 Americans are living with lymphoma.

In recent years, there have been exciting reports regarding the improvements in treatments for a number of forms of cancer, as well as reports that the incidence of cancer overall is declining. Regrettably, NHL stands in contrast to the general trends in cancer incidence, and the treatment options for NHL remain inadequate. Since the early 1970s, incidence rates for NHL have nearly doubled, although incidence rates have stabilized the last few years. And the 5-year survival rate for NHL stands at 59 percent. These are not satisfactory numbers, and they serve as measures of the work we still have to do.

## RESEARCH ON LYMPHOMA

We have learned a great deal about the genetic, molecular, and cellular basis of cancer. We do not know the cause of most lymphomas, but there is increasing information to suggest a link between environmental factors and infections and the development of many lymphomas. The environmental factors may include chemicals, toxins, drugs, infectious agents, such as hepatitis C and Epstein Barr virus, and the gastric pathogen *Helicobacter pylori*. There is strong evidence that in some individuals, immune dysfunction is a critical factor in the development of lymphoma.

Our knowledge of cancer has improved significantly in the last decade, in large part due to the strong commitment of Congress to the National Institutes of Health (NIH) and its willingness to boost NIH funding. These funds have supported strong basic and clinical researchers who are focused on unlocking the secrets to cancer. There is a need to sustain that commitment to NIH, in order to equip scientists engaged in basic research and facilitate the translation of basic research findings into new treatments. This is certainly true in the case of lymphoma. There is a need to clarify the interactions among the environmental, viral, and immunogenetic factors that contribute to development of lymphoma and to ensure the development of new treatments based on our enhanced understanding of lymphoma.

Over the last decade several new lymphoma treatments have been developed, expanding the options for those who are diagnosed with the disease. Lymphoma patients and researchers have clearly benefited from the nation's significant investment in research, and Congress deserves the appreciation of the community of lymphoma patients and researchers. Among the lymphoma treatments approved in the last decade are a monoclonal antibody and two different radioimmunotherapies. While we applaud the new treatments of the last decade, they are not magic bullets. For many, lymphoma remains a fatal disease.

New therapies that capitalize on different research approaches are currently under investigation. These include therapeutic vaccines, immunotherapies, proteasome inhibitors, and examination of the microenvironment of lymphomas. Other work is focused on refining the chemotherapy regimens and developing treatment regimens with lower toxicities. All of this work deserves the support of private and public research funders.

## ROLE OF NIH IN LYMPHOMA RESEARCH

Although LRF plays a critical and creative role in funding lymphoma research, NIH is, and will remain, the key player in this field. NIH is the pivotal player not only because of the magnitude of its financial commitment to lymphoma research, but also because of the role it can play in bringing together all of the partners in the research community—NIH intramural researchers, academic researchers, private foundations, industry, and the Food and Drug Administration (FDA).

NIH is also in the best position to encourage, facilitate, and fund the translation of basic research findings into new treatments. It is absolutely critical that we not lose the research momentum that has been the result, in significant part, because of the doubling of the NIH budget between fiscal year 1999 and fiscal year 2003. We recognize that funding for NIH will not be increased as rapidly in the near future as it was from fiscal year 1999 to fiscal year 2003, but we urge Congress to protect the investment in NIH research and to realize that a rapid deceleration in research funding threatens the past investment.

LRF recommends that Congress urge NIH to direct special attention to translational and clinical research. LRF proposes that NIH strengthen its lymphoma research program by several actions:

- The National Cancer Institute (NCI) should boost its support for translational and clinical lymphoma research. NCI should evaluate its current investment in clinical research and expand or initiate programs to strengthen the clinical research effort.
- NCI should also increase its support for correlative studies of tumor biology and treatment response, as well as its investment in research on the late and long-term effects of current lymphoma treatments.
- NCI should strengthen its research effort focused on understanding the complex interaction among environmental, viral and immunogenetic factors that are involved in the initiation and promotion of lymphoma.
- Although NCI has historically been the lead institute in funding lymphoma research, other institutes—the National Heart, Lung, and Blood Institute (NHLBI), the National Institute on Aging (NIA), and the National Institute of Environmental Health Sciences (NIEHS)—should also evaluate and improve their lymphoma research programs. A lymphoma-focused program to investigate environmental/viral links is warranted.

A strong partnership among voluntary health agencies like LRF, academic researchers, industry, and NIH will be optimal for advancing lymphoma research and improving the outlook for those who are diagnosed with the disease. New strategies are necessary for the rapid translation of basic research findings into new treatments. These strategies may include systems for funding collaborative research projects that engage researchers in multiple institutions and multiple disciplines, including academic researchers and industry. Private foundations are looking at creative means to ensure that their research dollars are optimized, and we encourage NIH to employ the same creative and flexible approaches.

ROLE OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION IN BLOOD CANCER EDUCATION

LRF is actively engaged in providing patients and their families and caregivers complete and up-to-date information about lymphoma, lymphoma research, and lymphoma treatment options. Because of our strong history in this area, we were gratified when Congress authorized and funded a program at the Centers for Disease Control and Prevention (CDC) for public and patient education on blood cancers. LRF was one of nine organizations that received grants, funded by fiscal year 2004 appropriations, for public and patient education regarding the blood cancers. The benefits of our federally funded program, Lymphoma Awareness for Multicultural Populations (LAMP), which includes outreach to underserved communities, are already being realized.

Congress was also generous in providing funding for this program in fiscal year 2005, an action that will allow the organizations to continue their programs and conduct full evaluations of their strategies for outreach and education. We urge Congress to provide a third year of funding, because the programs are being operated on a 3-year cycle. Their full potential will be realized only if they run for the full 3-year anticipated cycle.

LRF believes that strong partnerships will be a key feature of efforts to improve lymphoma treatments and provide lymphoma patients current information about their disease and treatment options. We encourage NCI to fund collaborative research ventures, and we urge CDC to continue its support of those private organizations that have years of experience in patient education. Those who receive a diagnosis of lymphoma face difficult choices, and we must work together to improve their options and their lives.

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PREPARED STATEMENT OF MENDED HEARTS, INC.

I am Robert H. Gelenter, a volunteer for the Mended Hearts, Inc., a national heart disease patient support group with more than 289 chapters across the United States and in Canada. We visit patients in approximately 460 hospitals throughout the United States. I have been appointed by the group to assist in this lobbying effort—a volunteer position.

More than 29 years ago, I was diagnosed with a rare heart disease. After having severe chest pains and trouble breathing for more than two years, I was diagnosed with hypertrophic cardiomyopathy (HCM), a disease in which the heart enlarges. The heart muscle eventually thickens so much that it can't pump blood effectively. The heart muscle does not grow in the normal parallel patterns. Rather it grows in a haphazard manner. It affects men and women of all ages. When you read of a young athlete who has dropped dead on an athletic field the odds are very good that he or she had HCM. HCM is one of the leading causes of sudden cardiac death. There is no cure for this disease.

Medication may work and there is a surgical procedure that may alleviate the pain. If that doesn't work a patient may need a heart transplant, yet spare organs are scarce. The doctor who made my diagnosis was trained at the National Heart, Lung, and Blood Institute of the National Institutes of Health.

Initially, I received several medications, which allowed me to engage in most activities. But, some activities, such as walking up hills, caused severe shortness of breath and severe chest pains. But, generally I could function normally. However, after about 11 years, the discomfort was increasing, and it became apparent that I was in serious trouble. I could not walk 60 feet without having to stop to catch my breath. Sometimes the pain was so great that I would almost double over in the middle of the street. My wife told me that my face would become gray. The perspiration would pour off my body. If I was lucky I could find a chair to sit on. The quality of my life had deteriorated so drastically that I knew I needed some treatment.

In 1988, I went to Georgetown University Medical Center for an angiogram—the gold standard for diagnosing heart problems. The cardiologist who performed the

angiogram told me that he had bad news and worse news. The bad news was that I had a 95 percent blockage in my left anterior descending heart artery—the so-called “widow makers spot.” The worse news was that I had a major chance of having a severe heart attack with a less than a 5 percent chance of surviving that heart attack because of the hypertrophic cardiomyopathy. At this point, my wife was quietly crying and I was perspiring profusely. Since Georgetown University Medical Center did not have the expertise to operate on me, they called the NIH to see if they would accept me as a patient. I was sent home pending notice from the NIH.

The NIH accepted me. After entering the National Heart, Lung, and Blood Institute on February 6, I was operated on February 11, 1988. No matter how trite the expression—that was the first day of the rest of my life. The surgery, considered drastic and rare as it is, is still the gold standard throughout the world for the treatment of hypertrophic cardiomyopathy. The Morrow Procedure, in honor of the innovator, was developed and improved at the NIH.

Although this surgery is no longer performed at the National Heart, Lung, and Blood Institute, there is another experimental ongoing protocol in which the same effect is being attempted by using alcohol to deaden the excessive heart tissue.

I am on medication for the rest of my life. My condition is progressive. Ten years ago, I was fitted with a pacemaker to insure that my heart beats at the correct rate. I am 100 percent dependent on this pacemaker. Without the pacemaker, there are times when my normal heart beat is so slow that I would die.

I am eternally grateful to the physicians funded by the National Heart, Lung, and Blood Institute, particularly to Dr. MacIntosh and his staff, for the gift of life. Because of this marvelous research supported by the NHLBI, I have lived 17 years pain free. I have seen two children graduate from college and three grandchildren born, I have shared these years with a wonderful wife. I have been able to work at my profession—attorney at law.

I have had the gift of life restored to me. To express my gratitude for that gift, I visit patients recovering from heart episodes at two hospitals, Washington Hospital Center and Washington Adventist Hospital.

If this tale of woe is not enough about 2½ years ago, I suddenly began to have mini strokes. I experienced four episodes within 7 months. The last episode was just a year ago. Medication now seems to have the incidents under control.

I respectfully ask for the fiscal year 2006 appropriation in the following amounts:

—NIH \$30 billion, including \$2.3 billion for heart research and \$341 million for stroke;

—NHLBI \$3.1, including \$1.9 billion for heart and stroke-related research; and

—NINDS \$1.6 billion, including \$183 million for stroke research.

My experience is proof that the research supported by the National Heart, Lung, and Blood Institute and the National Institute for Neurological Disorders and Stroke benefits not just the patients at the NIH Clinical Center, but throughout the United States. The benefits go worldwide as well.

Heart attack, stroke and other cardiovascular diseases remain the No. 1 killer and major cause of disability of men and women in the United States. Nearly 40 percent of people who die in the United States die from cardiovascular diseases. Last year, nearly 930,000 Americans died from cardiovascular diseases, including more than 150,000 under the age of 65.

Thank you for your support of National Heart, Lung, and Blood Institute's heart research and the National Institute for Neurological Disorders and Stroke's stroke research.

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#### PREPARED STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The 3 million volunteers and 1,400 staff members of the March of Dimes appreciate the opportunity to submit the Foundation's federal funding recommendations for fiscal year 2006. The March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants, and children by preventing birth defects and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 52 chapters in every state, the District of Columbia and Puerto Rico.

The volunteers and staff of the March of Dimes are deeply concerned that the funding recommendations and levels in the President's Budget and congressional Budget Resolutions will not be sufficient to support biomedical research and services needed to improve the health of children and families. For instance, the infant mortality rate increased in 2002 for the first time since 1958. Increases in deaths due



to premature birth, birth defects, and maternal complications during pregnancy account for most of the increase. In our judgment, the funding increases recommended below are fully justified and would have an immediate positive impact on this disturbing trend and thereby lead to an overall improvement in the health of the nation's children.

#### NATIONAL INSTITUTES OF HEALTH

The March of Dimes joins the larger research community in recommending a 6 percent increase in funding for the National Institutes of Health (NIH), bringing total federal support to just over \$30 billion. The Administration's fiscal year 2006 budget proposal is insufficient to keep up with inflation and certainly will not sustain the necessary investment in medical research.

##### *National Institute for Child Health and Human Development*

The mission of the National Institute for Child Health and Human Development (NICHD) is closely aligned with that of the March of Dimes. According to the National Center for Health Statistics (NCHS), in 2002, more than 480,000 babies were born prematurely in the United States—1 in 8 births. Premature birth accounts for nearly 24 percent of deaths in the first month of life. Those babies that survive are more likely than full-term infants to face serious multiple health problems including cerebral palsy, mental retardation, chronic lung disease, and vision and hearing loss. Preterm labor can happen to any pregnant woman and the causes of nearly half of all preterm births are unknown.

The NICHD has made a major commitment to understanding and preventing premature birth but additional funding is desperately needed. The March of Dimes recommends a 10 percent increase for NICHD in fiscal year 2006 and an increase of at least \$100 million over the next five years to boost prematurity-related research. This increase should be devoted to a comprehensive biomedical research program to study preterm delivery etiology, prevention, and treatment regimens.

Last year, the NCHS reported the first increase in the U.S. infant mortality rate since 1958 and 61 percent of this increase was due to an increase in the birth of premature and low birth weight babies. An analysis of Agency for Healthcare Research and Quality data conducted by the March of Dimes Perinatal Data Center estimated that the total national hospital bill for premature babies was \$15.5 billion in 2002. The financial burden of prematurity is expected to continue to worsen until prevention of preterm births is better understood and clinical interventions are developed.

The NICHD began a major new initiative involving genomic and proteomic research into the causes of premature birth in an effort to accelerate knowledge in the mechanisms responsible for premature birth. The RFA soliciting proposals for the establishment of a collaborative network for premature birth research was issued in June 2004. The NICHD received an excellent response to this RFA and had anticipated the start of this initiative in early 2005. The March of Dimes is very disturbed that the start of this crucial initiative has now been delayed because of insufficient funding.

Unfortunately, even a 10 percent increase in funding would not be enough to enable NICHD to begin implementing the National Children's Study (NCS) of environmental and genetic influences on child health and development. The goal of the NCS is to pinpoint causes and find prevention and treatment strategies for many of today's childhood diseases and disorders. The planning of the study is largely complete and the study is ready to be piloted. On November 16, 2004, the Request for Proposals for the first NCS study sites and the data-coordinating center were published. But beyond the pilot sites, the future of this important study is uncertain without additional funding. The cost of this study is dwarfed by the \$269 billion annual cost of treating the diseases and conditions it is designed to address, including preterm birth, according to NICHD estimates. If study findings were to result in only a 1 percent reduction in those costs, the expense of the entire study could be recovered in a single year. The March of Dimes believes it would be shortsighted to put off this study.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

##### *Division of Reproductive Health*

The National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health works to promote optimal reproductive and infant health, but does not have the resources it requires to study the growing problem of preterm birth. Therefore, the March of Dimes recommends a \$20 million increase in fiscal year 2006 to expand research related to preterm birth. Worsening rates of

preterm birth require an expanded, comprehensive prevention research agenda to identify the causes, risk factors, and to find clinical interventions that are effective in preventing preterm labor. In particular, two specific programs should receive additional funding: (1) the Pregnancy Risk Assessment Monitoring System and (2) epidemiological research.

The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state-specific, population based surveillance system designed to identify and monitor maternal behaviors and experiences before, during, and after pregnancy. Currently, CDC supports cooperative agreements with 29 states and New York City through which PRAMS monitors approximately 62 percent of all U.S. births. Data collected through PRAMS is used by researchers and policy makers to increase understanding of adverse pregnancy outcomes, to develop maternal and child health programs, and to incorporate the most up to date research findings into standards of practice. The March of Dimes recommends an increase of \$5 million to expand PRAMS so that CDC can develop better national estimates on behavioral as well as demographic risk factors for preterm birth.

Epidemiological research conducted at CDC is vital to reducing the incidence of preterm birth. The March of Dimes recommends an increase of \$15 million to expand research on the prevention of preterm delivery for women at risk, focusing especially on factors contributing to higher rates of preterm delivery among African-American women. Increasing CDC's activities related to identifying the causes of preterm birth would improve early detection of women at risk for preterm labor and lead to new interventions for those at greatest risk.

#### *National Center on Birth Defects and Developmental Disabilities*

Created by the Children's Health Act of 2000 (Public Law 106-310), the National Center on Birth Defects and Developmental Disabilities (NCBDDD) conducts programs to protect and improve the health of children and adults by preventing birth defects and developmental disabilities; promoting optimal child development and health and wellness among children and adults with disabilities. The March of Dimes recommends at least \$135 million in fiscal year 2006 funding for the NCBDDD.

Of particular interest to the March of Dimes is the NCBDDD's comprehensive birth defects program that includes surveillance, research and prevention activities. Of the four million babies born each year in the United States, 3 percent are born with one or more birth defects. Birth defects are the leading cause of infant mortality, accounting for more than 20 percent of all infant deaths. Children with birth defects who survive often experience lifelong physical and mental disabilities. In fact, birth defects contribute substantially to the nation's health care costs. According to CDC, the medical treatments and supportive services for the 17 most common birth defects exceed \$8 billion annually. A modest increase of \$6 million in funding for surveillance, research and prevention activities is a vital step to making progress in reducing the incidence of birth defects.

NCBDDD provides funding to states to develop, implement, and/or expand community-based birth defects surveillance systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. Surveillance is vitally important for the early detection of new birth defects, for discovering the causes of birth defects and for evaluating the effectiveness of prevention programs. Due to lack of funds, CDC will only fund 15 states in fiscal year 2005, down from 28 states in fiscal year 2004. Additional resources are needed to fund all states seeking CDC assistance and increase assistance to states already receiving funds.

The National Birth Defects Prevention Study is the largest case-control study of birth defects ever conducted. This CDC-funded study is being carried out by 9 regional Centers for Birth Defects Research and Prevention located in Arkansas, California, Georgia, Iowa, Massachusetts, New York, North Carolina, Texas, and Utah. These centers obtain data and identify cases for inclusion in the study and conduct epidemiological research on birth defects. With adequate funding, this study has the potential to dramatically increase understanding of the causes of birth defects and is already providing information for improvement of programs to prevent birth defects. The causes of nearly 70 percent of birth defects are still unknown.

The centers study possible genetic and environmental causes, the use of certain medications during pregnancy, maternal diet, and vitamin use. This study provides the nation a continuing source of information on potential causes of birth defects. For example, in response to a scientific study showing a possible association between the drug loratadine, also sold under the brand name Claritin®, and the occurrence of the birth defect hypospadias the National Birth Defects Prevention Study

conducted a review that showed no association. This information is useful to physicians as well as women who take loratadine and become pregnant.

The NCBDDD also is conducting a national public and health professions education campaign designed to increase the number of women taking folic acid. CDC estimates that up to 70 percent of neural tube defects (NTDs), serious birth defects of the brain and spinal cord including anencephaly and spina bifida, could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. Since fortification of U.S. enriched grain products with folic acid, the rate of NTDs in the United States has decreased by 26 percent. It is critical that CDC increase its campaign efforts to educate every woman of childbearing age and their providers about the importance of folic acid to further reduce the rates. Therefore, the March of Dimes recommends an appropriation of at least \$4 million in fiscal year 2006 for the Folic Acid Education Campaign.

#### ADDITIONAL CDC PROGRAMS

##### *National Immunization Program*

If we are to meet the Healthy People 2010 goals of vaccinating 90 percent of children and adults, CDC, states and localities will need sufficient resources to ensure that those in need of immunizations receive them. Annually, 4 million children should be immunized against 12 preventable diseases before the age of two. Yet, nearly 25 percent of two-year-olds have not received all of the recommended vaccine doses. CDC's National Immunization Program provides grants to 64 state, local, and territorial public health agencies to reduce the incidence of disability and death resulting from vaccine preventable diseases. To move the nation closer to the goal of vaccinating at least 90 percent of children and adults, the March of Dimes urges the Subcommittee to continue its longstanding policy of ensuring that federal vaccine programs are adequately funded. For fiscal year 2006, the March of Dimes recommends an overall increase of \$232 million in order to ensure that the National Immunization Program has the resources it needs to account for vaccine price increases, introduction of new vaccines, and to facilitate implementation of recommendations developed by the Institute of Medicine.

##### *Polio Eradication*

April 12, 2005 marks the 50th anniversary of the declaration that the poliovirus vaccine developed by Dr. Jonas Salk was safe and effective. The March of Dimes, formerly known as the National Foundation for Infantile Paralysis, funded Dr. Salk's groundbreaking work on the polio vaccine. Although eradication of polio in the United States resulted in a shift in the Foundation's focus to a new set of challenges pertaining to children's health, the March of Dimes continues to support completing the task of polio eradication worldwide. Global polio eradication will save lives and reduce unnecessary health-related costs. The March of Dimes supports a funding level of \$106.4 million for CDC's fiscal year 2006 global polio eradication activities. With polio epidemics now confined to only 6 countries (Nigeria, India, Pakistan, Niger, Egypt and Afghanistan), it is important that the U.S. government maintain its commitment to completion of the worldwide eradication initiative.

##### *National Center for Health Statistics*

The Foundation also supports the vital work of the National Center for Health Statistics (NCHS), which provides data essential for research and programmatic initiatives. For example, the National Vital Statistics System is a major source of information on the utilization of prenatal care and on adverse birth outcomes such as preterm births, low birthweight, and infant mortality. Increased funding would allow CDC to modernize this system using web-based technology that facilitates rapid compilation of accurate and comprehensive data obtained from health professionals and facilities. This information is needed to track trends in birth outcomes and to support birth defects registries. Data from NCHS' surveys are also important to identify emerging trends and optimal uses of existing program resources. Additional resources would also enable CDC to continue the National Survey of Family Growth, which provides essential information on factors affecting birth outcomes.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

##### *Newborn Screening*

Newborn screening is a vital public health activity used to identify genetic, metabolic, hormonal and/or functional conditions in newborns that left untreated can cause disability, mental retardation, and even death. Although nearly all babies born in the United States are screened for some genetic birth defects, the number and quality of these tests varies from state to state. The March of Dimes rec-

ommends that every baby born in the United States receive, at a minimum, screening for a core set of 29 metabolic disorders including hearing deficiencies.

In fiscal year 2005, the Congress provided funding for implementation of Title XXVI of the Children's Health Act of 2000. This program is designed to strengthen state newborn screening programs; to improve states' ability to develop, evaluate, and acquire innovative testing technologies; and to establish and improve programs to provide screening, counseling, testing and special services for newborns and children at risk for heritable disorders. Unfortunately, funding for Title XXVI activities was obtained by diverting a portion of the SPRANS section of the Maternal and Child Health Block Grant which the Administration proposes to level fund in fiscal year 2006. The March of Dimes recommends that Title XXVI of the Children's Health Act be funded at a level of \$25 million in new money to support HRSA's work with states to improve newborn screening programs across the nation.

*Maternal and Child Health Block Grant*

Federal funding for Title V of the Social Security Act, the Maternal and Child Health (MCH) Block Grant, has failed to keep pace with increased demand for services. Although the Block Grant provides funds for a growing number of community-based programs such as home visiting, respite care for children with special health care needs and "wrap around" services for pregnant women and children enrolled in Medicaid and SCHIP, the funding level for the Grant has not increased since fiscal year 2002. In order for maternal and child health programs to continue to shoulder responsibility for additional services, it must be adequately funded. The March of Dimes recommends fully funding Title V at the authorized level of \$850 million.

Thank you for the opportunity to testify on the federally supported programs of highest priority to the March of Dimes. The Foundation's staff and volunteers look forward to working with Members of the Subcommittee to improve the health of mothers, infants and children.

MARCH OF DIMES FISCAL YEAR 2006 FEDERAL FUNDING PRIORITIES

[In millions of dollars]

Program	Fiscal year 2005 funding	March of Dimes fiscal year 2006 recommendation
National Institutes of Health (Total) .....	28,444.0	30,150.0
National Institute of Child Health & Human Development .....	1,270.0	1,397.0
National Human Genome Research Institute .....	489.0	518.0
National Center on Minority Health and Disparities .....	196.0	208.0
Centers for Disease Control and Prevention (Total) .....	8,034.0	8,650.0
Center on Birth Defects and Developmental Disabilities .....	125.0	135.0
Birth Defects Research & Surveillance .....	14.0	20.0
Folic Acid Education Campaign .....	2.0	4.0
Immunization .....	479.0	711.0
Polio Eradication .....	106.4	106.4
Safe Motherhood/Infant Health (NCCDPHP) .....	45.0	65.0
Pregnancy Risk Assessment Monitoring System .....	7.3	12.3
Prevention Research (Preterm Birth) .....	1.5	16.5
National Center for Health Statistics .....	109.0	118.0
Health Resources and Services Administration (Total) .....	6,809.0	7,500.0
Maternal and Child Health Block Grant .....	730.0	850.0
Newborn Screening .....	2.0	25.0
Newborn Hearing Screening .....	10.0	10.0
Consolidated (Community) Health Centers .....	1,734.0	2,038.0
Healthy Start .....	102.0	102.0
Agency for Healthcare Research and Quality .....	319.0	440.0

PREPARED STATEMENT OF THE NATIONAL COALITION FOR HEART AND STROKE RESEARCH

My name is Jack Owen Wood. I solicit your support for more aggressive federal funding for research into prevention and treatment of the sister diseases, stroke and heart disease. Strokes and heart attacks are occurring at an alarming rate.

I am representing the National Coalition for Heart and Stroke Research. The coalition consists of 18 national organizations representing more than 5 million volun-

teers and members united in support for increased funding for heart and stroke research. Members of the Coalition include:

American Academy of Neurology; American Academy of Physical Medicine and Rehabilitation; American Association of Neurological Surgeons; American College of Cardiology American College of Chest Physicians; American Heart Association; American Neurological Association; American Stroke Association; American Vascular Association Foundation; Association of Black Cardiologists; Children's Cardiomyopathy Foundation, Inc.; Citizens for Public Action on Blood Pressure and Cholesterol, Inc.; Congress of Neurological Surgeons; Heart Rhythm Society; Mended Hearts, Inc.; National Stroke Association; Society of Interventional Radiology; and Society for Vascular Surgery.

I will deal primarily with one man's personal experience with stroke and its functional and financial costs—my own. I have only the use of my right arm.

I was born in 1937, raised in Vicksburg, Mississippi, earned an engineering degree at Mississippi State University and currently reside in Port Orchard, Washington. I worked for the Boeing Company in Seattle, am a former Director of the Washington State Energy Office, served as Director of Cost and Revenue Analysis and as the Forecasting Manager for a major Northwest Area Natural Gas Utility until May 1, 1995.

On May 1, 1995, at the age of 57, I was stricken and severely disabled by my stroke. Two years later I experienced a triple bypass heart operation. You might say I've "been there and done that" for both major cardiovascular diseases. So you see, I am an expert.

Years ago I was offered an exciting and rewarding volunteer opportunity. I was asked to lead the "Jack Wood Stroke Victor Tour" for the American Heart Association.

The Jack Wood Stroke Victor Tour was a 5-state lobbying tour. Through it I tried to meet personally with every Northwest Congressional representative on his or her home turf (in Alaska, Idaho, Montana, Oregon and Washington). In each meeting I was joined by local people, stroke survivors and their families and medical professionals. I told my story and asked them to join the Congressional Heart and Stroke Coalition and to support increased federal funding for heart and stroke research.

I am proud to say I traveled to 18 communities and met personally with 28 members of our delegation or their staff.

One of the most powerful memories for me was the frequency in which Members of Congress or staff members related their personal experience with stroke. One member I spoke to lost both parents to stroke. I suspect many of you have stories too.

I realize your interest is greater than the physical impact of my stroke. Your concern must include the financial impact, not only to me, but also on our country from increased health care costs and lost productivity and its many implications.

I have confronted the difficult and painful task of calculating that cost to me. Besides being a man whose stroke took his ability to pick up and play with his grandchildren and his livelihood, I remain a statistician at heart. I could not resist calculating and telling that part of my story. But please remember my story is not dissimilar to that of many of the 5.4 million stroke survivors in the United States. Many of whom were stricken in their prime earning years. Who in a matter of moments, seemingly without warning, are transformed from a contributor and provider to a receiver and patient.

Allow me to highlight three figures that I feel sum up my data and should be important to you. I estimate that my stroke at age 57:

- Reduced my earnings before retirement age 65 by more than \$600,000.
- Subsequently, the cost to the federal government in lost income and other taxes, early Medicare payments and Social Security disability payments is more than \$320,000.
- My HMO spent approximately \$150,000 to respond to and treat my stroke.
- One man, over \$1 million.

About 700,000 Americans will suffer a stroke this year costing this nation an estimated \$57 billion in medical expenses and lost productivity.

Earlier I described a stroke as occurring seemingly without warning. All too often as in my case, people either don't know or ignore the signs of a stroke, even one in progress. When my stroke hit I denied it. It took me two days after my stroke to acknowledge it and seek help. Because of research into new treatments, we now have tPA, a clot-busting drug, which if administered within 3 hours of the onset of stroke symptoms, can dramatically reduce the damage of clot-based strokes. Had I recognized and acknowledged my stroke, gone to a hospital with a neurologist on staff and had there been tPA, the impact of my stroke most certainly would have been lessened.

What is even more painful to me is that my impending stroke could have been detected. Unfortunately, we need to create easier and less expensive diagnostic techniques so that effective diagnostics can be given routinely as part of regular health exams. And they must be covered through insurance.

I am not asking for your sympathy. Instead, please think of me as two of the ghosts in the famous Dickens' story. Please don't misunderstand, I am not casting you as Scrooge. See me as both the ghosts of things past and things yet to be. I too am here to tell you, the future, which I represent, needs not be. It is largely up to you.

I hope my story and estimate of the cost of my stroke convinces you that taking on stroke and heart disease through increased research, leading to better prevention, diagnosis and treatment is fiscally responsible. The human and financial costs are astronomical.

Thank you for your past support of research.

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#### PREPARED STATEMENT OF THE NATIONAL HEMOPHILIA FOUNDATION

Thank you for the opportunity for the National Hemophilia Foundation (NHF) to submit testimony to the Chairman and Members of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. NHF is a national voluntary health organization dedicated to improving the health and welfare of people affected by bleeding and clotting disorders, including hemophilia, women's bleeding disorders, and thrombophilia.

#### BACKGROUND

Bleeding and clotting disorders are caused by genetic defects in the body's blood coagulation system, usually a missing protein that prevents or slows down blood clotting, or sometimes causes excessive clotting. There are several types of bleeding disorders. The most recognized bleeding disorder is hemophilia, a predominantly male disorder affecting approximately 20,000 individuals in the United States. The most common bleeding disorder is von Willebrand disease, which affects between one to two percent of the U.S. population. Thrombophilia, a blood clotting disorder effecting 2 million people each year, puts both men and women at risk of developing dangerous blood clotting in veins and arteries. These clots can obstruct the blood flow through the vessels causing pain and swelling of the tissue in the area and can lead to permanent tissue damage as well as death.

#### PREVENTION AND TREATMENT

##### *Centers for Disease Control and Prevention*

The national network of hemophilia treatment centers (HTCs) created by Congress in 1974 remains essential to ensuring that comprehensive and specialized care is available for persons with bleeding and clotting disorders. The HTC role has expanded dramatically over the last three decades, evolving with the needs of the hemophilia and bleeding disorders community to provide coordinated care, blood safety surveillance, prevention, and improved disease management. This expansion also has included outreach and treatment for women with bleeding disorders and persons with thrombophilia.

These programs, carried out by the Hereditary Blood Disorders Program in the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC), have demonstrated significant reductions in mortality and morbidity. More than 75 percent of the hemophilia community participates in one of the 140 centers that comprise the HTC network and more than 10,000 women receive care at a HTC. Despite this dramatic growth in support and services, HTC funding has not increased in the last 10 years. Support for an increase has been identified in Congress, and Congressman Tom Price (R-GA) and many of his colleagues have sponsored a letter of support encouraging the Committee to allocate an additional \$7 million for HTC funding. NHF urges the Committee's strong support for this additional funding to ensure HTCs can carry out needed education, prevention, blood safety, surveillance, and outreach programs with the bleeding and clotting disorders community.

##### *Health Resources and Services Administration*

HTCs also receive needed funding as a special project of regional and national significance within the Maternal and Child Health Bureau (MCHB) Block Grant set-aside. MCHB funds are utilized by HTCs to cover the non-reimbursable costs of providing on-going nursing, prevention, dental, and rehabilitative services and support.

MCHB funding for HTC has remained steady for the past 20 years, resulting in eroded resources over time. MCHB funds for the HTC disease management network are essential to meeting the needs of the bleeding and clotting disorders community. NHF urges the Committee to maintain funding support for the HTCs through MCHB.

#### HEMOPHILIA RESEARCH

##### *Bleeding and Clotting Disorders Research*

NHF is appreciative of the Committee's continued commitment to research. The strengthened research funding provided by the Committee to the National Institutes of Health has brought about rapid advances in science. Within NIH, the National Heart, Lung, and Blood Institute (NHLBI) has taken the lead on advancing research on bleeding and clotting disorders and the complications of these disorders. NHF is particularly appreciative of NHLBI's collaborative research program with the Foundation to support research on improved and novel therapies for treating these disorders and, like the Institute, has been overwhelmed by the scientific community's positive response to this approach. NHF encourages the Committee to increase its funding support for NHLBI such that valuable initiatives like the collaborative research program can be sustained.

##### *Hepatitis C Virus*

HCV continues to severely impact the hemophilia and bleeding disorders community. As a result of their dependence on blood-based products, the hemophilia and bleeding disorders community has been severely affected by HIV and hepatitis. More than 80 percent of people with hemophilia born before 1992 have the Hepatitis C Virus (HCV). Today, nearly half of all persons with hemophilia have HCV. NHF has been grateful for the support of the Committee in encouraging continued partnerships between NHF and the National Institute of Allergy and Infectious Disease (NIAID) to address the importance of developing and advancing research initiatives for addressing HCV within the bleeding disorders community. NHF requests that NIAID continue to work with the Foundation's medical and scientific leadership and develop a report by March 31, 2006 on HCV research strategies that are being pursued within the bleeding disorders community.

Over the last 20 years, the National Cancer Institute (NCI) has collected samples from patients with hemophilia infected with HIV and HCV through the Multi-Center Hemophilia Cohort Study. This cohort offers a rich database for improving the understanding of HCV and has served as the basis of significant peer reviewed findings. NHF understands that NCI has decided to no longer fund further research studies of the cohort. NHF requests the Committee's support in urging NCI to ensure the samples obtained through this cohort are preserved and accessible for future research. NHF also requests a report on possible future research opportunities provided by the cohort samples.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has played a significant role in advancing and coordinating NIH's HCV research activities. With the high incidence of HCV within the bleeding disorders community, it is critical to further investigate and understand treatment options and advancements. NHF urges the Committee's support for NHF to work with NIDDK in developing and advancing research initiatives to address HCV within the bleeding disorders community.

#### RECOMMENDATIONS

We are grateful for the Committee's support of bleeding and clotting disorders research, prevention, treatment, and outreach initiatives. For fiscal year 2006, we urge the Committee to:

- Strengthen funding support for hemophilia and bleeding and clotting disorders prevention and treatment programs by providing an additional \$7 million for the HTC network through CDC's Hereditary Blood Disorders Program.
- Provide continued support for the HTC network through MCHB.
- Maintain support at NHLBI for research on improved and novel therapies for bleeding and clotting disorders.
- Provide support for continued collaboration between NHF and NIAID in developing and advancing research initiatives for addressing HCV within the bleeding disorders community.
- Preserve NCI samples obtained through the Multi-Center Hemophilia Cohort Study and ensure their accessibility for future research initiatives.
- Provide support for NIDDK to work with NHF in addressing HCV within the bleeding disorders community.

Thank you for the opportunity to provide this statement to the Committee.

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PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and distinguished members of the Subcommittee, we appreciate the opportunity to submit written testimony on behalf of the National Multiple Sclerosis Society. The Society was founded in 1946. Since its inception, the Society's highest priority has been to support research aimed at finding the cause of MS, better treatments, and a cure. In 2005, the National MS Society will spend over \$35 million on MS research supporting over 350 MS investigations. By the end of 2005, the Society cumulatively will have expended some \$460 million since awarding its first three grants in 1947. This represents the largest privately funded program of basic, clinical, and applied research and training related to MS in the world.

The federal government must continue its vital role in furthering the scientific understanding of MS. To this end, the Society supports the following:

- That the National Institutes of Health (NIH), in partnership with the Society, invest additional funds to identify and characterize MS susceptibility genes and bring additional research focus to the primary progressive form of MS.
- That NIH, in collaboration with the Society, other MS organizations, and other federal research agencies, undertake a study of the incidence, demographics and environmental factors that may contribute to disease onset.
- The National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education fund one additional Medical Rehabilitation Research and Training Center for MS and take steps to stimulate individual research projects.
- That Congress increase fiscal year 2006 NIH funding by 6 percent.

Multiple sclerosis is a chronic, unpredictable and often disabling disease of the central nervous system. Symptoms range from numbness in the limbs, to loss of vision, memory deficits, and in some instances partial or total paralysis. The progress, severity and specific symptoms of MS in any one person can vary and cannot yet be predicted, but advances in research and treatment are giving hope to those affected by the disease.

The federal investment in the National Institutes of Health (NIH) and the National Institute on Disability and Rehabilitation Research (NIDRR) plays a major role in MS research. At the NIH, there are two institutes that conduct or fund the majority of MS research: the National Institute of Neurological Disorders and Stroke (NINDS) which funds 75 percent, and the National Institute of Allergy and Infectious Diseases (NIAID) which funds about 20 percent. The National Center for Medical Rehabilitation Research (NCMRR—a unit of the National Institute of Child Health and Human Development) also funds a small amount of MS research specifically targeting rehabilitation issues. In addition to the NIH, the NIDRR through the Department of Education invests in MS research.

For fiscal year 2005 and fiscal year 2006, it is estimated that NIH expenditures on MS research will be approximately \$102 and 103 million, respectively. For fiscal year 2005 and fiscal year 2006 NIDRR expenditures on MS research will be approximately \$1.5 million per year out of a total budget of \$140 million per year. While this demonstrates one measure of the federal investment in MS research, this amount pales in comparison with the annual direct and indirect disease cost—approximately \$23 billion for all people with MS in the United States.<sup>1</sup>

The National MS Society has had a long and productive relationship with the NIH, particularly with NINDS. Our founder Sylvia Lawry helped spearhead the legislation that established NINDS in 1950. The Society has been pleased to work with the NINDS on many areas of mutual interest and we hope to strengthen our partnership with NINDS and expand our relationships with other federal funders of MS research in the coming year.

The Society supports the NIH Neuroscience Blueprint, announced last Fall, that reinforces intra-collaboration and information-sharing among 14 NIH Institutes that conduct or support research on the brain and nervous system. The Blueprint should accelerate the translation of basic neuroscience discoveries into better ways to treat and prevent nervous system disease.

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<sup>1</sup>Based on a 1994 Duke University study, indexed for 2004 by the National MS Society, the average annual cost of MS is estimated at \$57,500 per person due to lost wages, increased medical care and other expenses. Nationwide, there are an estimated 400,000 people with MS.



## INVESTING IN RESEARCH PRIORITIES RELEVANT TO MS

The National MS Society will continue to pursue research opportunities with NIH and NIDRR in priority areas that are key to furthering the understanding of MS. We continue to monitor NIH's progress in expanding its commitment to MS research as suggested by Congress.

In 2004, as part of our NIH advocacy efforts, the Society had the following congressional "report language" added by the House and Senate Appropriations Conference Committee as an instruction to NIH in the fiscal year 2004 omnibus appropriations package:

"The conferees urge NINDS to increase its overall investment in multiple sclerosis (MS) research. Special emphasis on imaging, biological markers and clinical trials for new therapeutics should be areas of high priority. The conferees are pleased to note the development of a joint symposium on MS genetics sponsored by NINDS and the National MS Society, and encourage the Institute to take a more active role at the NIH in furthering MS genetics research by developing collaborative strategies with the National Human Genome Research Institute and other relevant NIH institutes. The conferees request that NIH report back to Congress no later than September 30, 2004 with progress in its efforts to expand its commitment to multiple sclerosis. The conferees also are pleased to note a major success in past years in the creation of a joint collaborative research program in "gender and immunity" between the National Institute on Allergy and Infectious Diseases (NIAID) and a major voluntary association for the disease, in which NINDS participates. The conferees encourage NINDS to seek similar collaborative activities related to MS."

The Society was pleased to receive a copy of the report. While the Society is gratified by the many intramural and extramural activities and progress described in the report, we are disappointed to note that it did not address steps that NINDS would take to expand its commitment MS research as requested by the committee. We urge NINDS to increase its commitment to MS by:

- Partnering with the Society to invest additional resources to help solve the genetic basis of MS.
- Working with the Society to bring additional research focus to the primary progressive form of MS (PPMS).

Family studies of people with MS and their relatives, have shown that the risk for MS depends on relatedness to the affected individual, that is, a sibling has a higher risk of developing MS than a cousin. In no other disease have recurrence risks been so comprehensively catalogued in groups of biological and social relatives. A strategy is needed to penetrate the genetics of MS. Although the NIH and the National MS Society have invested independently substantial funds in MS genetics over the past decade, this is an area that calls for additional collaboration. The past few years have seen real progress in the development of laboratory and analytical approaches to the study of genetic disorders. The Society encourages the NIH to move forward with the Society as a true partner in identifying those DNA regions that can be prioritized for encoding MS susceptibility genes. The identification and characterization of the MS genes will help to define the basic etiology of the disease, to help predict the course of the disease, and to influence therapeutics.

Advances in immunology have provided clinicians with powerful tools to better understand the underlying causes of MS, leading to new therapeutic advances. Although there are FDA-approved treatments for relapsing MS, there are no approved treatments for progressive MS. The primary progressive form of MS (PPMS) is characterized from the onset by the absence of acute attacks and instead involves a gradual clinical decline. Approximately 10 percent of individuals are diagnosed with PPMS from the onset. Clinically this form of the disease is associated with a lack of response to any form of immunotherapy. This leads to the concept that PPMS may in fact be a very different disease as compared to relapsing remitting MS. The Society identifies the study of progressive MS as an area that merits greater attention by the research community in order to increase our understanding of PPMS and to have effective therapies for this progressive form of the disease. In the upcoming year, the Society encourages NIH to help the Society address this underserved area of MS research.

In addition to efforts at the NIH, the Society is pleased to note that for more than 20 years, NIDRR has funded a Medical Rehabilitation Research and Training Center (MRRTC) for MS. However, the institute's overall investment in MS research remains limited, \$1.5 million in fiscal year 2005. The NIDRR portfolio includes only two current projects related to MS, the aforementioned MRRTC and a Rehabilitation Research and Training Center on Health and Wellness in Long Term Disability that is only partially focused on MS. In contrast, spinal cord injury, with a preva-

lence less than that of MS, has 39. Since the advent of FDA-approved MS disease-modifying treatments in 1993, persons with MS have had access to therapeutics which can slow the progression of disability. However, in order to maintain maximum levels of independence, persons with MS need rehabilitation to address residual deficits. Unfortunately, due to the limited support for MS rehabilitation research, we know relatively little about the efficacy of rehabilitative interventions in MS. We therefore urge the NIDRR to increase its support for MS rehabilitation research through the funding of at least one additional MRRTC along with initiatives to stimulate individual research projects.

#### THE IMPORTANCE OF COLLABORATION

The National MS Society cannot overemphasize the importance of collaboration. We are pleased to see that the Roadmap Initiative—a 3-year plan addressing key research issues throughout NIH—continues to develop. The National MS Society encourages NIH to continue its efforts to increase collaboration across institutes and to pursue collaborative opportunities with other organizations. As we see it, there is no other choice.

An area in critical need of attention concerns data related to the incidence, prevalence, and distribution of MS. The last national study of incidence and prevalence of MS in the United States took place more than 30 years ago. Since that time the population of the United States has changed dramatically in size, composition, and distribution. Moreover, numerous questions have arisen concerning possible ethnic, geographic, and local variations in the distribution of MS. Knowledge concerning these distributions and possible causal factors may provide important information concerning the nature of MS and its triggers. Moreover, rational policy formulation for MS health care requires up-to-date information concerning numbers and characteristics of persons with MS down to the state level. Addressing these information needs is beyond the resources of the Society. We therefore urge the NIH, the CDC/ATSDR to work with the Society and perhaps other MS organizations such as the Consortium of MS centers, to begin the task of understanding how many Americans have MS, where they reside, and what environmental factors may have contributed to disease onset.

To date, the Society has been successful with NIH on jointly funding a major initiative on gender and immune function. In 2001, the Society entered into a \$20 million collaborative project with NIAID and other NIH institutes to investigate gender effects on the immune function, including autoimmunity. This is important because most autoimmune diseases (including MS) are far more prevalent in women than men. The Society is co-funding six projects and will contribute up to \$4 million to this project. We would like to engage in other collaborative projects, especially with NINDS.

The Society also was pleased that in 2004 NINDS and NMSS co-sponsored a scientific workshop on biomarkers in MS. As outcomes from this workshop, the Society is looking to work closely with NINDS projects, such as the development of collaborative and international efforts to identify biomarkers for MS. Such efforts would significantly advance our efforts to effectively diagnose and treat MS.

The Society was also pleased that in 2004 NINDS and NMSS co-sponsored a scientific workshop on design of clinical trials in MS. The tremendous increase in potential therapies for MS has created new challenges in the design and execution of new MS therapies. The Society was pleased that an outcome of this workshop was an effort to draft a white paper for the Food and Drug Administration on the topic of use of magnetic resonance imaging (MRI) as a surrogate measure in MS clinical trials. Acceptance of MRI as a valid surrogate measure by the FDA would represent a significant step forward in testing the potential MS therapies and bringing them to approval in a more expeditious manner.

The Society is also currently collaborating with the National Center for Medical Rehabilitation Research (NCMRR—a unit of the National Institute of Child Health and Human Development) on an international workshop to foster rehabilitation research in MS. This workshop will address the critical need to expand the quality and quantity of MS rehabilitation research. It is hoped that from this workshop may emerge opportunities for collaborative support of research initiatives to advance scientific knowledge concerning MS rehabilitation.

#### OVERALL NIH FUNDING INCREASE FOR FISCAL YEAR 2006

The Society is concerned that NIH may face a third year of overall low funding increases. Furthermore, in fiscal year 2004 and fiscal year 2005, only bioterrorism research received a healthy increase, with much smaller increases allocated for disease research. We fear the same may occur in fiscal year 2006. This is particularly

disappointing after the fiscal year 1999–2003 funding campaign that doubled the NIH budget in the 5-year period.

—We urge Congress to appropriate a 6 percent fiscal year 2005 funding increase for NIH.

—While there is a need to increase our country's investment in bioterrorism research, we ask Congress to balance the fiscal year 2006 NIH appropriation to allow growth across all NIH institutes and all areas of disease research.

We thank the Subcommittee for this opportunity to comment and applaud your commitment to advancing the health and well-being of all Americans through investment in biomedical research.

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PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

1. A 6 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

2. Continue to expand the NIDDK Nephrotic Syndrome (NS)/Focal Segmental Glomerulosclerosis (FSGS) research portfolio by aggressively supporting grant proposals in this area and encouraging the National Center for Minority Health and Health Disparities (NCMHD) to initiate studies into the incidence/cause of NS/FSGS in the African-American population.

3. The NephCure Foundation encourages we encourage follow up to the scientific workshop that took place in January, 2005, sponsored by NIDDK, in effort to initiate grant proposals focused on achieving the goals developed by the workshop. The workshop examined observations and opportunities for improved diagnosis and therapeutic interventions for Glomerular disease and Focal Segmental Glomerulosclerosis (FSGS).

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the NephCure Foundation (NCF), a non-profit organization driven by a blue-ribbon panel of respected medical experts and a dedicated band of patients and families working for a common goal—to save kidneys and lives.

I am Ed Hearn, former Major League catcher for the 1986 World Series Champion New York Mets and the Kansas City Royals. My career as a professional athlete came to an abrupt end in 1991, due to a shoulder injury. Upon recuperation, I intended to return to my team. While I was out due to my injury, I began to experience symptoms that indicated kidney malfunction, and within six months, I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS), a debilitating and degenerative kidney disease. Today, after three kidney transplants, the aid of a breathing machine at night, a \$3,000 IV once a month, and \$40,000 of medication to pay for up to 50 pills that I must swallow each day, I live to tell my story and to speak for those suffering from FSGS. My hope is that we can find the means to prevent this life-threatening disease from affecting our youth and from jeopardizing the normalcy of their lives as it has mine and many others. I remain hopeful that a cure for FSGS will be uncovered, but until then, our focus must be on prevention.

TREATMENT TRIALS BEGINNING, BUT NO CURE IN SIGHT

Mr. Chairman, FSGS is one of a cluster of glomerular diseases that attack the one million tiny filtering units contained in each human kidney. These filters are called nephrons and these diseases attack the portion of the nephron called the glomerulus, scarring and often destroying the irreplaceable filters. Scientists do not know why glomerular injury occurs and they are not sure how to stop its inevitable destruction of the kidney.

When I was a teenager, doctors found protein in my urine and told me that some day I might have kidney trouble. I pushed it out of my mind, thinking that some day meant when I was an old man down the road. Some day came faster than anyone expected. I believe that because I was a highly conditioned athlete, and catchers are more conditioned than most athletes, my body initially masked the symptoms of FSGS. Consequently, I retained the façade of physical health, and I do not know when FSGS initially began to internally attack my body.

My first kidney transplant lasted more than seven years until the FSGS returned, as it often does. I received a second kidney from my aunt in 2000, but my body rejected it almost immediately, and I received a third kidney transplant in May of 2002. My story is not unique; there are thousands of other people in this country who have had their lives disrupted due to the sudden onset of FSGS. Although kidney transplants have been very successful for thousands of FSGS patients, there are many patients of whom the body rejects the transplanted kidney or the FSGS comes

back and attacks the transplanted kidney, leaving the patient with no functioning kidneys. He or she must then rely on daily dialysis as a means of survival.

FSGS patients are often on several medications, which cause medical complications and unbearable side effects. FSGS patients, upon diagnosis, often take a downward plunge at a rapid rate, and it is extremely difficult to make a comeback. In the last four years, I have undergone two kidney transplants, two years of dialysis, and a six week course of daily radiation treatment for rapidly spreading cancer that was primarily the result of the high doses of immunosuppressant drugs I am taking for FSGS. In the last three months alone, I have had over 65 medical appointments. As you can see, it is nearly impossible for an FSGS patient to live a normal life.

We are extremely thankful that an NIDDK-funded clinical trial began last year to study the efficacy of the current treatments for FSGS, and that ancillary studies are underway to examine tissue samples of injured glomerulus. However, these clinical trials hold no particular hope for patients who suffer from FSGS.

There are thousands of young people who are in a race against time, hoping for a treatment that will save their lives. The NephCure Foundation today raises its voice to speak for them all, asking you to take specific actions that will aid our quest to find the cause and the cure of NS/FSGS.

First and foremost, we support a 10 percent increase for the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

#### TOO LITTLE DATA ABOUT A GROWING PROBLEM

When glomerular disease strikes, the resulting Nephrotic Syndrome causes loss of protein in the urine and symptoms such as edema, a swelling that often appears first in the face. For example, many physicians mistake children's puffy eyelids as an allergy symptom. Stories of similar misdiagnoses are common at our Foundation. With experts projecting a substantial increase in Nephrotic Syndrome in the coming years, there is a clear need to educate pediatricians and family physicians about glomerular disease and its symptoms.

The NephCure Foundation has numerous education programs underway, including patient education seminars; the most recent of which took place in March 2004. The next patient education seminar will take place in Washington, DC in May 2005. News of our most recent activities can be found on our web site at [www.nephcure.org](http://www.nephcure.org). However, our efforts alone are not enough.

NIDDK launched a major federal outreach program early in 2002—the National Kidney Disease Education Program—we seek your support in urging NIDDK to assure that glomerular disease receives high visibility in this important program.

#### GLOMERULAR DISEASE STRIKES MINORITY POPULATIONS

Nephrologists tell us that glomerular diseases such as FSGS affect a disproportionate number of African-Americans and, according to NIDDK, “the worst prognosis is observed in African-American children.” NephCure officials have described this situation in a meeting with Dr. John Ruffin, director of the National Center for Minority Health and Health Disparities (NCMHD).

As the NCMHD becomes fully operational and plans programs, our Foundation will continue to work with the Center to encourage the creation of programs to study the high incidence of glomerular disease within the African-American population.

We ask the Committee to join with us in expanding the NS/FSGS research portfolio by requesting that the National Center for Minority Health and Health Disparities seize the opportunity to establish research into the phenomenon of glomerular disease within the African American community.

#### MORE BASIC SCIENCE IS NEEDED

The current FSGS clinical trials which follow an estimated 400 patients over a three year period, are limited, according to the RFA, to examining the “impact of immunomodulatory therapy on proteinuria.” While the trials may lead to safer or more efficient care for children with FSGS, no one is suggesting that they will bring us closer to finding the cause and cure. Science has yet to prove that FSGS is an immune-mediated disease.

Scientists tell us that much more needs to be done in the area of basic science, beginning with collection of tissue and fluid samples from a large number of patients on which years of important scientific research can be founded. NephCure is collaborating with the NIH in a major way to work for such progress.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has agreed to match, dollar-for-dollar, funds raised by NephCure that will allow re-

searchers to obtain DNA samples from hundreds of FSGS patients in upcoming clinical trials. The NIDDK will match up to \$300,000 raised by NephCure for a combined total of \$600,000. These trials are an ancillary study in conjunction with the first-ever national medication trials of FSGS treatment that may possibly lead to better understanding of the more common Nephrotic Syndrome, which can be a precursor to FSGS.

We encourage follow up to the Scientific Workshop that took place in January, 2005, sponsored by NIDDK, in effort to initiate grant proposals focused on achieving the goals developed by the workshop. The workshop examined observations and opportunities for improved diagnosis and therapeutic interventions for glomerular disease and Focal Segmental Glomerulosclerosis (FSGS). This goal is consistent with the NIH Roadmap to Research initiative developed by NIH Director, Dr. Elias Zerhouni.

The workshop united basic science and clinical investigators, FSGS patients, physician researchers, nephrologists from around the world and anyone with an interest in treatment for glomerular diseases to share and collaborate upon advances, challenges and research potential of these debilitating diseases. We must use the conference as a stepping stone and build upon the information collectively gathered to determine the resources needed to carry out these opportunities and challenges. The workshop/conference gave hope to the thousands of young people whose kidneys and lives are threatened by this terrible disease, and it gave honor to their heroic stories.

We anticipate the potential for a Program Announcement and the potential for a Special Emphasis Program Announcement resulting from the conference or some other traditional mechanism to generate grant proposals. These mechanisms to encourage investigator initiated grant proposals should help to continue to expand the NS/FSGS portfolio at NIH.

Mr. Chairman, as you know, patient support and advocacy groups such as the NephCure Foundation work closely with medical research organizations. They share a mutual understanding that unless major research efforts are undertaken, advances and improvements in the health of patients will not occur. Every year, the NephCure Foundation participates in advocating increased funding for the NIH and NIDDK. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

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#### PREPARED STATEMENT OF THE NATIONAL PROSTATE CANCER COALITION

Mr. Chairman and members of the Committee, thank you for the opportunity to share my remarks. The National Prostate Cancer Coalition (NPCC) was founded in 1996 to combat a long overlooked killer of men. I came to NPCC in 2001, having just recently been impacted by the disease myself. In 2000, my grandfather was diagnosed with prostate cancer. Having served his country so valiantly in World War II, he was now facing a new battle. Luckily, because of early detection through the prostate specific antigen (PSA) test and the digital rectal exam (DRE), the disease was caught early and, following a radical prostatectomy, he is now cancer free. But there are many men who are not so lucky. That's why you must adequately fund prostate cancer research for veterans like my grandfather, families like mine, and men all over America.

Under the leadership of this committee we have seen prostate cancer research funding increase by nearly \$300 million since in the last 6 years. While we have come a long way, there is still much work to be done. For the second year since the founding of NPCC, prostate cancer deaths will continue to increase in 2005. More than 30,000 lives will be lost to the disease. Occurrences of prostate cancer are increasing as well, to over 230,000 men this year. While cases continue to grow, more men are catching the disease in its early stages, when the disease is most treatable, by early detection through screening.

NPCC would like to offer its gratitude on behalf of the 2 million American men with prostate cancer for the support this committee has offered in the past. The recent doubling of the National Institutes of Health's (NIH) budget has helped prostate cancer research funding to expand to record levels, but we must ensure this funding is used appropriately. To that end, your committee was instrumental in requiring NIH and the National Cancer Institute (NCI) to submit a professional judgment budget for fiscal year 2003–fiscal year 2008 to outline the agencies' plans for prostate cancer research. You have also been influential in requesting a fiscal budget for that document, which was Congress received passed the April 2004 deadline.

The budget requested lacked connectivity to the previous plan and made no references to goals or priorities. While no one disputes the historic importance of doubling, we ask you to encourage NIH and NCI to coordinate with each agency to put forward a comprehensive and cohesive plan that brings us closer to eradicating cancer. Additionally, we respectfully request your oversight to ensure this funding is producing results for prostate cancer.

Huge sums of taxpayers' money have been allocated to NIH over the years and it is now time to examine what this windfall has produced. Therefore, we request that you to ensure that NIH to submits the yearly update on its prostate cancer research portfolio that reflects its progress according to the fiscal year 2003–fiscal year 2008 professional judgment budget that was requested in fiscal year 2005.

We are entering an exciting time in biomedical research. The recent Food and Drug Administration's approval of Avastin has opened a new door for cancer research. Avastin targets cancerous cells by blocking their blood supply, an idea that had been previously dismissed by the medical community as "absurd". The drug not only signals a turning point in changing cancer into a manageable, chronic disease but also demonstrates the value of seeking out novel and innovative research. We must encourage this kind of research at NIH, including assessing the value of stem cell research which has shown promise in research for neurological diseases, diabetes, and cancer.

Developing a new approach to research is a priority for NPCC. The Prostate Cancer Research Funders Conference, first convened in 2001 and then revitalized last fall, seeks to formulate a collaborative, public-private approach to seek out new ways of attacking the problem of prostate cancer. Originally co-convened by NPCC and NCI, participants now also include the Department of Defense, the Veterans Health Administration, the Centers for Disease Control and Prevention, the Food and Drug Administration, Canadian and British government agencies, private foundations/organizations and representatives from industry. Members of the Conference have come together to form a partnership that allows them to focus on key objectives and to address commonly recognized barriers in research. This could propel research forward significantly. As the Conference continues, we ask that the Committee make its functionality part of its oversight commitments to prostate cancer research. Currently, federal agencies participate voluntarily, but they can opt in or out based on the tenure of executive leadership and its time-limited decisions. For the conference to be successful federal agencies engaged in the prostate cancer research should, in our opinion, be required to participate, and we ask for your leadership to make that happen.

Recognizing the importance of cutting edge research initiatives and collaborative research efforts, NIH director Elias Zerhouni, M.D. recently unveiled the NIH Roadmap. The Roadmap's strategy mirrors that of the Funders Conference, specifically by seeking out new approaches and ideas and stimulating cross-institutional and cross-center research for all NIH driven biomedical research. Believing, we think correctly, that the synergies in the Roadmap can achieve outcomes that are greater than those any one Institute or Center can achieve, we support its efforts to advance key biomedical research initiatives at an exponential rate. NPCC applauds the Roadmap and pledges its support to take biomedical research in new directions.

As NIH and NCI look to redefine and increase the efficiencies of their research programs, Congress must equip them with the resources they need to implement new initiatives. Unprecedented increases in NIH and NCI's funding over the last 6 years have created opportunities never before available. We must take advantage of these achievements, to not do so will not only harm cancer patients everywhere but is, quite simply, poor business sense.

NPCC was heartened when the President stated 2 years ago that "in order to win the war against cancer, we must fund the war against cancer," but we are very concerned by recent reports suggesting the Administration's budget for fiscal year 2006 will propose a cut in the overall budget of the National Institutes of Health and other critical programs. Such a cut would be a major reversal in our nation's commitment to the fight against cancer.

Societies for Experimental Biology (FASEB) have stated if increases are held to 2 percent–3 percent the grant funding rate at NIH will drop below 30 percent and approximately 500 fewer grants would be funded. To allow NIH and NCI to adequately continue to fund promising grants and research first realized during the budget doubling, Congress must appropriate at least (\$30.1 billion) in funding for these agencies in fiscal year 2006. That may seem like a large number, but in reality, it is only a small fraction of the estimated \$189 billion that cancer alone costs this nation yearly.

Increasing NIH's budget by 8.5 percent would also allow NCI to dedicate more than \$400 million to prostate cancer research in fiscal year 2005. Last year, NCI

received only a 3.3 percent increase in funding over the previous year's level. Yet, with previously committed grant awards and outlays to the NIH Roadmap, NCI is "effectively operating with a budget that is \$2.7 million less than last year's operating budget (NCI Cancer Bulletin 2/3/04)." The President's fiscal year 2006 budget allocates over \$4.8 billion to NCI, is much less than the fiscal year 2005 increase. This level will mean even tougher choices in awarding grants at NCI. We believe that Congress should fully fund the NCI Director's Bypass Budget at \$6.2 billion, which would rapidly accelerate the nations' fight against all cancers.

As you know, education and early detection through screening are the catalyst to beating prostate cancer. Right now, the PSA blood test and DRE physical exam are the best measures for detecting prostate cancer early. We ask the Committee to allocate at least \$20 million to the Center for Disease Control and Prevention's (CDC) prostate cancer awareness program. We also encourage the Committee to work with CDC to address our concern that the agency places insufficient value on these screening tools.

Thank you again for the leadership you have shown in advancing biomedical and, more specifically, prostate cancer research. Under your leadership, the nation's war on cancer has reached heights never before realized. We look forward to continuing to work with you and the members of the Committee until a cure is found.

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PREPARED STATEMENT OF THE NATIONAL SLEEP FOUNDATION

SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- Provide a 6 percent increase for fiscal year 2006 to the National Institutes of Health (NIH) and a proportional increase of 6 percent to the individual institutes and centers, specifically, the National Heart, Lung, and Blood Institute (NHLBI).
- Urge the National Center on Sleep Disorders Research (NCSDR) to partner with other federal agencies, such as the Centers for Disease Control and Prevention (CDC), and voluntary health organizations, such as the National Sleep Foundation (NSF), to develop a collaborative sleep education and public awareness initiative.
- Urge the United States Surgeon General to issue a Surgeon General's Report on Sleep and Sleep Disorders.

Mr. Chairman and members of the Subcommittee, thank you for allowing me to present testimony on behalf of the National Sleep Foundation or NSF. I am Dr. James Walsh, Chairman of the Board of Directors of the National Sleep Foundation, Executive Director of the Sleep Medicine and Research Center affiliated with St. John's Mercy and St. Luke's Hospitals, and Clinical Professor of Psychiatry at St. Louis University. The National Sleep Foundation is an independent, non-profit organization whose mission is to enhance public awareness about the need for sufficient restorative sleep, to increase the detection and treatment of sleep disorders, to foster sleep-related programs and policy for the betterment of public health, and to promote sleep research. We work with thousands of sleep medicine and other health care professionals, researchers, patients, drowsy driving victims throughout the country, and collaborate with many government and private organizations with the goal of preventing health and safety problems related to sleep deprivation and untreated sleep disorders.

Sleep problems, whether in the form of medical disorders, or related to work schedules and a 24/7 lifestyle, are ubiquitous in our society. At least 40 million Americans suffer from sleep disorders; yet more than 60 percent of adults have never been asked about the quality of their sleep by a physician, and fewer than 20 percent have ever initiated such a discussion. Millions of individuals struggle to stay alert at school, on the job, and on the road. The latest estimates from the National Highway Transportation Safety Administration and the Federal Motor Carriers Safety Administration implicate fatigue and sleepiness in 1.1 million crashes annually. A recent study in Sweden showed that sleep disturbances are the second greatest risk factor for fatal accidents at work. Sleep apnea, a sleep-related breathing disorder which affects at least 5 percent of adult Americans, is closely related to some of America's most pressing health problems, such as obesity, hypertension, heart failure, and diabetes. Chronic insomnia, experienced by 10 percent of our population is a strong risk factor for depression and other widespread mental health conditions. Sleep disorders, sleep deprivation, and excessive daytime sleepiness add approximately \$15 billion to our national health care bill each year. The National Center on Sleep Disorders Research estimates that by the year 2050, sleep problems will affect as many as 100 million Americans.

Sleep science has clearly demonstrated the importance of sleep to health and well being, yet research studies continue to show that millions of Americans are at risk for the serious health, safety consequences of sleep disorders and inadequate sleep. Moreover their quality of life suffers and the personal and national economic impact is staggering. NSF believes that every American needs to understand that good health includes healthy sleep, just as it includes regular exercise and balanced nutrition. We must elevate sleep to the top of the national health agenda. We need your help to make this happen.

Our biggest challenge is bridging the gap between the outstanding scientific advances we have seen in recent years and the level of knowledge about sleep held by health care practitioners, educators, employers, and the general public. This gap in knowledge is being discussed as I present this testimony today, by hundreds of concerned professionals. Yesterday and today, the National Center on Sleep Disorders Research, the National Heart, Lung, and Blood Institute, and the Trans-NIH Sleep Research Coordinating Committee are sponsoring a translational conference entitled "Frontiers of Knowledge in Sleep and Sleep Disorders: Opportunities for Improving Health and Quality of Life." This two-day program has assembled health care providers, public health and education experts, policy makers, patient advocacy organizations, sleep medicine specialists, and other stakeholders. It is intended to address how information about sleep and sleep disorders can translate into improvements in public health and safety using cost-effective, comprehensive, and broadly-applied strategies for education, societal change, and improved sleep-related health care.

This conference is an important step in translating research into practice and into a broad-based public health message. The development of a sleep education and public awareness initiative would serve as a key legacy for the sleep translational conference and provide a forum for dissemination of the outcomes of the sleep translational conference. The National Sleep Foundation has been leading the way on public education regarding sleep and sleep disorders since it was founded in 1990. NSF and others have done a lot, but so much more needs to be done in order to educate the public and actually change behavior. Because resources are limited and the challenges great, we think creative and new partnerships need to be created to address the issues that are before us.

In the fiscal year 2005 appropriations bill, Congress recommended that The National Center on Sleep Disorders Research partner with other federal agencies, such as the Centers for Disease Control and Prevention, and voluntary health organizations, such as NSF, to develop an ongoing, inclusive mechanism for public and professional awareness on sleep, sleep disorders, and the consequences of fatigue. Such a collaboration between federal agencies and voluntary health organizations will create an opportunity for dramatically improving public health and safety as well as the quality of life for millions, if not all, Americans. Beginning steps have been taken to establish this collaboration, but continued support from the National Center on Sleep Disorders Research and the Centers for Disease Control and Prevention is critical.

Last year, at a National Institutes of Health sleep conference, the U.S. Surgeon General reported on the profound impact that chronic sleep loss and untreated sleep disorders have on all Americans. He emphasized that dissemination of the existing body of medical knowledge and implementation of expanded clinical practice guidelines regarding sleep and sleep disorders are critically important.

Conferences and workshops held by the Surgeon General involve educating the public, advocating for effective disease prevention and health promotion programs and activities, and providing a highly recognized symbol of national commitment to protecting and improving the public's health.

We believe that it is time that the federal government helps promote sleep as a public health concern through the development of a Surgeon General's report on sleep and sleep disorders in order to call attention to the importance of sleep and develop strategies to protect and advance the health and safety of the nation.

Thank you again for the opportunity to present testimony to this Subcommittee.

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PREPARED STATEMENT OF THE NTM INFO & RESEARCH, INC.

SPECIFIC RECOMMENDATIONS

NTMIR requests an allocation in the budget to enable NIH, (NIAID & NHLBI) to advance diagnostics and treatments for patients suffering from pulmonary Non-tuberculous Mycobacteria (NTM) disease.



NTMIR requests funds to facilitate and increase multi-centered trials to advance the effectiveness of treatments and to develop new treatments.

NTMIR recommends that CDC/NCHS engage in surveillance to better understand the incidence of NTM disease and assess the level of awareness within the medical community.

NTMIR supports the American Lung Association's request for an increase of \$77 million in funding to combat TB so that we avoid the risk of a rise in incidence that complacency can yield.

NTMIR supports the request of the Ad Hoc Group for Medical Research Funding for a \$30 billion appropriation for NIH in fiscal 2006.

#### WHAT IS PULMONARY NONTUBERCULOUS MYCOBACTERIAL DISEASE (NTM)?

NTM is an infectious disease considered to be of environmental origin as these bacteria are ubiquitous in the water and soil that surround us. Although NTM is diagnosed by the same basic test used to diagnose traditional tuberculosis (TB), it is significantly more difficult to treat. NTM progressively diminishes lung capacity, with all the attendant negative consequences in life.

Unfortunately, even though TB has a significantly high profile, NTM does not because education and awareness have been lacking. Furthermore, there is growing evidence that NTM is many times more prevalent than TB in the United States. For example, the State of Florida Infectious Disease Laboratory reports receiving over twice as many specimens that are NTM positive for every one that is positive for TB. Even more startling, the Agency for Health Care Administration for Florida hospital patient discharges shows almost 9 times the number of patients with the primary diagnosis of NTM versus those with TB.

Doctors in leading treating facilities are reporting that even though NTM is not reportable, they are seeing more NTM patients than TB patients. A current report from Toronto, Ontario indicates that the prevalence may be six times higher than the older data we have in the United States.

NTM is not limited to one strain and has certain strains that are inherently resistant to drug therapy, and in all cases multiple drugs are required on a lengthy to permanent basis. A significant number of patients require short to long term intravenous medication and this is a particular hardship for the elderly because Medicare does not cover in-home therapy. Medicare recipients must be hospitalized one to three times a week driving treatment costs significantly higher than in alternate settings.

#### NTM INFO & RESEARCH (NTMIR)

NTMIR was founded through a partnership of concerned patients and interested physicians who see increasing numbers of people affected by this devastating disease. NTMIR was created to expand professional awareness, diagnosis and treatment, facilitate research and provide patient support. Our mission is a public/private partnership to advance the science and the outcomes for countless patients with NTM disease.

NTMIR has already demonstrated a track record of success since it commenced its activities just two years ago. These include, successful implementation of the NTMInfo.com website and online support group, patient education throughout the country through the replication of an NTM information pamphlet, initiating professional education and Grand Round lectures to increase professional education both for specialists and family physicians, establishment of a partnership of cooperation with public health in the State of Florida and with the American Lung Association of Florida. Our most recent effort resulted in agreement between a major pharmaceutical company, the FDA and a division of HRSA to provide an urgently needed drug for patients who could not otherwise obtain it, some of whom might have died without it.

We anticipate that these efforts will serve as models in other states and at the federal level.

#### FERN R. LEITMAN, PATIENT & DIRECTOR, NTM INFO & RESEARCH, INC.

Fern Leitman is a patient who has severe pulmonary NTM disease that has required ongoing medical therapy since 1996. Nonetheless, in addition to serving as vice president of Philip Leitman, Inc. where she is responsible for asset and acquisition evaluation, she is co-founder of the NTM website and NTM Info & Research, Inc.

Since becoming ill, Fern has dedicated many hours each week to communicating with patients from around the United States to help them understand how they help themselves to battle NTM disease by being an active participant in their own

treatment and care. In spite of living with devastating and chronic illness, Fern Leitman is committed to helping others to live a full life by enhancing the role that NTM Info & Research can play in bringing patients, physicians, and government organizations to a partnership that will raise awareness and actively pursue treatment options to improve the quality of life of those suffering with NTM.

STATEMENT OF FERN LEITMAN

Thank you for the opportunity to submit a statement on behalf of NTM Info & Research and all the patients suffering with pulmonary NTM disease. NTM is an infectious disease that challenges treating physicians. Lung transplantation is usually not an option because immune suppressants complicate treatment.

Before NTM struck and caused me to be very ill, I was extremely driven, highly competitive and very independent. I spent much of my life in sales and was the first woman to sell cars in Florida. I was a partner in a New York based garment manufacturing business and I survived that without a scratch. I enjoy being extremely active but life with nontuberculous mycobacterial disease (NTM) is really tough and debilitating.

This disease has taken away my drive and endurance, one activity at a time. It is insidious, frightening, and misunderstood. Many patients have told us that they can no longer function because they are so short of breath. Others can no longer work and many are hospitalized repeatedly.

The symptoms and the tests to diagnose NTM are much like those for TB. Unfortunately, it is much harder to treat. I am witness to the fact that after almost nine years of drug therapy I am still not well and have been told I will likely require lifelong drug therapy including IV medicines.

Not enough is done because most doctors don't look for this disease. When NTM infected my lungs, I coughed continuously and was fatigued. I had a low-grade fever for years but never looked ill; I had repeated bouts of pneumonia, coughed up blood, and it took 10 years for a diagnosis. We hear the same story from other patients. Unfortunately, it was too late to repair the damage because the middle portion of my left lung was destroyed and there were areas where the tissue had been destroyed throughout both lungs. Many others are suffering with NTM and most don't even know it yet because, sadly, they haven't been diagnosed. Please help them.

PHILIP LEITMAN, PRESIDENT, NTM INFO & RESEARCH, INC.

Philip Leitman co-founded NTM Info & Research when his wife Fern became ill with severe pulmonary NTM disease. Fern and Philip began meeting and hearing from numerous patients who were struggling with NTM and had a lack of understanding about it. His personal commitment has drawn the support of numerous physicians, the media, as well as government and government organizations at various levels. Efforts that began by developing the website, (NTMInfo.com) are now an established not-for-profit seeking to enhance knowledge about NTM through collaborative efforts with leading institutions, government, and patients, as well as increased education to provide broader awareness and understanding of the need for timely diagnosis and effective multi-faceted treatments.

Mr. Leitman has an extensive background in business and international business. He currently is a Regional Vice-Chair of the Council of National Trustees of National Jewish Medical and Research Center, President and co-founder of NTM Info & Research, Inc., Board member of the American Lung Association of Florida, member of the Florida TB Control Coalition, and a former Board member of Senior Care and JVS Rehabilitation Sheltered Workshop.

Philip Leitman is also President and CEO of Philip Leitman, Inc. He is active as a real estate developer in South Florida. He and his wife Fern live in Pinecrest, Florida, and their children and grandchildren live nearby.

STATEMENT OF PHILIP LEITMAN

Fern's doctors say she sets a standard for wanting to survive, wanting to live, and wanting to function highly. I am proud to follow her lead. This is why!

In September 1996, shortly after lung surgery, Fern's health deteriorated to the point where her doctors suggested that we call our children. Fern was rushed to a procedure room to put a bronchoscope into her lungs to see what was happening. At that moment, Fern told me to go back and talk to her roommate at the hospital because that woman had the same illness and was about to have lung surgery. Fern said, "Please tell her that she is not as sick and this won't happen to her." The other woman looked very much like Fern. NTM can affect any one of us but for some unknown reason, it affects more women than men.

What Fern is going through is simply not unique! There are support groups in New York, California, Texas, Florida, and soon in Boston. The NTMInfo.com website has now exceeded one million hits. A number of leading hospitals and a branch of the CDC are linked.

Fern's normal morning routine starts with pulmonary therapy to clear her airways. Then there is a sinus wash. With breakfast, Fern takes five different oral drugs and IV medicines. In addition, there are inhaled medicines. The total time from awakening to being able to leave the house is usually four (4) hours.

While tuberculosis is often known to appear in inner cities and immigrant populations, NTM knows no such boundaries. However, current epidemiologic data is not available. The latest data that we have from the Centers for Disease Control was collected in the 1980's and we urgently need newer data. Current data from the University of Toronto suggests that the prevalence may be six times higher than our older information. We have no reason to believe that Toronto is any different than Chicago or any other major U.S. city.

#### PREPARED STATEMENT OF THE OVARIAN CANCER NATIONAL ALLIANCE

On behalf of the Ovarian Cancer National Alliance (the Alliance), I thank the Subcommittee for this opportunity to submit comments for the record regarding the Alliance's fiscal year 2006 funding recommendations that we believe are necessary to help reduce and prevent suffering from ovarian cancer. For 8 years, the Alliance has worked to increase awareness of ovarian cancer and advocated increased federal resources to support research on identifying more effective ovarian cancer diagnostics and treatments. While I recently joined the Alliance as executive director, my journey with ovarian cancer began with my own diagnosis 3 years ago.

As an umbrella organization with 46 state and local groups, the Alliance unites the efforts of more than 500,000 grassroots activists, women's health advocates, and health care professionals to bring national attention to ovarian cancer. As part of this effort, the Alliance advocates sustained federal investment in the Centers for Disease Control and Prevention's (CDC) Ovarian Cancer Control Initiative. The Alliance respectfully requests that Congress provide \$9 million for the program in fiscal year 2006.

#### OVARIAN CANCER'S DEADLY STATISTICS

According to the American Cancer Society, in 2005, more than 22,000 American women will be diagnosed with ovarian cancer, and approximately 16,000 will lose their lives to this terrible disease. Ovarian cancer is the fourth leading cause of cancer death in women. Currently, more than half of the women diagnosed with ovarian cancer will die within 5 years. Among African American women, only 48 percent survive 5 years or more. When detected early, the 5-year survival rate increases to more than 90 percent, but when detected in the late stages, the 5-year survival rate drops to 28 percent.

Today, it is both striking and disheartening to see that despite progress made in the scientific, medical and advocacy communities, ovarian cancer mortality rates have not significantly improved during the past decade, and a valid and reliable screening test—a critical tool for improving early diagnosis and survival rates—still does not yet exist for ovarian cancer. Behind the sobering statistics are the lost lives of our loved ones, colleagues and community members. While we have been waiting for the development of an effective early detection test—thousands of our sisters, including one-third of our founding board members, have lost their battle to ovarian cancer.

I am considered one of the lucky ones. When I was diagnosed 3 years ago, my two cancers—ovarian and endometrial—were found to be in early Stage 1 when I had the best chance for surviving beyond 5 years—something only 25 percent of women with this disease can claim. Like most women diagnosed in early stage ovarian cancer, my good fortune was not the result of my awareness of the symptoms, it was not the result of my awareness that I was at a higher risk, and it was not the result of having access to a currently non-existent early screening test. My good fortune was the lucky result of my perseverance with my doctor, and my subsequent treatment by the appropriate gynecologic oncologist specialist.

I have come to work for the Alliance to ensure that other women can have the opportunity to be as fortunate as I have been. We cannot rely on luck for our survival. All women should have access to treatment by a specialist. All women should have access to a valid and reliable screening test. We must deliver new and better treatments to patients and the physicians and nurses who treat patients with this disease tell us that until we have a test, we must continue to increase awareness

and educate women and health professionals about the signs and symptoms associated with this disease.

THE OVARIAN CANCER CONTROL INITIATIVE AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

As the statistics indicate, among the most urgent challenges in the ovarian cancer field are late detection and poor survival. The CDC's cancer program, with its strong capacity in epidemiology and excellent track record in public and professional education, is well positioned to address these problems. As the nation's leading prevention agency, the CDC plays an important role in translating and delivering at the community level what is learned from research, especially ensuring that those populations disproportionately affected by cancer receive the benefits of our nation's investment in medical research.

Specifically, the CDC's Ovarian Cancer Control Initiative helps give all women the opportunity to survive ovarian cancer. Public awareness and education programs funded by the program make women and health professionals aware of the warning signs of ovarian cancer and examine survival trends based on care received, so they can better detect the cancer by identifying and understanding symptoms exhibited in early stages.

In addition, the CDC has a strong tradition of partnering with primary care physicians to combat two key barriers to early detection—recognition and diagnosis of the disease. Primary care physicians usually are the first to see women presenting with the disease. Increasing awareness and understanding of the signs and symptoms of ovarian cancer among these physicians can help improve early detection and survival rates.

Prompted by efforts from leaders of the Alliance and championed by Representative Rosa DeLauro—with bipartisan, bicameral support—Congress established the Ovarian Cancer Control Initiative at the CDC in November 1999. Congress' directive to the agency was to develop an appropriate public health response to ovarian cancer and conduct several public health activities targeted toward reducing ovarian cancer morbidity and mortality.

Currently, the Ovarian Cancer Control Initiative supports several national program grants, including three new CDC funded state initiatives:

- The Center for Health Promotion and Prevention Research at the University of Texas in Houston—Funded to conduct a study focusing on symptoms relating to early detection of ovarian cancer and staging distinctions.
- The School of Public Health at the University of Alabama at Birmingham—Funded to conduct a study focusing on barriers to early detection of ovarian cancer.
- The North American Association of Central Cancer Registries (NAACCR)—Funded to analyze and report data on ovarian cancer incidence by race, and to find new ways to improve accuracy of ovarian cancer incidence and mortality data among women who are neither Caucasian nor African American.
- The Department of Preventive Medicine at the University of Southern California—Funded for 1 year to analyze cancer registry data on borderline ovarian cancer cases in California.
- The Oklahoma University Health Sciences Center—Funded to conduct a 2-year, multiple component study of women experiencing possible ovarian cancer symptoms, how they seek treatment, and possible barriers to their medical care.
- Battelle Centers for Public Health and Evaluation—Funded to conduct a review of medical literature on clinical management of non-specific abdominal and pelvic symptoms potentially suspicious of ovarian cancer in older women. The review will provide the foundation for CDC funding to develop evidence-based guidelines for primary care providers to increase ovarian cancer cases detected in early stages.
- State tumor registries in California, Maryland, and New York—Each state received funding from the National Program of Cancer Registries to conduct a 3 year study to determine the proportion of women who had their initial surgery performed by a gynecologic oncologist and to detail aspects of the second course of treatment provided.

TAKING THE NEXT STEP IN PREVENTION AND AWARENESS

In only 5 years, the CDC's Ovarian Cancer Control Initiative, with its support of studies on early detection and underserved populations, has made an important contribution to a better understanding and awareness of the disease. However, without a screening test, it is clear that more needs to be done. Additional funding in fiscal year 2006 will enable the CDC to expand the reach and scope of its current ovarian

cancer initiatives to help advance our nation's efforts to reduce and prevent ovarian cancer morbidity and mortality. The allocation of \$9 million in fiscal year 2006 funding will continue the excellent progress being made and could expand the program's efforts to include:

- Development of a risk model for ovarian cancer like the model for breast cancer. This would help health care professionals identify high-risk women, who then could be monitored regularly. By helping health care providers to be “on alert,” they have the information and tools they need to catch the disease early and improve survival rates.
- Conduct an education campaign targeted to high-risk women to educate them about the signs and symptoms of ovarian cancer, the importance of regular monitoring, and strategies for risk reduction.
- Development and implementation of a national campaign to inform primary care physicians, who are usually the first to see women with symptoms, about ovarian cancer.
- Examination of the reasons why minority women have higher mortality rates and development of appropriate strategies for addressing this terrible health disparity.
- Conduct an education initiative targeted to health care professionals about best practices for treating the disease, especially referral to a gynecologic oncologist for optimal survival outcome.

#### A SUSTAINED COMMITMENT TO FUND CANCER RESEARCH

When funding stagnates or does not keep pace with inflation, progress in critical research programs is halted or slows significantly. Inadequate funding for the National Institutes of Health (NIH) and the National Cancer Institute (NCI) means smaller “trickle down” occurs for the lesser-known or less popular—yet terribly devastating—diseases like ovarian cancer. To ensure adequate funding for all types of cancer, particularly those most deadly and least understood, the Alliance joins the cancer community in asking for \$30.1 billion for NIH and \$6.17 billion for NCI in fiscal year 2006.

#### SUMMARY

The Alliance maintains a long-standing commitment to work with Congress, the Administration, and other policymakers and stakeholders to improve the survival rate from ovarian cancer through education, public policy, research, and communication. Please know that we appreciate and understand that our nation faces many challenges and Congress has limited resources to allocate, however, we are concerned that without increased funding to bolster and expand ovarian cancer education, awareness, and research efforts, the nation will continue to see growing numbers of women losing their battle with this terrible disease.

On behalf of the entire ovarian cancer community—patients, family members, clinicians and researchers—we thank you for your leadership and support of federal programs that seek to reduce and prevent suffering from ovarian cancer. Thank you in advance for your support of \$9 million in fiscal year 2006 funding for the CDC's Ovarian Cancer Control Initiative.

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#### PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

- \$250,000 within the Centers for Disease Control and Prevention (CDC) for a pulmonary hypertension awareness and education program.
- A 6 percent increase for the National Heart, Lung and Blood Institute (NHLBI) and the establishment of Pulmonary Hypertension Centers of Excellence at the Institute.
- \$30 million for the Health Resources and Services Administration's (HRSA) “Gift of Life Donation Initiative.”

Mr. Chairman, thank you for the opportunity to submit testimony on behalf of the Pulmonary Hypertension Association.

I am Dr. Anne Caesar, a professor of medicine at Georgetown University and a pulmonary hypertension patient (PH). PH is a rare disorder involving both the heart and the lungs. The walls of the blood vessels that supply the lungs thicken and often constrict, making them unable to carry normal amounts of blood. The heart works harder to compensate and eventually can't keep up. Life is threatened. Currently, there is no cure. Symptoms of pulmonary hypertension include shortness of breath with minimal exertion, fatigue, chest pain, dizzy spells and fainting.

When PH occurs in the absence of a known cause, it is referred to as primary pulmonary hypertension (PPH). This term should not be construed to mean that because it has a single name it is a single disease. There are likely many unknown causes of PPH.

Secondary pulmonary hypertension (SPH) means the cause of the disease is known. Common causes of SPH are the breathing disorders emphysema and bronchitis. Other less frequent causes are scleroderma, CREST syndrome and systemic lupus. In addition, the use of diet drugs can lead to the disease.

While new treatments are available, unfortunately, PH is frequently misdiagnosed and often progresses to late stages by the time it is detected. Although PH is chronic and incurable with a poor survival rate, the new treatments becoming available are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Eleven years ago, when three patients who were searching to end their own isolation founded this organization, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was not enough and as membership began to grow—driven by a newsletter written by patients and distributed by doctors—and as a community began to form, an 800 number support line was launched, support groups were established, a Scientific Advisory Board (SAB) was formed, a Patient's Guide to Pulmonary Hypertension was written, and a web site was launched.

Today, PHA includes:

- Over 5,000 patients, family members, and medical professionals.
- An international network of over 100 support groups.
- An active and growing patient telephone helpline.
- A new and fast-growing research fund. (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund five, five-year, mentored clinical research grants and PHA has awarded seven Young Researcher Grants.)
- A host of numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension—published quarterly and distributed to all cardiologists, pulmonologists and rheumatologists in the United States.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

PHA applauds the subcommittee for its leadership in encouraging CDC to initiate a professional and public PH awareness campaign. We continue to work with officials at the CDC to establish this important program which will better inform health care professionals and the general public about PH, its symptoms, and treatment options.

PHA knows that Americans are dying because of a lack of awareness of both pulmonary hypertension and recent advances in research and treatments. Most particularly, this is true among underserved populations. These are the least likely and the least able to see the three and four doctors it often takes to get a correct diagnosis. We believe that activities proposed below need to include special focus on reaching underserved populations and their medical services.

The following is a description of the specific initiatives we hope to launch in collaboration with CDC.

(1) Increasing awareness and understanding of PH among primary care physicians is critically important, because these practitioners are usually the first point of contact for PH patients. If the primary care doctor misses the symptoms, then the chance for early diagnosis depends upon the intuition and persistence of the patient. They have a chance, if they aggressively pursue diagnosis by trained and aware specialists. If they are not aggressive, or if they are in a health plan that requires their general practitioner to prescribe the referral, they are more likely to go undiagnosed until it is too late to control their illness. To increase awareness we propose to launch the following:

- Written and video diagnostic tools for placement on the Internet.
- Working with state health departments and clinic administrators to develop information for mailing to primary care physicians, medical schools and medical centers in the United States drawing their attention to the new web resources.
- A simplified and visually attractive print version of the proper diagnostic procedures, which will be targeted to primary care physicians, public health clinics, medical schools, and medical centers in the United States.

- Advertising in publications general practitioners and public health professionals are likely to read. The emphasis will be the importance of early diagnosis and the ease of accessing diagnostic tools via the Internet.
- Improvements to an already produced CD-ROM that explains pulmonary hypertension from a variety of perspectives. We would like to make these available to the medical community and patients through our web site on an as requested basis and at conferences and through targeted mailings.
- (2) Due to the advancements in treatment for PH, it is important that we also focus on educating cardiologists and pulmonologists. Our strategies for reaching cardiovascular specialists include:
  - Expansion of the first Pulmonary Hypertension Journal focused on educating a cardiologists and pulmonologists on issues related to the diagnosis and treatment of the illness.
  - Placement of additional detailed information on the illness on the web. The PH Journal and other publications will promote this availability.
  - Expansion of the medical section of PHA's international conference on pulmonary hypertension (the largest PH conference in the world).
  - Expansion of PHA's Pulmonary Hypertension Resource Network. This program is focused on increasing awareness and knowledge of PH among nurses, respiratory therapists, technicians and pharmacists through peer education.
- (3) Finally, PHA is committed to increasing PH awareness among the general public through the development of the following initiatives:
  - A series of 10, 15, and 30 second public service announcements on PH. These PSAs will be in both audio and video form.
  - A PH media relations manual.
  - An organ donation and transplant listing Awareness Campaign (unfortunately, many PH patients die before finding a suitable organ donor).
  - Expansion of awareness and information activities on PHA's web site.
  - Continuation of PH Awareness Month.

PHA and CDC have engaged in an ongoing dialogue about these and other strategies designed to increase awareness of PH. We are grateful for CDC's support of a DVD focused on the diagnosis of PH. However, despite repeated encouragement from the subcommittee, CDC has not established an ongoing awareness and education initiative on this devastating disease. Therefore, for fiscal year 2006, we encourage you to provide \$250,000 within CDC's Cardiovascular Disease program for the formal establishment of this important initiative.

#### NATIONAL HEART, LUNG AND BLOOD INSTITUTE

Mr. Chairman, PHA commends the leadership of the National Heart, Lung and Blood Institute (NHLBI) for its support of PH research. Three years ago, two separate groups of scientists funded by NHLBI simultaneously identified a genetic mutation associated with primary pulmonary hypertension.

The two groups independently reported that defects in the *BMPR2* gene, which regulates growth and development of the lung, are associated with PPH. The defects in the gene lead to the abnormal proliferation of cells in the lung characteristic on PPH.

Although both studies suggest that only one gene is involved in PPH, neither group identified the defects in *BMPR2* as the sole cause of PPH. In addition, since many people without a known family history of PPH get the disease, both groups suggested that other factors may interfere with control of the tissue growth. Now that we have pinpointed a gene, we can focus on learning how it works. Hopefully, that information will enable researchers to devise better treatments and perhaps eventually a preventive therapy or cure.

We greatly appreciate NHLBI's commitment to advancing research to better understand and ultimately cure this disease. Moreover, we applaud the subcommittee's strong support of PH research at the Institute. For fiscal year 2006, PHA recommends a 6 percent increase for NHLBI and the NIH overall. In addition, PHA recommends the establishment of three pulmonary hypertension "Centers of Excellence" at NHLBI to support the expansion of research, training and information dissemination. Finally, we encourage the establishment of a PH data system and clearinghouse at the Institute.

#### GIFT OF LIFE DONATION INITIATIVE AT HRSA

Mr. Chairman, PHA applauds the success of the Department of Health and Human Services "Gift of Life" Donation Initiative. Currently, there are three drugs that PH patients can be prescribed to help improve the quality of life with PH. Eventually, many patients must move toward lung or heart and lung transplan-

tation. PH is a difficult to diagnose illness and while patients often list soon after diagnosis, for many PH patients it is too late. This why PHA is developing the Bonnie's Gift Project.

Bonnie's Gift was started in memory of Bonnie Dukart, one of PHA's most active and respected leaders. Bonnie was a PH patient herself. She battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use Bonnie's Gift as a way to disseminate information about PH, the importance of early listing, the importance of organ donation to our community and organ donation cards.

PHA has entered into a partnership with the "Gift of Life" Donation Initiative to increase awareness of the importance of organ donation and early listing within the PH community. For fiscal year 2006, PHA supports an appropriation of \$30 million for HRSA's Gift of Life program.

#### CONCLUSION

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the subcommittee to improve the lives of pulmonary hypertension patients. If you have any questions or would like additional information, please do not hesitate to contact me or the Pulmonary Hypertension Association's National Office.

#### PREPARED STATEMENT OF THE SOCIETY OF NUCLEAR MEDICINE

The Society of Nuclear Medicine (SNM) appreciates the opportunity to submit written testimony for the official record regarding federal funding for biomedical research in fiscal year 2006.

SNM is an international, scientific, and professional organization with more than 16,000 members dedicated to promoting the science, technology, and practical application of nuclear medicine. Over the last 50 years, since biomedical imaging first began, the Nuclear Medicine community has made groundbreaking discoveries thanks to the research and development that was facilitated at the National Institutes of Health (NIH). To that end, the Society strongly recommends sufficient levels of federal funding to sustain and seize new opportunities in biomedical research.

The Society of Nuclear Medicine stands ready to work with policymakers at the local, state, and federal levels to advance biomedical research policies and programs that will reduce and prevent suffering from disease.

#### WHAT IS NUCLEAR MEDICINE?

Nuclear Medicine is an established specialty that performs non-invasive molecular imaging procedures to diagnose and treat diseases, and also to determine the effectiveness of therapeutic treatments—whether surgical, chemical, or radiation. It contributes extensively to the treatments and diagnoses of patients with cancers of the brain, breast, blood, bone, bone marrow, liver, lungs, pancreas, thyroid, ovaries, and prostate. Molecular imaging continues to provide expert information to help doctors, technicians, and other health care personnel manage abnormalities of the heart, brain, and kidneys. In fact, recent advances in the detection and diagnosis of Alzheimer's disease can be attributed to Nuclear Medicine imaging procedures, specifically positron emission tomography (PET) scans. These advances—which were made possible by research from nuclear medicine professionals—helped lead the Centers for Medicaid and Medicare Services (CMS) to extend Medicare coverage to include PET scans for some beneficiaries who suffer from Alzheimer's and other dementia-related diseases.

CMS Administrator Mark B. McClellan announced the coverage by saying: "Together with outside experts and other agencies we examined the available data and determined that we ought to approve coverage for patients who've been worked up but whose diagnosis is uncertain."<sup>1</sup>

CMS' decision was also explained by Dr. Sean Tunis, CMS' Chief Medical Officer. He said: "The available evidence supports the conclusion that PET scans help to evaluate patients with progressive symptoms of dementia, but for whom a diagnosis remains unclear despite a thorough standard medical evaluation. We will also support the conduct of additional studies that will determine the value of PET scans

<sup>1</sup> CMS Press Release—Sept. 14, 2004—Medicare Posts Coverage Decision to Expand Coverage of PET Scans for Alzheimer's. <http://www.cms.hhs.gov/media/press/release.asp?Counter=1200>.



required in a broader population of Medicare beneficiaries who develop symptoms of dementia.”

The effect nuclear medicine has on people is far-reaching. Annually, more than 16 million men, women, and children require noninvasive molecular/nuclear medical procedures. These safe, cost-effective procedures include PET scans to diagnose and monitor treatments in cancer; cardiac stress tests that analyze heart function; bone scans for orthopedic injuries; and lung scans for blood clots. In addition, patients undergo procedures to diagnose liver and gall bladder functional abnormalities and to diagnose and treat hyperthyroidism and thyroid cancer.

#### SUSTAIN AND SEIZE RESEARCH OPPORTUNITIES

For decades, Americans and people from across the world have benefited from the strong federal investment in nuclear medicine and biomedical research at the National Institutes of Health. We can safely say, in the words CMS Administrator McClellan, “the technology is promising.”<sup>2</sup> The Society hopes that this subcommittee will continue its trend of forward thinking and federally fund NIH and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) and the National Cancer Institute (NCI) at sufficient levels for fiscal year 2006.

SNM is proud to join its colleagues in the public health community in recommending that in fiscal year 2006, NIH is funded at a level totaling \$30.1 billion. This funding level will permit NIH to sustain and build upon its current research activities, which are a byproduct of the recent NIH budget doubling effort. Even a minimal decrease or slowed momentum of increased funding in NIH’s budget could cause severe disruption in the research activities and capabilities.

In 1946, the first successful nuclear magnetic resonance (NMR) experiments were performed. This led to the first nuclear magnetic resonance imaging (MRI) exam performed on a human being 31 years later in 1977. From the first MRI in 1977 to today, critical advances in technology have developed, allowing physicians, nuclear medicine technicians and other health care professionals to image in seconds what used to take hours, days, or even weeks. Research in biomedical imaging and bioengineering is progressing rapidly and recent technological advances have revolutionized the diagnosis and treatment of disease. In 2000, the National Institute of Biomedical Imaging and Bioengineering was created. This NIH institute, specifically focused on biomedical imaging and bioengineering, has made great strides in helping the health care community and its patients recognize and understand different diseases and disorders. Pancreatic transplantation, brain scans, improvement to epilepsy surgeries are just a few examples of how NIBIB research is helping diagnose and treat patients. In order for NIBIB to continue moving forward with its research, SNM requests \$350 million in federal funding for fiscal year 2006. This funding level will allow NIBIB to further its research, development, and application of emerging and breakthrough biomedical technologies that will facilitate improved disease detection, management, and prevention.

In addition, SNM advocates that another arm of NIH that uses molecular imaging, NCI, receive sufficient funding—\$5.21 billion—in fiscal year 2006. The American Cancer Society predicts that more than a million Americans will be diagnosed with cancer in 2005. We have made significant gains in the war on cancer, and there have been successful breakthroughs in diagnosing and treating this terrible disease. Currently PET scans are available to detect more than a dozen types of cancer. Cancer research is leading to new therapies that translate into longer survival and improved quality of life for cancer patients. Extraordinary advances in cancer research have resulted because of the strong commitment by the federal, state, and local governments in combating cancer. Effective prevention, early detection, and treatment methods for many cancers have resulted from this governmental interest, intervention and public education campaign. In order to continue making a strong case against cancer, SNM requests that the Committee allocate \$5.21 billion in federal funds for the NCI in fiscal year 2006.

#### CONCLUSION

As outlined above, SNM has a strong and vested interest in making sure that biomedical research in the United States is sufficiently funded. It is in everyone’s best interest that the federal government invests the needed dollars to continue the pursuit of medical breakthroughs in technology and science. Without the sufficient funding levels—which include \$30.1 billion for NIH, \$350 million for NIBIB, and

<sup>2</sup> CMS Press Release—Sept. 14, 2004—Medicare Posts Coverage Decision to Expand Coverage of PET Scans for Alzheimer’s. <http://www.cms.hhs.gov/media/press/release.asp?Counter=1200>.

\$5.21 billion for NCI—the positive effects and results of research and development are seriously compromised.

SNM stands ready to work with policymakers from both sides of the aisle to advance biomedical research and innovation to help reduce and prevent suffering from disease for all Americans. Again, on behalf of the members of SNM, I thank you for the opportunity to submit testimony regarding the absolute need for increased federal funding for biomedical research. I am available to answer any questions you may have.

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#### PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION OF AMERICA

On behalf of the more than 70,000 individuals and their families who are affected by Spina Bifida, the Spina Bifida Association of America (SBAA) appreciates the opportunity to submit written testimony for the record regarding increased funding for the National Spina Bifida Program and other related Spina Bifida initiatives in fiscal year 2006. SBAA is the national voluntary health agency working on behalf of people with Spina Bifida and their families through education, advocacy, research, and service. The Association was founded in 1973 to address the needs of the Spina Bifida community and today serves as the representative of 57 chapters serving more than 125 communities nationwide. SBAA stands ready to work with Members of Congress and other stakeholders to ensure that our Nation takes all the steps necessary to reduce and prevent suffering from Spina Bifida.

#### BACKGROUND ON SPINA BIFIDA

Spina Bifida is a neural tube defect (NTD) and occurs when the spinal cord fails to close properly during the early stages of pregnancy, typically within the first few weeks of pregnancy and most often before the mother knows that she is pregnant. Over the course of the pregnancy—as the fetus grows—the spinal cord is exposed to the amniotic fluid which becomes increasingly toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida, from mild—with little or no noticeable disability—to severe—with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this neural tube defect is that most children with it suffer from a host of physical, psychological, and educational challenges—including paralysis, developmental delay, numerous surgeries, and living with a shunt in their skulls, which helps to relieve cranial pressure associated with spinal fluid that does not flow properly. We are pleased to report that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living long enough to become adults with Spina Bifida. These gains in longevity are principally due to breakthroughs in research, combined with improvements generally in health care and treatment. However, with this extended life expectancy, our Nation and people with Spina Bifida now face new challenges—education, job training, independent living, health care for secondary conditions, aging concerns, among others. Despite these gains, individuals and families affected by Spina Bifida face many challenges—physical, emotional, and financial.

Recent studies have shown that if all women of childbearing age were to consume 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy, the incidence of Spina Bifida could be reduced by up to 75 percent. However, even if we are successful in preventing the majority of Spina Bifida cases in the future, our Nation still must take steps to ensure that the tens of thousands of individuals living with Spina Bifida can live full, healthy, and productive lives. To ensure the highest quality-of-life possible, prevention interventions and treatment therapies must be identified, developed, and delivered to those in need.

#### COST OF SPINA BIFIDA

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare Programs. Our Nation must do more to help reduce the emo-

tional, financial, and physical toll of Spina Bifida on the individuals and families affected. Efforts to reduce and prevent suffering from Spina Bifida help to save money and save lives.

#### IMPROVING QUALITY-OF-LIFE THROUGH THE NATIONAL SPINA BIFIDA PROGRAM

Secondary conditions associated with Spina Bifida include full or partial paralysis, neurological disorders, bladder and bowel control difficulties, learning disabilities, depression, latex allergy, obesity, skin breakdown, and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty paying attention, expressing or understanding language, and grasping reading and math. Early intervention with children who experience learning problems can help considerably to prepare them for school. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida likely will have a normal or near normal life expectancy. Ensuring access to these services is essential to improving the quality-of-life for those born with this birth defect.

SBAA has worked with Members of Congress to ensure that our Nation is taking all the steps possible to prevent Spina Bifida and diminish suffering for those living with this condition. As part of this comprehensive effort, SBAA collaborated with Members of Congress and other interested parties to secure an essential increase in fiscal year 2005 funding for the National Spina Bifida Program at the National Center for Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). SBAA thanks the Members of the Subcommittee for their expression of support for this new and integral program by allocating \$3.6 million in fiscal year 2005.

The National Spina Bifida Program works on two critical levels—to reduce and prevent Spina Bifida incidence and morbidity and to improve quality-of-life for those living with Spina Bifida. The program seeks to ensure that what is known by scientists is practiced and experienced by the 70,000 individuals and families affected by Spina Bifida. For example, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, which range from learning disabilities and depression to severe allergies and skin problems that make life difficult for these individuals. All of these problems can be treated or prevented, but only if those affected by Spina Bifida—and their caregivers—are properly educated and taught what they need to know to maintain the highest level of health and well-being possible.

Second, the National Spina Bifida Program offers benefits to those who live with Spina Bifida and their families by working to improve the outlook for a life challenged by this complicated birth defect—principally identifying potentially valuable therapies from in-utero throughout the lifespan and making them available and accessible to those in need. These secondary prevention activities represent a tangible quality-of-life difference to the 70,000 individuals living with Spina Bifida. With the goal being living well with Spina Bifida, the secondary prevention initiatives are focused on the creation and implementation of strategies to improve the quality-of-life. These quality-of-life efforts center on reaching the general population with Spina Bifida, advancing treatment of Spina Bifida and its related conditions, and working with adolescents living with Spina Bifida to address their specific academic, psycho-social, and vocational needs. In addition, the National Spina Bifida Program will create and implement a comprehensive program to assist teens with Spina Bifida in the development of life skills for independence, self-reliance, and success in the world.

SBAA advocates that the National Spina Bifida Program receive \$5.5 million in fiscal year 2006 so the NCBDDD can expand and continue to promote quality-of-life programs that support people with Spina Bifida so they can live fulfilling and productive lives. In its first three years, this program already has made a difference for our community and with additional resources it can expand its reach and provide additional assistance and hope to those with an affected loved one. Increasing funding for the National Spina Bifida Program will help ensure that our nation continues to mount a comprehensive effort to prevent and reduce suffering from Spina Bifida.

#### PREVENTING SPINA BIFIDA

While the exact cause of Spina Bifida is unknown, over the last decade, medical research has confirmed a link between a woman's folate level before pregnancy and the occurrence of Spina Bifida. Sixty million women are at-risk of having a child born with Spina Bifida and each year approximately 3,000 pregnancies in this country are affected by Spina Bifida, resulting in 1,500 births. As mentioned above, re-

search has found that the consumption of 400 micrograms of folic acid daily prior to becoming pregnant and throughout the first trimester of pregnancy can help reduce incidence of Spina Bifida up to 75 percent. There are few public health challenges that our Nation can tackle and conquer by three-fourths in such a straightforward fashion. However, we must still be concerned with addressing the 25 percent of Spina Bifida cases that cannot be prevented by folic acid consumption, as well as ensuring that all women of childbearing age—particularly those most at-risk for a Spina Bifida pregnancy—consume adequate amounts of folic acid.

The good news is that progress has been made in convincing women of the importance of folic acid consumption and the need to maintain diet rich in folic acid. Since 1968, the CDC has led the Nation in monitoring birth defects and developmental disabilities, linking these health outcomes with maternal and/or environmental factors that increase risk, and identifying effective means of reducing such risks. Former CDC Director Jeff Koplan has stated that the agency's folic acid prevention campaign has reduced neural tube defect births by 20 percent. This public health success should be celebrated, but it is only half of the equation as approximately 3,000 pregnancies still are affected by this devastating birth defect. The Nation's public education campaign around folic acid consumption must be enhanced and broadened to reach segments of the population that have yet to heed this call—such an investment will help ensure that as many cases of Spina Bifida can be prevented as possible.

SBAA works collaboratively with CDC and other nonprofits to increase awareness of the benefits of folic acid, particular for those at elevated risk of having a baby with neural tube defects (those who have Spina Bifida themselves or those who have already conceived a baby with Spina Bifida). With additional funding in fiscal year 2006 these activities could be expanded to reach the broader population in need of these public health education, health promotion, and disease prevention messages. SBAA advocates that Congress provide additional funding to CDC to allow for a particular public health education and awareness focus on at-risk populations (e.g. Hispanic-Latino communities) and health professionals who can help disseminate information about the importance of folic acid consumption among women of childbearing age.

In addition to a \$5.5 million fiscal year 2006 allocation for the National Spina Bifida Program, SBAA supports a fiscal year 2006 allocation of \$135 million for the NCBDDD so the agency can enhance its programs and initiatives to prevent birth defects and developmental disabilities and promote health and wellness among people with disabilities.

#### IMPROVING HEALTH CARE FOR INDIVIDUALS WITH SPINA BIFIDA

The mission of the Agency for Healthcare Research and Quality (AHRQ) is to improve the outcomes and quality of health care; reduce its costs; improve patient safety; decrease medical errors; and broaden access to essential health services. The work conducted by the agency is vital to the evaluation of new treatments in order to ensure that individuals and their families living with Spina Bifida continue to receive the high quality health care that they need and deserve. SBAA recommends that AHRQ receive \$440 million in fiscal year 2006 so that it can continue to conduct follow-up efforts to evaluate Spina Bifida treatments, promulgate associated standards of care, and further the provision of evidence-based care stemming from the outcomes of the 2003 Spina Bifida Research Conference. A new partnership between the Centers for Disease Control and AHRQ to develop treatments for Spina Bifida brings new hope for families living with Spina Bifida.

#### SUSTAIN AND SEIZE SPINA BIFIDA RESEARCH OPPORTUNITIES

SBAA seeks to support individuals and families affected by Spina Bifida, maximize the prevention of Spina Bifida, and ensure that all babies born with Spina Bifida have the greatest chance of survival and the highest quality-of-life—through the lifespan. When families recently diagnosed with a Spina Bifida pregnancy contact SBAA, the organization puts them in touch with other families who have a child with the condition so they can learn of the joys and challenges of having a child with the birth defect. Unfortunately, traditionally when families are faced with a Spina Bifida diagnosis they have had two difficult options. The first is to continue the pregnancy with the expectation of multiple surgeries for the child after birth, uncertain life expectancy, and many physical and developmental challenges and complications. The second, unfortunately, is to terminate the pregnancy. Fortunately, now there may be an important and effective third option.

Since the late 1990s, doctors at three U.S. hospitals—Children's Hospital of Philadelphia, Vanderbilt University Medical Center in Nashville, and the University of

California at San Francisco—have been operating before birth on fetuses diagnosed with Spina Bifida. In 2003, the University of North Carolina became the fourth hospital in the Nation to perform the in-utero operations. By closing the spinal lesion early in pregnancy, physicians believe they can minimize the damage created by fluid leaking from the spine, as well as limit by the harm done due to the spinal cord's contact with the amniotic fluid. Surgeons have found that closing the hole in the spine in this fashion before birth may correct breathing problems in 15 percent of the children receiving the procedure and may reduce the need for a shunt to drain fluid from the brain by between 33 percent and 50 percent.

To determine whether or not this new procedure is safer and more effective than the traditional post-birth surgery to address the condition, the National Institute of Child Health and Human Development (NICHD) is conducting a large study involving the Children's Hospital of Philadelphia, Vanderbilt University Medical Center, and the University of California at San Francisco. While these three institutions have undertaken preliminary studies of the in-utero surgery technique, the overall and long-term effectiveness of this approach as compared to traditional therapy remains unknown. Given the potential for this surgery to ameliorate many of the conditions associated with Spina Bifida, we must do a better job of studying and evaluating this procedure, educating health care providers about this surgery as a potential option, and making information about it available to more families facing a Spina Bifida pregnancy.

Our Nation has benefited immensely from past federal investment in biomedical research at the National Institutes of Health (NIH). SBAA joins with the rest of the public health community in advocating that NIH receive \$30.1 billion in fiscal year 2006. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBAA urges the NIH to explore the following as they relate to individuals with Spina Bifida: assistive technology, in utero surgery, cost of care, women's and men's health, tethered cord, hydrocephalus, latex allergies, and other related factors.

#### CONCLUSION

SBAA stands ready to work with policymakers to advance policies that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views on funding for programs that will improve the quality-of-life for the 70,000 Americans and their families living with Spina Bifida and stand ready to answer any questions you may have.

#### PREPARED STATEMENT OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

(1) A 6 percent increase for all of the National Institutes of Health and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

(2) Encourage NIAMS to create and enhance academic and educational opportunities for the advancement of scientific investigation of skin health and dermatologic diseases.

(3) Encourage NIAMS to sponsor further burden of skin disease research and epidemiology activities to investigate general and skin-disease specific measures in order to generate data surrounding the incidence, prevalence, economic burden, quality of life, disability and handicaps attributable to these diseases.

(4) Promote the development of NIH-supported training resources dedicated to attract more individuals to careers in skin disease research.

Mr. Chairman, and members of the subcommittee—I am very grateful for this opportunity to testify on behalf of the Society for Investigative Dermatology. I am Dr. Kevin Cooper, Professor of Dermatology, Chairman and Director of the Skin Diseases Research Center at the Department of Dermatology at Case Western Reserve University. I have been a physician and investigator serving the VA for 20 years in a part time capacity as a component of my academic work. I also serve as President of the Society for Investigative Dermatology.

#### BACKGROUND

The Society for Investigative Dermatology has over 2000 members worldwide dedicated to the advancement and promotion of the sciences relevant to skin health and disease through education, advocacy, and the scholarly exchange of scientific information. Members include scientists and physician researchers from universities, hospitals, and industries committed to the science of dermatology. Each member

firmly believes that further research is critical to improved prevention, diagnosis, and treatment for the 3,000 different diseases of the skin, hair, and nails, which affect about 80 million Americans each year.

My purpose in being here today is to emphasize the need for increased funding for the National Institutes of Health (NIH) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and to encourage follow-up to the “Burden of Skin Disease” workshop that took place in 2002. The workshop was held with the intention to investigate general and skin-disease specific measures in order to generate data surrounding the incidence, prevalence, economic burden, quality of life, disability and handicaps attributable to these diseases.

Good health depends on healthy skin. Much of what we see on the outside of the body is a reflection of a person’s health inside. From the yellow of hepatitis, to the deep purple lesions of Kaposi’s sarcoma—a common side effect of AIDS, from the sizeable skin lesions of lupus erythematosus, to the painful deformed nails which may occur in patients with severe arthritis and psoriasis—health disorders often show up first as problems on the skin’s surface. Skin samples are often used to make genetic diagnoses of internal disorders and in the future, the skin may be a target for gene replacement.

Advances in cell biology allow us to understand the life cycle of skin and hair-producing cells and to explain how a malfunctioning immune system undermines the health of the body overall and the skin, in particular. Furthermore, the ongoing revolution in molecular and cell biology, genetics, immunology, information and laser technology provides unprecedented opportunities for achieving advances in basic research and medical treatment. We are becoming rapidly more adept at growing skin cells in the laboratory and at producing artificial skin. Increasingly, laser surgery is commonly replacing more invasive and traditional surgical methods.

I would like to thank you for the increase in funding the subcommittee provided in fiscal year 2004 for NIH overall and for NIAMS. This year, we recommend a 6 percent increase for the NIH budget, and a similar percentage increase for NIAMS, which would lead to a funding level of \$542 million for NIAMS. As the population ages and we live longer, dermatologists will be asked increasingly to treat cancers and other skin disorders that appear more often in aged individuals. Dermatologists will need to find new and better ways to help prevent and heal common conditions of the elderly, such as bed sores. Ulcers of the skin alone cost \$8 billion per year to diagnose and treat.

I would also like to thank the subcommittee for the inclusion of the conference report language in your fiscal year 2005 bill, calling for further attention to the numerous research opportunities and developments identified during the September 2002 Burden of Skin Disease workshop. Further exploration into the economic and social costs of skin disease in the U.S. population is necessary, as an analysis into many related areas has not been updated since 1979. More data must be collected to determine the prevalence of skin diseases and the disabilities they inflict upon those suffering from them. The translation of statistical data and methodology into improved bedside care must be a priority.

The costs to society for medical care and lost wages due to conditions of the skin, hair and nails is estimated to be in the billions annually. However, the costs to those suffering from these debilitating conditions are immeasurable: they encounter discomfort and pain, physical disfigurement, disability, dependency and death. Skin conditions affect an individual’s ability to interact with others and compromise the self-confidence of those inflicted.

#### RESEARCH ADVANCES

The past two decades have seen explosive growth in technology and in increased sophistication in our understanding of the genetic and cellular mechanisms underlying many skin, hair and nail disorders. One consequence of these findings is a radical new paradigm shift in which the skin is now viewed as a complex organ that is intimately responsive to the immune system of the body. Several distinct cell types in the skin actively generate, regulate and perpetuate immune responses. Other important new research findings include the following:

- A gene responsible for the inherited form of basal cell carcinoma has been identified and may lead to new information as to the origins of skin cancer.
- A gene for an inherited form of hair loss has been discovered.
- A new protein that links collagen and vascular defects in scleroderma has been identified.
- Advances in the design of drug-delivery systems allow for sustained release of drugs through the skin, which will most likely lead to treatments that are more effective.

—Methods to grow real and artificial skin in laboratories are used to prepare skin grafts for burn victims.

The past two decades have focused on developing evaluation techniques such as clinical epidemiology, biostatistics, economics, and the quantitative social sciences used to determine the effectiveness of certain procedures and whether they contribute to the quality of life and health of both patients and society.

As you know, medical research organizations such as the Society for Investigative Dermatology work closely with patient support and advocacy groups. We are pleased to say for many years we have worked with the Coalition of Skin Diseases for Skin Disease Research. The many organizations that participate in the Coalition have been the best possible advocates for increased funding, as they understand that unless major research efforts are undertaken, advances in understanding and improvements in the health of patients will not occur. Every year, we participate with these organizations in advocating increased funding for the NIH and NIAMS. We want to reiterate how deeply grateful we are for your leadership and that of the subcommittee on medical research matters, which means so much for the health of the people in our nation.

I will be pleased to answer any questions you may have.

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PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH AND THE  
WOMEN'S HEALTH RESEARCH COALITION

On the behalf of the Society for Women's Health Research and the Women's Health Research Coalition, we are pleased to submit testimony in support of increased funding for biomedical research, and more specifically women's health research.

The Society is the only national non-profit women's health organization whose mission is to improve the health of women through research, education, and advocacy. Founded in 1990, the Society brought to national attention the need for the appropriate inclusion of women in major medical research studies and the need for more information about conditions affecting women disproportionately, predominantly, or differently than men.

The Coalition was created by the Society in 1999 as a way to strengthen our grassroots advocacy with scientists and researchers and clinicians from across the country who are concerned and committed to improving women's health research. The Coalition now has more than 620 members from across the country, including leaders within the scientific community and medical researchers from many of the country's leading universities and medical centers, directors from various Centers of Excellence on Women's Health as well as leading voluntary health associations, and pharmaceutical and biotechnology companies.

The Society and the Coalition are committed to advancing the health status of women through the discovery of new and useful scientific knowledge. We believe that sustained funding for the women's health research programs that are conducted across the federal research agencies is necessary if we are to accommodate the health needs of the population and advance the nation's research capability. We urge your support for all these federal agencies and programs described below that are working to meet these goals.

NATIONAL INSTITUTES OF HEALTH

From decoding the human genome to elucidating the scientific components of human physiology, behavior, and disease, scientists are unearthing exciting new discoveries which have the potential to make our lives and the lives of our families longer, healthier, and safer. The National Institutes of Health (NIH) has made this all possible by conducting and supporting our nation's biomedical research. The world-class NIH researchers, scientists, and programs are dedicated to understanding how the human body works and to gain insight into countless diseases and disorders. Due to robust investment and support from Congress, NIH has made the United States the world leader in medical research and has had a direct and significant impact on women in science and on women's health research.

In planning for fiscal year 2006 funding for the NIH, the Administration has proposed a 0.5 percent increase. This proposed amount however will not keep pace with the Biomedical Research and Development Price Index. It is vital that United States' commitment to medical research be sustained in order not to erode the foundation created over the past several years and to continue to build upon promising research to enhance the quality of life for all Americans touched by illness and disease.

Therefore, to continue the momentum of scientific advancement and expedite the translation of research from the laboratory to the patient, the Society encourages an increase of six percent (6 percent) for the NIH, for a budget of at least \$30 billion for fiscal year 2006. In addition, we request that you strongly encourage the NIH to assure that women's health research receives resources sufficient to meet the health needs of Americans.

Scientists have long known of the anatomical differences between men and women, but only within the past decade have they begun to uncover significant biological and physiological differences. Sex differences have been found everywhere from the composition of bone matter and the experience of pain to the metabolism of certain drugs and the rate of neurotransmitter synthesis in the brain. Sex-based biology, the study of biological and physiological differences between men and women, has revolutionized the way that the scientific community views the sexes. The evidence is overwhelming, and as researchers continue to find more and more biological differences, they are gaining a greater understanding of the biological and physiological composition of both sexes.

Much of what is known about sex differences is the result of observational studies, or is descriptive evidence from studies that were not designed to obtain a careful comparison between females and males. The Society has long recognized that the inclusion of women in study populations by itself was insufficient to address the inequities in our knowledge of human biology and medicine, and that only by the careful study of sex differences at all levels, from genes to behavior, would science achieve the goal of optimal health care for both men and women. This has given rise to sex-based biology.

Many sex differences are already present at birth, whereas others develop later in life. These differences play an important role in disease susceptibility, prevalence, time of onset and severity and are evident in cancer, obesity, coronary heart disease, autoimmune, mental health disorders, and other illnesses. Physiological and hormonal fluctuations may also play a role in the rate of drug metabolism and the effectiveness of response in females and males. This research needs to be supported and encouraged. Congress recognizes this importance and should support NIH at an appropriate level of funding and direct NIH to continue and expand this research into sex-based biology.

#### OFFICE OF RESEARCH ON WOMEN'S HEALTH

The NIH Office of Research on Women's Health (ORWH) has a fundamental role in improving women's health research at NIH. Within the Office of the Director, ORWH advises the NIH Director on matters relating to research on women's health; strengthens and enhances research related to diseases, disorders, and conditions that affect women; works to ensure that women are appropriately represented in biomedical and behavioral research studies supported by NIH; and develops opportunities for and supports recruitment, retention, re-entry and advancement of women in biomedical careers. ORWH works in partnership with the NIH Institutes and Centers to ensure that women's health research is part of the scientific framework and improve interdisciplinary research opportunities in women's health within NIH. ORWH's ambitious agenda encompasses issues that go far beyond reproductive capacity, cutting across and integrating scientific disciplines, medical specialties, psychosocial and behavioral factors, and environmental determinants in a multidisciplinary and collaborative approach. ORWH endeavors to address sex and gender perspectives of women's health and women's health research, as well as differences among special populations of women across the entire life span, from birth through adolescence, reproductive years, menopausal years and the more advanced, elderly years.

Two highly successful pioneering programs offered through ORWH that are critical to further advancing women's health research are Building Interdisciplinary Research Careers in Women's Health (BIRCWH) and Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR). These programs benefit both women's and men's health through sex and gender research, interdisciplinary scientific collaboration, and provide tremendously important support for young investigators in a mentored environment.

The BIRCWH program is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. What makes BIRCWH so unique is that it bridges advanced training with research independence, as well as across scientific disciplines. Since 2000, 177 scholars have been trained in the 24 centers recording over 634 publications and 526 abstracts. The scholars have secured 40 NIH grants and 70 awards from industry and institutional sources.



The BIRCWH program offered at Magee Women's Hospital in Pittsburgh, for example, has been able to successfully support the transition of eight young faculty at the beginning of their careers. In the current environment young faculty are expected to generate their income by teaching, clinical care or grant support. However, being that they are new, grant support for salary is unlikely and they end up with heavy clinical and/or teaching loads—at just the time in their careers when they should be perfecting their recently developed research skills. The BIRCWH program allows young researchers at Magee to become established and ready to apply for extramural funding and salary support. Magee has also been able to provide additional mentoring, courses, and career guidance to young investigators in women's health research.

The SCOR program was established in 2001 and now has 11 centers throughout the country. ORWH, along with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute of Child Health and Human Development, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute on Drug Abuse, the National Institute of Mental Health, and the National Institute of Environmental Health Sciences, published a request for applications to create these centers as a way to meet some of the health promotion and disease prevention objectives outlined in the "Healthy People 2010" initiative, a Public Health Service-led national activity for setting priority areas.

The objective of the SCOR program is to expedite interdisciplinary development and application of new knowledge to human diseases, to learn more about the causes of these diseases, and to foster improved approaches to treatment and/or prevention. The program was designed to complement other federally supported programs addressing women's health issues such as BIRCWH.

The Institutes and Centers at the NIH, working with the ORWH, have identified many research priority areas to be undertaken by SCORs. Some of these include studying the influence of toxic environmental factors on women's health; examining the sex and/or gender factors in acute and chronic pain conditions or syndromes; undertaking studies to examine kidney disorders, including the impact of pregnancy, diabetes, and hypertension on renal function; studying urologic and urogynecologic disorders; examining the biological and behavioral risk factors, including sex and/or gender factors, in the development of mental disorders such as addictive behaviors, schizophrenia, mood, anxiety, and eating disorders; and the developmental biology of the vascular system and the role of the fetal environment in programming lifelong cardiovascular function.

We strongly encourage Congress to direct NIH to continue its support of ORWH and its programs. This step is needed to assure that advancements in discoveries of sex differences and, in particular, women's health that are long overdue are not lost. From the discovery and understanding of illness and diseases to the formulation of treatments, pain relief and potential cures, knowledge base gained from these important efforts must not be lost, as the benefits are of critical importance to all Americans, men and women.

#### WOMEN'S HEALTH OFFICES WITHIN DEPARTMENT OF HEALTH AND HUMAN SERVICES

In addition to the ORWH, there are several other offices throughout the Department of Health and Human Services (HHS) that enhance the focus of the government on women's health research. Agencies with offices, advisors or coordinators for women's health or women's health research are the Department of HHS, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Agency for Healthcare Quality and Research, the Indian Health Service, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration, and the Centers for Medicare and Medicaid Services. There is a vital need for these agencies to be funded at levels adequate for them to perform their assigned missions.

We are grateful for the Committee's continuing support for the work of these entities. But with the exception of NIH and SAMSHA, none of these offices, advisors, or coordinators is statutorily authorized. Although an authorization does not guarantee an appropriation, having one makes it easier. The Society and its Coalition are addressing that issue in the appropriate venue through the Women's Health Office Act (H.R. 949 and S. 569). But, within your jurisdiction, we ask that the Committee Report clarify that Congress supports these offices and would like to see them continued and strengthened in the coming fiscal year.

The focus on women's health within HHS has been of critical importance to the advances made in women's health in the last decade. As previously mentioned, prior to the early-mid 1990's biomedical research had been firmly rooted in the male model—the belief that male biology (outside of the reproductive system) was rep-

representative of the species, and that where female biology differed from male biology it was “atypical” or “anomalous”. This led to a lack of knowledge about female biology that has significantly compromised women’s health. It is the offices, advisors and coordinators in the agencies listed above who played an essential role in trying to make up for time lost in the last decade. We have only just scratched the surface of understanding female biology. Now is the time to press ahead and make those discoveries and educate women about their health and the misinformation they have been given for years and these offices are critical to the success of this effort.

There are many wonderful programs that we could identify from these agencies but we would like to specifically mention two that have instrumental programs and initiatives that are vital to women’s health. The HHS Office on Women’s Health and the Agency for Healthcare Research and Quality each have a unique mission but are unified in advancing women’s health research.

#### HHS OFFICE OF WOMEN’S HEALTH

The HHS Office of Women’s Health is the government’s champion and focal point for women’s health issues, and works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. The HHS Office on Women’s Health coordinates women’s health efforts in HHS to eliminate disparities in health status and supports culturally sensitive educational programs that encourage women to take personal responsibility for their own health and wellness. A program initiated by the HHS Office on Women’s Health that is critical to women’s health is the National Centers of Excellence in Women’s Health (CoEs). Developed in 1996, this program offers a new model for university-based women’s health care. Selected on a competitive basis, the current twenty-one CoEs seek to improve the health of all women across the lifespan through the integration of comprehensive clinical health care, research, medical training, community outreach and public education, and medical school faculty leadership development.

Located in leading academic health centers across the United States and Puerto Rico, these Centers are developing new models for women’s health care that are setting standards beyond what is traditionally offered at hospital-sponsored women’s clinical health centers. The CoEs are able to reach a more diverse population of women, including more women of color and women beyond their reproductive years. In addition, the CoEs have a strong commitment to integrating research, education, and clinical care than most traditional women’s health centers.

A recent evaluation of the CoEs conducted by HHS Office of Women’s Health concluded that the CoEs provided comprehensive clinical preventive services, served a broader cross-section of women, reached underserved subpopulations, including minority and economically compromised communities, produced higher levels of patient satisfaction, and aided in mentoring more women in their professional roles as clinicians and/or researchers. However, the report also concluded that CoEs remain vulnerable to pressures including, obtaining adequate funding and having to compete for scarce resources.

Coalition member and Director of the University of Illinois Chicago National Center of Excellence in Women’s Health Stacie Geller, Ph.D., strongly believes that her CoE has been instrumental in promoting advancement and leadership opportunities for female researchers on campus and beyond. In addition, the University of Illinois Chicago CoE has improved healthcare for women with a “one-stop shopping” model within the medical center by incorporating an adolescent clinic, midlife practice, and a clinic designed to meet the needs of perimenopausal and postmenopausal women in the same facility. The CoE also works to reduce barriers to health care for underserved urban women, and partners with surrounding communities to disseminate health information.

Considering the advancements that have been made and those that still need to be achieved, we urge Congress to provide an increase of \$1.5 million for the HHS Office on Women’s Health to allow it to continue to sustain and expand the National Centers of Excellence in Women’s Health.

#### AGENCY FOR HEALTHCARE AND RESEARCH QUALITY

The Agency for Healthcare Research and Quality (AHRQ) is the lead Public Health Service agency focused on health care quality, including coordination of all federal quality improvement efforts and health services research. AHRQ’s work serves as a catalyst for change by promoting the results of research findings and incorporating those findings into improvements in the delivery and financing of health care. This important information provided by AHRQ is brought to the attention of policymakers, health care providers, and consumers who can make a difference in the quality of health care women receive.

Congress has had an active role in the Agency's work, providing funding while adding responsibilities. This has allowed AHRQ to enhance its research on how to: reduce deaths from medical errors; improve access and quality of care; promote evidence based health care; eliminate racial and ethnic disparities; compile the first national report on quality; and assist in improving emergency responsiveness.

AHRQ has a valuable role in improving health care for women. Through AHRQ's research projects and findings, lives have been saved and underserved populations have been treated. For example, women treated in emergency rooms are less likely to receive life-saving medication for a heart attack. AHRQ funded the development of two software tools, now standard features on hospital electrocardiograph machines that have improved diagnostic accuracy and dramatically increased the timely use of "clot-dissolving" medications in women having heart attacks.

While AHRQ has made great strides in women's health research, the Administration's budget for fiscal year 2006 could threaten life-saving research. If a budget request of \$319 million were enacted, AHRQ would be flat funded at fiscal year 2005 levels. In reality, AHRQ's funding has been kept flat for two years as the recent \$15 million increase is dedicated to a specific project. Flat funding prior to application of taps by Congress seriously jeopardizes the research and quality improvement programs that Congress demands or mandates from AHRQ. Congress through the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 directed AHRQ to research comparative effectiveness of drugs and other products but provided no appropriated funds in fiscal year 2003 or 2004. In fiscal year 2005, AHRQ received \$15 million to conduct such extensive and important research, far less than is needed to do the project.

It is important that Congress continues its support for AHRQ by increasing their funding to \$443 million for fiscal year 2006. This will ensure that adequate resources are available for high priority research, including women's health care, gender-based analyses, Medicare, and health disparities.

In conclusion, Mr. Chairman, we thank you and this Committee for its strong record of support for medical and health services research and its unwavering commitment to the health of the nation through its support of peer-reviewed research. We look forward to continuing to work with you to build a healthier future for all Americans.

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PREPARED STATEMENT OF THE UPPER COUNTY BRANCH OF THE MONTGOMERY COUNTY, MARYLAND STROKE CLUB

A STROKE SURVIVOR: A PERSONAL STORY

My name is Susan Emery. I am the presiding officer of the Upper County Branch of the Montgomery County Stroke Club and I am a stroke survivor.

Our club conducts education and support activities for stroke survivors, their family members, and caregivers. We serve people in the Maryland suburbs of Washington, D.C., and are fortunate to be in the same county as the National Institutes of Health. We have benefited on many occasions by the participation of NIH staff members in our membership meetings. They have been generous in sharing with us information about their research into stroke prevention and treatment.

On December 26, 1965 at the age of 9, I was playing a new game with my brother and a few friends at the kitchen table. That is the last thing that I remember. I was unconscious for the next two days. My mother first learned, incorrectly, that I had spinal meningitis. I was transferred to another hospital where my mother was told that I had little chance of survival. Yet, I am here, more than 37 years later, and I have survived a stroke.

People seldom associate strokes with children. These strokes are rare, but they do happen. There are about three cases of stroke per year in every 100,000 children under age 14. One of the difficulties in dealing with strokes in children is getting the right diagnosis quickly. There are often delays in diagnosis of childhood stroke.

I spent 2 weeks in the hospital and the following 4 months in intensive physical therapy. My 10th birthday was spent in the hospital, and I have a picture in my photo album of myself with my mother and a new friend. My right eye is turned down, my mouth is turned down, but I am still smiling. During the 4 months in therapy at Holy Cross in Detroit, I learned the basics: how to walk, how to talk, and how to move the fingers on my right hand. My mother followed the doctor's instructions and sent me back to school very quickly, where classmates helped me button and unbutton my coat and carry my books, and teachers taped papers to the desk so I could learn to write again. I survived that 4 months, and would never wish to repeat it.

I have been in therapy six times in my life. I need to tell you about the one time that was the most important to my family. I was 26 years old and had just had my first child. I kept her safe, for I knew my limitations. I always used my left hand to support her. But when she was 6 months old, she got to be a little heavy, and twice, as I was putting her on the floor to change her diaper, my right hand slipped from under her buttocks. She fell only inches in both cases and did not even notice. But I noticed. I went in for 2 or 3 months of therapy close to Denver, Colorado, where I was living at the time. Here for the first time, they helped my right hand and arm dexterity through occupational therapy. I also learned that I had aphasia—the inability to speak, write or understand spoken or written language because of brain injury—because I called things like cornucopias, unicorns instead of fruit baskets. Instead of the word being the same, I picked a word that sounded the same. These therapists in Colorado worked with my mind and my body and I will forever be in their debt.

Close to 15 years ago, I made a new life for myself in Maryland. Here, I have been an outpatient at the National Rehabilitation Hospital three times: once for my right foot, once for my Achilles tendon and once for my right knee. I have seen numerous physiatrists, all of whom are excellent in their field. I have also seen my fair share of therapists. Since I have had therapy off and on for most of my life, I can honestly say that the first few times you go in to see a therapist, you will come out hurting more than when you went in. But in the long run, they help tremendously.

On a work related note, I received a Bachelor of Science in 1978 from Michigan State University in Computer Science and worked for 12 years in the field. I started working in the telecommunications industry in 1990, and got a Master of Science from the University of Maryland, University College in Telecommunications Management. I now work for ITT Industries as a senior engineer on a contract supporting the Federal Aviation Administration's leased telecommunications activities, and have worked there for more than 6 years. I have done more than survive. I have become a productive member of society.

Stroke research has changed my life. Without the research carried out 40 to 50 years ago, I would not have benefited from electric shock therapy that made me understand the muscles that moved my fingers. Without research done 30 years ago, I may not have been able to understand how to exercise my hand for dexterity. Without research performed 10 years ago, the people around me would not understand that they need to get me to the hospital quickly if ever I have another stroke. Without current support, researchers may never understand how to stop strokes before they happen or how to make current stroke survivors live healthier lives.

Stroke remains America's No. 3 killer and a major cause of permanent disability. An estimated 5.4 million Americans live with the consequences of stroke and about 1 in 4 is permanently disabled. Yet, stroke research continues to receive a mere 1 percent of the National Institutes of Health budget. I strongly urge you to significantly increase funding for the National Institutes of Health-supported stroke research, particularly for National Institute of Neurological Disorders and Stroke-supported stroke research. NIH stroke research is essential to prevent strokes from happening to children and adults in the first place, and to advance recovery and rehabilitation of those who survive this potentially devastating illness.

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#### DEPARTMENT OF EDUCATION

##### PREPARED STATEMENT OF THE ALAMO NAVAJO SCHOOL BOARD, INC.

The Alamo Navajo School Board, Inc. operates under resolution from the Alamo Navajo Community and from the Navajo Nation and was organized within the Alamo Navajo chapter community to establish and operate Federal and State programs that provide education, health and community development services to the people of Alamo under contracts, grants or cooperative agreements. We are responsible for operation of nearly all federal programs that serve the 2,000 Navajo people who live on the Alamo Reservation. Our 10-square mile reservation is isolated in south-central New Mexico, 250 miles from the Big Navajo Reservation, thus it is critical that we provide local services to persons living on the Alamo Reservation. On an annual basis, we operate over \$13 million of federal and state supported programs.

In summary our recommendations for the fiscal year 2006 Labor-HHS-Education and Related Agencies budget are:

—Reject the Administrations proposal to de-fund the Perkins vocational program and provide at least a modest increase;

- Direct the Department of Education to allow BIA-funded schools to apply directly for Library Literacy Grant funding;
- Reject the Administration's proposal to de-fund the Safe and Drug Free schools program and provide at least a modest increase;
- Allow Indian Head Start program to have the flexibility to allocate funds between their Early and regular Head Start programs;
- Support a four percent tribal allocation under the Head Start Program;
- Increase funding for the Workforce Investment Act;
- Reject the proposal to consolidate Supplemental Youth Services funding into a block grant which would probably cause the loss of Indian SYS funding;
- Reject the Administration's proposals to reallocate and/or rescind \$92 million of already-appropriated fiscal year 2006 CPB funds and to end forward funding for the CPB.
- Support continued and increased CPB support for Native radio.

#### VOCATIONAL EDUCATION

We operate a very successful and much-needed program funded through the Carl Perkins Vocational and Applied Technology Act and we strongly oppose the Administration's proposal to totally de-fund the Carl Perkins vocational education program. We are pleased that the House and Senate authorizing committees are proceeding with reauthorizing the Perkins Act, which sends a clear signal to the White House that Congress finds this a valuable program that should be continued.

We have been administering a Section 116 Perkins Act grant under which we are successfully helping Indian people access and complete postsecondary education. Our project is named Access-Retention-Completion (ARC) We are working toward development of a Navajo professional workforce that will enable people, if they so choose, to fill job needs on the Alamo Navajo Reservation that must now be filled by persons from outside the community. Under ARC, our students are able to gain academic and technical skills both on and off the reservation, via distance learning and on-site classes. The Alamo Navajo School Board has articulation agreements with several postsecondary institutions to offer classes both on and off reservation. We are able to help students with transportation to off-reservation education sites through the use of our 15-passenger van. We are making education more accessible and affordable for postsecondary students who are also parents. Our child care program provides pre-natal to early head start child care. We also have an after school tutoring program for older school-age children. Finally, we are providing support services to all postsecondary students through counseling, placement, advisement and facilitation.

While we feel very good about the development of our Access-Retention-Completion project, it takes more than four years to fully develop this multifaceted program. We are currently serving 83 students, with an 80 percent completion rate for on-site classes and 100 percent completion rate for students taking off-reservation classes. Our placement rate is 80 percent for on-site and 90 percent for off-reservation. Our students are about evenly split between on and off reservation programs. We also believe that our ARC project has the very real potential to be a model for other isolated communities—both Indian and non-Indian—and having several more years of assured funding would bring the necessary additional experience to serve as a model program.

#### IMPROVING LITERACY THROUGH SCHOOL LIBRARIES

The Alamo-Navajo School Board is excluded from applying for these much needed funds that would, as Congress intended, enable us to update our school library materials and media center equipment and assure an appropriately credentialed media specialist is on hand to assist our students. The Department of Education has taken the position that because the BIA-funded schools receive a 0.5 percent set-aside from the annual appropriations for this program, they cannot apply for discretionary grants as an LEA (local education agency) under the program operated by the Department. The average grant award under the Department's discretionary grant program ranges from \$150,000 to \$300,000.

In fiscal year 2005, the Department of Education transferred \$99,211 to the BIA for the use of the BIA-funded schools. The BIA, however, determined that instead of making the funds available—by discretionary or formula grant—to all of the 184 schools in the BIA school system, the entire fiscal year 2005 amount would be allocated to only two schools. The schools selected were on the BIA Center for School Improvement list for proposed restructuring, meaning they had not met adequate yearly progress (as required by the No Child Left Behind Act) despite earlier intervention.

We understand that poorly performing schools require much assistance to enable them to help their students achieve academic success, and it is unlikely that the entire \$99,000 would be sufficient to correct the deficiencies experienced by just one BIA-funded school. Nonetheless, it is unfair to all BIA schools if the Department of Education excludes BIA-funded schools from the discretionary program and the BIA adopts a policy to restrict funds made available to a select few. We urge the Congress to direct the Department of Education to reconsider its exclusionary practice and allow the BIA-funded schools to apply directly to the Department for the Library Literacy grant funding.

#### SAFE AND DRUG FREE SCHOOLS AND COMMUNITIES

The Alamo-Navajo School Board strongly opposes the Administration's proposal to eliminate funding for the Safe and Drug Free Schools State Grants program (\$437.4 million in fiscal year 2005). Under the 1 percent set-aside for BIA-funded schools, we received \$29,000 that partially funded a school-home liaison who works directly with parents and community on matters identified by the school that would aid in ensuring a healthy learning environment.

As you are no doubt aware, alcohol and drug-related illnesses and crime levels in Native American communities greatly exceed the mainstream populations. By tapping all available sources of funds, we seek to provide our students the drug prevention and school safety programs that will help them develop the life skills that may enable them to live better, healthier lives. We urge Congress to reject the Administration's proposal to eliminate this valuable program and instead provide at least a modest increase.

#### HEAD START

The American Indian Head Start and Early Head Start programs receive a less than 3 percent share of the 13 percent set-aside for Indian, migrant, territorial, children with disabilities programs. In fiscal year 2004, that translated to \$161.6 million for Indian Head Start (ages 3–5 years) and \$27.5 million for Indian Early Head Start (ages 0–3 years), which served a combined total of nearly 24,000 children. Under the Administration's proposal, our programs would receive none of the requested \$45 million increase since all of it is targeted for pilot projects whereby states would consolidate Head Start and other state children's programs.

Although level funding in these constrained budgetary times may be viewed as a success, programs such as ours which are located in very rural areas are faced with rising costs that are greater than those located in more metropolitan areas, i.e., fuel costs for transportation, food, staff training. Level funding also does not address the increasing costs related to higher salaries for staff who achieve the high quality staff requirements of the program nor the unfunded mandate to install small child restraints in program vehicles (which cost \$6,000 but was not in our budget nor were we provided reimbursement from the national Head Start office).

Further, with the myriad and increasingly stringent requirements, small programs such as ours are losing the flexibility to structure our services to best meet the needs of our children. We need to be able to structure our Early Head Start and Head Start programs to the changing dynamics of our community yet current Head Start policies restrict us from being able to allocate our program funds to provide the services in accordance with the demographic changes. For instance, this year our Early Head Start has a waiting list which could result in an additional classroom of students while our enrollment for the Head Start program is less than anticipated. The logical reaction would be to respond to the need and utilize program funds to establish the necessary additional Early Head Start class but we were informed by the Head Start Grant office that even though we receive our Early Head Start/Head Start funds in one grant document, we must expend the monies under two separate budgets. Therefore, a number of Early Head Start eligible children in our community are not being served since there are no other early education programs available in our isolated area.

We ask that when Congress takes up the reauthorization of the Head Start Act, that (1) the Indian Head Start set-aside be increased from the present 2.8 percent to no less than 4 percent; and (2) provide program flexibility so that Indian Early Head Start/Head Start grant recipients may allocate funds between their Early and regular Head Start programs in the manner that best meet the needs of the population served.

#### WORKFORCE INVESTMENT ACT

The Alamo Navajo School Board receives funding under the Workforce Investment Act's Section 116 Program and the Supplemental Youth Services program. The Ad-

ministration has proposed level funding (\$54.2 million) for the Section 116 program which provides grants to Indian Tribes, Urban Indians, Hawaiians and Samoans. This program has been flat funded for years and we support the National Congress of American Indians request of \$75 million for the Section 116 program.

We oppose the Administration's proposal that the Supplemental Youth Services Program (of which the tribes receive \$1.5 percent allocation, or about \$15 million annually) be combined with three other streams of money and put into a block grant, with no obvious guarantee that the tribal money would be preserved. We are pleased that the House bill reauthorizing the WIA (H.R. 27) did not go along with this consolidation proposal and urge that the Appropriations Committee likewise reject this proposal and to provide an increase for Supplemental Youth Services which has been flat funded for years.

#### CORPORATION FOR PUBLIC BROADCASTING

The Alamo Navajo School Board is the licensee for a community radio station—KABR-AM in Magdalena, NM—which receives a modest amount of funding from CPB. We commend CPB for increasing funding for rural sole source radio stations—of which we are one. We also appreciate that CPB has provided start-up funds for a Center for Native American Radio which is to provide technical and other service to Indian radio stations. Our radio signal reaches approximately 13,000 people, including the Alamo population of 2,072. Of the 432 Alamo households, only 25 percent have telephones, and there is no cell phone service. So you can see what an important role our community radio station plays at Alamo Navajo.

There are currently 33 Indian-owned radio stations—all noncommercial—in thirteen states. Most are licensed to nonprofit organizations. We ask for this Committee's continued support of Native radio.

We are extremely concerned about the Administration's proposal to rescind \$10 million and divert an additional \$82 million of already appropriated fiscal year 2006 CPB funds to digital conversion and satellite interconnection. Such a rescission/diversion of funds would be a terrible setback for our station, which already runs on a shoe string. Should Congress approve the Administration's request and if it were applied across-the-board, we would be faced with a 25 percent reduction of CPB funds.

We ask Congress to again reject—as you have done the past four years—the Administration's proposal that the advance funding for CPB be eliminated.

Thank you for your consideration of concerns and recommendations of the Alamo Navajo School Board.

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#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) respectfully submits this statement highlighting funding priorities for nursing education and research programs in fiscal year 2006. AACN represents over 580 senior colleges and universities with baccalaureate and graduate nursing programs, and over 190,000 students and 10,000 faculty members. These institutions are responsible for educating about half of our nation's registered nurses (RNs) and all of the nurse faculty and researchers. Nursing represents the largest health profession in the nation, with approximately 2.7 million dedicated, trusted professionals delivering primary, acute, and chronic care to millions of Americans daily across the spectrum of settings.

#### THE NATIONWIDE NURSING SHORTAGE

Our country continues to be plagued by a shortage of nurses that is only expected to intensify in the future. While AACN is cognizant of the difficult budget environment in which the Subcommittee and the entire Congress must operate, patient safety is compromised without a sufficient number of RNs. Indeed, the American College of Healthcare Executives reported in 2004 that 72 percent of hospitals were experiencing a nursing shortage. Furthermore, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) found in 2002 that the nursing shortage contributes to nearly a quarter of all unexpected incidents that kill or injure hospitalized patients. Since nurses comprise the largest component of hospital staffs, shortages also result in emergency room overcrowding and diversions, increased wait time for or outright cancellation of surgeries, discontinued patient care programs or reduced service hours, and delayed discharges.

The U.S. Bureau of Labor Statistics (BLS) has projected that by 2012, our nation will need an additional 1.1 million new and replacement registered nurses. Despite nursing being identified by BLS as the fastest growing occupation, according to the

Health Resources and Services Administration (HRSA), the United States still will be roughly 800,000 nurses short in 2020, unless there is a significant and sustained increase in the number of nurses graduating each year and entering the workforce. There are nursing vacancies throughout all sectors of health care, including long-term care, home care, and public health. These alarming predictions are coupled with little change in the multitude of contributing factors such as the aging of America's population, the aging nurse workforce, high numbers of RN retirements, and the increasing demand for more intensive health care services by chronically ill, medically complex patients. It is clear that federal support must continue to play a critical role in the nation's effort to address the nursing shortage.

#### NURSING WORKFORCE DEVELOPMENT

Acknowledging the situation, Congress passed The Nurse Reinvestment Act of 2002. This legislation reauthorized and expanded Nursing Workforce Development programs, administered by HRSA under Title VIII of the Public Health Service Act, to address the inadequate supply and distribution of RNs across the country. These authorities fund nursing education and retention programs as well as support individual students in their nursing studies. The seven Title VIII grant and student programs stimulate innovation in nursing practice and bolster nursing education throughout the continuum, from entry-level preparation through graduate study. Thoughtful and well-written authorities, Title VIII programs are the largest source of federal funding for nursing education. In fiscal year 2004, these programs provided loan and scholarship support to over 28,000 student nurses.

Given the demonstrated need for these outstanding programs, past funding levels have been insufficient, receiving only \$150.67 million in fiscal year 2005. AACN respectfully requests \$175 million for Title VIII Nursing Workforce Development in fiscal year 2006, an additional \$24.33 million over fiscal year 2005. New monies would support these crucial Title VIII programs designed to help resolve the nursing shortage through education, recruitment, and retention efforts for the nursing workforce. During the last serious nursing shortage in 1974, Congress appropriated \$153 million for nursing education programs. Translated into today's dollars, that appropriation would total \$592 million, almost 4 times the current level.

#### COLLEGES OF NURSING RESPOND

The approximately 1,500 schools of nursing nationwide have been working diligently to expand enrollments. In fact, AACN found in a recent study that enrollments increased in 2004 by 15.5 percent for entry-level baccalaureate, master's, and doctoral nursing programs, over the 9.1 percent increase experienced in 2003. These increases are attributed to intensive marketing efforts by the private sector, public-private partnerships providing additional resources to expand capacity of nursing programs, and state legislation targeting funds towards nursing scholarships and loan repayment.

While impressive, these increases still cannot meet the demand. In the November 2003 issue of Health Affairs, Dr. Peter Buerhaus reported that nursing school enrollments would have to increase by at least 40 percent annually just to replace those nurses who retire, due to declining numbers of young RNs over the past 20 years. It is important to note that in spite of protracted efforts by colleges nationwide, AACN found that enrollments have increased only by a total of 53.5 percent over the last 5 years in entry-level baccalaureate programs.

In spite of increasing enrollments and the demonstrated need for RNs, U.S. colleges of nursing must still turn away eligible students. In 2004, AACN found that at least 32,797 qualified applicants were turned away, up sharply from over 18,000 in 2003. These students were turned away due to insufficient numbers of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Over 75 percent of the schools surveyed cited the faculty shortage as the primary barrier to increasing enrollments. Some of these qualified students are being placed on waiting lists that may be as long as 2 years.

#### BOTTLENECK: THE COEXISTING FACULTY SHORTAGE

AACN strongly believes that the most effective strategy for the resolution of the nursing shortage is addressing the underlying faculty shortage. HRSA reported in 2000 that just 9.6 percent of the RN workforce holds master's degrees, while only 0.6 percent holds doctorates. AACN found that more than half, 53.4 percent, of the nurse faculty vacancies in 2004 were for faculty positions requiring the doctoral degree. In 2003 AACN reported there were 10,500 full-time master's and doctorally prepared faculty teaching in baccalaureate and graduate nursing programs. Projections through 2012 show that the faculty pool will shrink by at least 2,000 as com-



pared to 2003, even after accounting for retirements, resignations, and additional entrants. Note that these figures do not take into account the need for faculty in new or expanded programs, but represent only present staffing requirements. If the faculty vacancy rate holds steady, it is expected the deficit of nurse faculty will swell to over 2,600 unfilled positions in 2012.

The situation is only expected to worsen with time. Faculty age continues to climb, narrowing the number of productive years nurse educators can teach. Significant numbers of faculty are expected to retire in the coming years, as the average age is 52. Likewise, there are not enough candidates in the pipeline to take their places. For example, an average of 410 individuals are awarded doctoral degrees in nursing each year, but almost a quarter, 23 percent, take jobs outside of academic nursing. Higher compensation in clinical and private sector settings lures current and potential nurse educators away from the classroom. The average salary of a nurse practitioner in an emergency department was \$80,697, according to the 2003 National Salary Survey of Nurse Practitioners. In contrast, AACN found that the average salary for a nurse faculty member was \$60,357 in 2003. Without sufficient nurse faculty, schools of nursing will not be able to expand their capacities to educate new generations of the nurses.

#### REVERSING THE TREND: THE NURSE FACULTY LOAN PROGRAM

This trend can be reversed—with your help. Additional appropriations for the Nurse Faculty Loan Program, Section 846A of Title VIII, will provide targeted assistance. Designed to help increase the number of nurse faculty, grants are provided to colleges of nursing in order to create a loan fund. To be eligible for these loans, students must be pursuing either a master's or doctoral degree on a full-time basis. Loan recipients will have up to 85 percent of their educational loans cancelled over a four-year period, if they agree to teach at a school of nursing. The loan is cancelled at a rate of 20 percent for the first three years, increasing to 25 percent in the final year. A student may receive a maximum loan award of \$30,000 per academic year for tuition, books, fees, laboratory expenses, and other reasonable educational costs. In fiscal year 2004, 61 grants were made to schools of nursing, which in turn supported a projected 419 future nurse faculty members. In fiscal year 2005, \$4.83 million was appropriated.

For example, if the current funding was doubled to almost \$10 million, based on this year's projections, colleges of nursing could educate over 800 future faculty. Though the student to faculty ratios vary by state, a common average is one faculty member for every ten students. Then one could surmise from that estimate that the doubled funding could help to educate over 800,000 future nurses.

#### OTHER SOURCES OF RELIEF

AACN would like to highlight the following programs in addition to the Nurse Faculty Loan Program: the Advanced Education Nursing program, the Workforce Diversity program, and the Nurse Education, Practice, and Retention program.

The Advanced Education Nursing program supports the majority of colleges of nursing that prepare graduate-level nurses to be primary care providers, some of whom become faculty. Receiving \$58.17 million in fiscal year 2005, this grant program helps schools of nursing, academic health centers, and other nonprofit entities improve the education and practice of nurse practitioners, nurse-midwives, nurse anesthetists, nurse educators, nurse administrators, public health nurses, and clinical nurse specialists. Out of the 149 applications received for this program in fiscal year 2004, 82 new grants were awarded to institutions and 75 previous awarded grants were continued. In addition, 408 schools of nursing received traineeship grants, which in turn directly supported 8,925 individual student nurses.

The health system's increasing demand for primary care, increased utilization of case management—particularly for chronic illnesses, prevention and cost-efficiency, and a shortage of physicians are driving the nation's need for nurse practitioners, certified nurse-midwives, and other RNs with graduate education and advanced clinical skills, known as advanced practice nurses (APNs). Mounting studies demonstrate the quality of APN care is at least equal to, and at times better than comparable physician services rendered by physicians, and often at lower cost. This is especially important, as the 78 million Baby Boomers age, their demand for health care services will skyrocket. AARP reported that the rate of physician office visits by those 65 and older jumped 22 percent from 1985 to 1999.

Workforce Diversity grants prepare disadvantaged students to become nurses. As the United States becomes ever more heterogeneous, it is imperative that the composition of our nursing workforce mirrors this shift. According to the U.S. Census Bureau, roughly 30 percent of the population was reported as a racial or ethnic mi-

nority in 2000, but by 2050 that percentage will jump to over 52 percent. This program awards grants to schools of nursing and other entities seeking to increase access to nursing education for disadvantaged students, including racial and ethnic minorities under-represented among RNs. The program provides scholarships or stipends, pre-entry preparation, and retention activities to enable students to complete their nursing education. In fiscal year 2004, 144 applications were submitted, from those 27 new grants were awarded and 35 previously awarded grants were continued. Under the scholarship program alone, 473 students each received \$7,000 scholarships. Workforce Diversity received \$16.27 million in fiscal year 2005.

The Nurse Education, Practice and Retention program helps schools of nursing, academic health centers, nurse-managed health centers, state and local governments, and health care facilities strengthen programs that provide nursing education, facilitate innovations in nursing practice, and retention of the nursing workforce. Education grants are made to enable schools to expand enrollments in baccalaureate nursing programs, develop internship and residency programs, and provide for new technology. Practice grants are made to expand arrangements in non-institutional settings to improve primary health care in medically underserved communities, provide care for underserved populations, enhance practitioner skills, and develop cultural competencies. Retention grants are made to the Career Ladder program, which supports efforts to assist people to obtain the necessary education to either enter the profession or to advance within it; enhance patient care delivery systems through incorporation of best practices, and improved communication. In fiscal year 2004, 336 applications were submitted, from those, 40 new grants and 85 continuation grants were awarded. Nurse Education, Practice, and Retention received a total of \$36.48 million in fiscal year 2005.

#### NATIONAL INSTITUTE OF NURSING RESEARCH

One of the 27 Institutes and Centers at the National Institutes of Health (NIH), the efforts of the National Institute of Nursing Research (NINR) improve patient care and foster advances in nursing and other health professions' practice. These practices must be constantly updated and validated based on rigorous, peer-reviewed research. The outcomes-based findings derived from NINR research are important to the future of the health care system and its ability to deliver safe, cost-effective, and high quality care. Through grants, research training, and interdisciplinary collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life in those with chronic illness, and care for individuals at the end of life. To advance this research, AACN requests a funding level of \$160 million in fiscal year 2006, an additional \$21.91 million over the \$138.09 million NINR received in fiscal year 2005.

#### *NINR Addresses the Need for Translational and Clinical Research*

NINR emphasizes translational research, the means by which basic findings relating to behavior, molecules, and genes are tested in the clinical setting and translated into innovative medical practices and improvements in public health. This effort is incorporated into the NIH Roadmap for Medical Research. Under the framework of the Roadmap Initiative, NINR and nurse researchers are addressing the development of new interdisciplinary research teams and enhanced clinical research to move the overall NIH portfolio of social, behavioral, and medical research forward in this coordinated and cohesive effort.

#### *NINR Addresses the Shortage of Nurse Researchers and Faculty*

NINR allocates 8 percent of its budget, a high proportion when compared to other NIH institutes, to research training to help develop the pool of nurse researchers. In fiscal year 2004, NINR training dollars supported 88 individual researchers and provided 186 institutional awards, which in turn supported a number of nurse researchers at each site. Since nurse researchers often serve as faculty members for colleges of nursing, they are actively educating our next generation of RNs.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

While NIH supports biomedical research that improves health care by focusing on disease cause, cure, and prevention; the Agency for Healthcare Research and Quality (AHRQ) supports research from a systems perspective, collecting evidence-based information on health care outcomes. AHRQ research findings are used by patients, clinicians, health system decision makers, and public policymakers to guide healthcare delivery systems and patient care. The research supported by AHRQ not only improves the quality of health care services, but also helps people make more informed decisions about their healthcare. AACN joins the Friends of AHRQ in rec-

ommending a funding level of \$440 million for fiscal year 2006, an additional \$121 million over the fiscal year 2005 level of \$318.7 million.

*Health Systems Research at AHRQ Addresses Nurses' Role in Patient Safety*

AHRQ research has demonstrated that inefficient work processes, overwhelming work loads, extended work hours, and poor workplace designs create obstacles to providing patients safe, cost-effective, and high quality health care. The New England Journal of Medicine published a study of over 6 million patients in May, 2002 that found hospitalized patients had better outcomes when the majority of their nursing care was provided by RNs. Decreased hours of RN care, stemming from the nursing shortage, correlated with longer hospital stays, increased incidence of urinary tract infections and gastrointestinal bleeding, as well higher rates of pneumonia, shock, and cardiac arrest. When patients received additional hours of RN care, the death rates dropped for pneumonia, shock or cardiac arrest, upper gastrointestinal bleeding, sepsis, and deep venous thrombosis.

*AHRQ Research Demonstrates that Nurse Education Affects Patient Outcomes*

Another AHRQ study found that by employing a greater proportion of more highly educated nurses reduced the mortality and failure to rescue rates from life threatening complications. This extensive study in the September 2003 issue of the Journal of the American Medical Association found that surgical patients have a "substantial survival advantage" if treated in hospitals with higher proportions of nurses educated at the baccalaureate or higher degree level. In hospitals, a 10 percent increase in the proportion of nurses holding BSN degrees decreased the risk of patient death and failure to rescue by 5 percent.

CONCLUSION

Nurses can no longer simply give care to a patient at the bedside. They must evaluate research that promotes evidence-based practice and utilize technical innovations to provide quality patient care. To achieve this level of excellence, AACN recognizes that our nation desperately needs a dedicated, long-term vision for educating the new nursing workforce. Strategies must encompass state support, public-private sector initiatives, and increased federal funding for nursing education and research. Title VIII Nursing Workforce Development programs enable colleges of nursing to innovate and prepare students for the realities of caring for our nation's diverse population in many health care settings across the lifespan. NINR, NIH, and AHRQ provide the research that supports the evidence base for safe practice and quality care delivery. We ask the Subcommittee to graciously consider our appropriations requests for fiscal year 2006.

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PREPARED STATEMENT OF THE AMERICAN CHEMICAL SOCIETY

Chairman Specter and other members of the Labor, Health and Human Services and Education Subcommittee, I appreciate the opportunity to submit written testimony on behalf of the American Chemical Society. The American Chemical Society (ACS) is the world's largest scientific society with over 159,000 members. We represent individual chemists and engineers in academia, industry, and government.

Mr. Chairman, the ACS recognizes that ensuring the continued economic supremacy and homeland security of this nation depends upon maintaining our global technological leadership. This leadership has resulted from the ready availability of a domestic workforce of highly trained scientists, technicians, engineers, and mathematicians (the STEM workforce). But today's high school students are not performing well in math and science overall, and a decreasing number of American students are pursuing college degrees in STEM fields. At the elementary school level, the recent PISA test showed that America's 15 year-olds perform below average in mathematics problem solving compared to their peers in other developed countries.

Thanks to your leadership, the Department of Education budget has increasingly reflected a commitment to remedy this situation through investments in a number of STEM initiatives from the K-12 to postsecondary level. These programs must continue to receive strong support in order to ensure a globally competitive U.S. workforce.

Central to this quest is ensuring the supply of qualified K-12 science and mathematics teachers. As you know, the Math and Science Partnerships, authorized in the No Child Left Behind Act at an increasing annual level to reach \$450 million by fiscal year 2007, are the sole source of dedicated DoEd K-12 math and science funding. This program supports valuable long-term, content-based continuing education

for math and science teachers—the type of training that research shows is most effective in improving student achievement.

Chairman Specter, we greatly appreciate your past support of the Partnership program which has grown from \$12.5 million in fiscal year 2002 to \$180 million in fiscal year 2005. We applaud you for this and urge you to work toward the authorized level by funding the program at the level of \$400 million in fiscal year 2006. Reaching the authorized level is critical, as the No Child Left Behind Act requires science testing to begin in the 2007–2008 school year.

ACS also urges you to reject the Administration's proposal to earmark its requested \$120 million increase in the program for a new high school mathematics initiative. This proposal strays from the intent of the No Child Left Behind Act, which seeks to address the equally critical needs in both math and science. A similar proposal was made by the Administration in the fiscal year 2005 budget and, in our view, wisely rejected by your Committee.

The ACS recognizes the value of encouraging chemists retiring early or those desiring a change from industry work to consider and train for a second career in high school teaching. To that end, we support the president's Adjunct Teacher Corps initiative, which brings experienced professionals with subject-matter knowledge into the classroom to teach part or full-time in areas of high need, including science and math. These professionals can offer valuable insights into the content and practical applications of their subject areas. We recommend that funding be provided to ensure adequate teacher development and to ensure effective communication of their expertise to their students.

On another front, the ACS opposes the Administration's proposal to eliminate the Vocational and Technical Education program. We feel it would have a very negative impact upon our technological leadership. In addition to scientists and engineers, the STEM workforce relies on highly trained technicians, of whom many enter the workforce through tech-prep programs that are currently supported under the Vocational and Technical Education program (\$110.7 million in fiscal year 2005). It is unrealistic to expect states to assume the burden of funding tech-prep programs through the new High School Intervention program, due to its emphasis on meeting academic state standards.

At the post-secondary level, the Department of Education provides incentives to students to pursue science and engineering occupations. The Graduate Assistance in Areas of National Need program (GAANN) is one such example. GAANN provides graduate and doctoral students with enhanced fellowship opportunities. We believe this program should support at least 1,200 fellowships, up from the 850 in fiscal year 2004 and the 721 fellowships that would be supported under the current budget request. This increased support is vital at a time when our nation must have the intellectual resources to respond to homeland security threats and maintain our economic growth.

Furthermore, we strongly support programs such as the Minority Science and Engineering Improvement program in order to increase the participation of underrepresented minorities in scientific and technological careers.

In closing, we appreciate your past support and leadership on behalf of the Department of Education's programs. We strongly believe that proactively investing in STEM education today, will pay real dividends with a more competitive, innovative and successful American workforce tomorrow.

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#### PREPARED STATEMENT OF THE AMERICAN COLLEGE OF RHEUMATOLOGY

The American College of Rheumatology (ACR) is pleased to provide this statement for the record in support of the several important agencies and programs that address arthritis within the Department of Health and Human Services.

The ACR is an organization of physicians, health professionals and scientists that serves its members through programs of education, research and advocacy that foster excellence in the care of people with arthritis, rheumatic and musculoskeletal diseases.

Arthritis means swelling, pain and loss of motion in the joints of the body. There are more than 100 rheumatic diseases that cause this condition, which can sometimes be fatal, in both children and adults of all ages. One in three adults, or 70 million people in the United States, are affected by arthritis and other rheumatic conditions according to the Centers for Disease Control and Prevention (CDC). Arthritis and other chronic joint problems are the leading cause of disability among adults in the United States, costing more than \$86 billion a year in medical costs and lost productivity. These numbers and related costs are expected to increase as the U.S. population ages.

This burden will surely increase, possibly uncontrollably, as the baby boomer group continues to age. Although some forms of arthritis are predominant in older individuals, arthritis also affects children and adults of all ages. The number of individuals affected, as well as associated costs, will increase as the size of our elderly population continues its upswing.

Current research is providing breakthrough advances that have the potential to revolutionize our understanding of arthritis and rheumatic diseases, leading to more effective treatments, decreased costs and increased quality of life for patients suffering from these conditions. The federal government is doing critical medical research into the causes, treatment and prevention of arthritis and rheumatic diseases. The ACR urges the subcommittee to increase its investment in research and arthritis programs to further progress made in preventing, diagnosing and treating these prevalent diseases.

#### THE NATIONAL INSTITUTES OF HEALTH

The ACR supports a 2006 appropriation of \$30 billion for the National Institutes of Health (NIH) in order for it to carry out its goal to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability. The NIH disperses funding to the different institutes within it, including the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Allergy and Infectious Diseases (NIAID). Therefore, overall funding for NIH is extremely important to the federal medical research effort in arthritis and rheumatic diseases.

#### THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

The ACR strongly supports a 2006 appropriation of \$541.6 million for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), which leads the federal medical research effort in arthritis and rheumatic diseases. The NIAMS conducts research related to the causes, treatments and prevention of diseases of the bone, joints, muscle, skin and other connective tissues. The NIAMS sponsors research and research training at universities and medical centers throughout the United States. Research sponsored by the NIAMS leads to the development of more effective treatments, which leads to decreased costs and improved quality of life for patients suffering from rheumatic diseases.

#### THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The ACR recommends a 2006 appropriation of \$4.667 billion for the National Institute of Allergy and Infectious Diseases (NIAID), which conducts research that strives to understand, treat, and ultimately prevent the myriad of infectious, immunologic, and allergic diseases. The NIAID's research focuses on the basic biology of the immune system and mechanisms of immunologic diseases including autoimmune disorders. To accomplish its goals, the NIAID carries out a wide range of basic, applied, and clinical investigations within its own laboratories, and provides research grant, contract, and cooperative agreement support to scientists at universities and other research institutions throughout the country and the world.

#### THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The ACR supports a 2006 appropriation of \$440 million for the Agency for Healthcare Research and Quality (AHRQ) to carry out its mission to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. AHRQ's health services research complements the biomedical research of the NIH by helping physicians, hospitals, purchasers and other stakeholders in health care delivery make informed decisions about what treatments work best, for whom, when, and at what costs.

#### THE NATIONAL ARTHRITIS ACTION PLAN

The ACR recommends a 2005 appropriation of \$15 million for the National Arthritis Action Plan (NAAP). The NAAP, housed within the CDC National Center for Chronic Disease Prevention and Health Promotion, helps deliver the advances made in the biomedical research system to millions of Americans who have arthritis. The NAAP is designed to increase recognition among the general public, people with arthritis and their families, medical care providers, and policy makers, of the impact of arthritis, what can be done to prevent or delay its onset, and what effective interventions and are available to reduce disability and improve the quality of life. The NAAP has made a tremendous impact in how state public health departments ad-

dress this national health problem, and with increased funding, programs could be established in more states and existing programs could be expanded.

IMPACT OF CONTINUING RESOLUTIONS ON MEDICAL RESEARCH

The ACR urges Congress to recognize the difficulties imposed on researchers by interruptions in the medical research funding cycle caused by delays in the federal appropriations process. Use of the continuing resolution mechanism to fund government operations in the absence of the normal appropriations process often causes federally funded researchers to halt their research until the appropriations process is resolved. These disruptions have the potential to not only significantly compromise the validity of the basic medical research being conducted, but can result in the unnecessary expenditure of federal funds to reactivate specific research studies. In order to preserve the integrity of federally supported medical research, the ACR urges Congress to minimize the use of continuing resolutions.

SUMMARY

The ACR appreciates the subcommittee's support for these important programs in recent years. As physicians involved in both research and specialized patient care, ACR members are acutely aware of the magnitude of the challenges that disease and disability place on the health care delivery system. The ACR encourages the subcommittee to provide a strong investment in the programs listed above for 2006 so that necessary research and programs to combat arthritis and related diseases can continue. These programs are critical to the development of more effective treatments, decreasing costs and improving the quality of life for patients suffering from rheumatic diseases.

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) is grateful for the opportunity to provide testimony with regard to fiscal year 2006 appropriations for Federal programs that help to educate the future dental workforce, encourage the prevention of dental disease and provide access to oral health care for underserved populations. These programs are critical to academic dental institutions in fulfilling their primary mission to educate, conduct research and provide patient care. ADEA strongly urges Congress to enhance funding for the programs and preserve their fundamental structure.

ADEA is the premier national organization that speaks for dental education. It is dedicated to serving the needs of all 56 U.S. dental schools, nearly 730 dental residency programs and 550 allied dental programs, as well as the tens of thousands of faculty, dental residents and students engaged in training. It is at dental education institutions that future practitioners and researchers gain their knowledge; the majority of dental research is conducted; and significant dental care is provided to underserved low-income populations, including individuals covered by Medicaid and the State Children's Health Insurance Program (SCHIP).

Academic dentistry endeavors to address the oral health needs of the nation's uninsured, underinsured and publicly insured citizens. Profound disparities in the oral health of the nation's population have resulted in what the Surgeon General<sup>1</sup> called a "silent epidemic" of dental and oral diseases affecting the most vulnerable among us. These disparities, combined with the current shortage of dental school faculty, the scarcity of underrepresented minority dentists, and the need for targeted incentives to draw dentists to practice in rural and underserved communities, make our funding recommendations critically important.

The Administration's fiscal year 2006 budget proposal reduces by approximately 96 percent funding for Title VII Health Professions Programs and eliminates 100 percent of the funding for pediatric, general and public health dental residency programs. Title VII programs embody the federal government's commitment to educating the nation's future health care providers. Such programs focus on wide-ranging and important matters including interdisciplinary training, geriatric and rural health care, allied health education, advanced training for dental, allopathic and osteopathic residents. Eliminating funding for the programs will gravely weaken the health infrastructure of the nation.

Zeroing out funding for the dental residency training programs means that essential advanced education for dental residents and the oral health services they provide to underserved communities will be eliminated. Abandoning these programs

<sup>1</sup>Oral Health in America: A Report of the Surgeon General, 2000.

will intensify and contribute to the growing crisis in accessing oral health services as more states reduce Medicaid dental benefits for adults, the frail elderly and compromised patients. Furthermore, restrictions in Medicaid and SCHIP enrollment and eligibility have reduced access to oral health care for children.

As Congress wrestles with the fiscal year 2006 appropriations for federal agencies and programs of importance to dental education and research, ADEA respectfully urges that the following programs' funding be restored and enhanced at the levels recommended:

\$15 MILLION FOR TITLE VII GENERAL DENTISTRY AND PEDIATRIC DENTISTRY RESIDENCY TRAINING PROGRAMS

ADEA recommends that Congress restore and enhance funding for dental residency training programs. These programs are instrumental in educating dentists who work in underserved communities and treat Medicaid, SCHIP or other underserved populations, particularly those with special needs. Furthermore, dentists training in Title VII funded programs staff clinics that provide treatment at low or no cost.

\$19 MILLION FOR THE RYAN WHITE HIV/AIDS DENTAL REIMBURSEMENT PROGRAM OF THE RYAN WHITE CARE ACT (PART F)

The Dental Reimbursement and the Community-based Dental Partnerships programs, the smallest component of the CARE Act, are successful in increasing access and educating and training dental students, dental residents and allied dental students in the provision of care for patients afflicted with the disease. The Dental Reimbursement Program (DRP) accomplishes significant benefits for both patient care and education of future oral health practitioners.

Academic dental institutions (ADI) are safety net providers of oral and dental care for low-income, uninsured or underinsured immunocompromised patients who are prone to oral infections. A recent study<sup>2</sup> found that providing HIV/AIDS patients with regular diagnostic and preventive care reduced the need for more complex and costly services. Thus, two federal objectives—service to patients of limited means and education of future providers—are accomplished with this modest but important program.

\$420 MILLION FOR THE NATIONAL INSTITUTE FOR DENTAL AND CRANIOFACIAL RESEARCH (NIDCR)

NIDCR is the only Institute within the National Institutes of Health (NIH) whose mission is to improve oral, dental and craniofacial health through research, research training, and the dissemination of health information. Oral disease affects nearly every American. It is essential that Congress increase support for NIDCR's diverse and critical research initiatives. Of paramount importance is funding for clinical research and dental school research infrastructure. Among the ongoing research projects being conducted by dental researchers is work on saliva as a reliable diagnostic fluid to detect systemic diseases in a non-invasive way, including the detection of cancer-associated molecules associated with oral squamous cell carcinoma as well as research on how to engineer teeth in the laboratory and transplant them into the mouth to replace a missing or damaged tooth. In any future NIH reorganization NIDCR should remain independent.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

*\$18 million for the CDC Oral Health Program*

The CDC Oral Health Program supports state and community-based programs that work to prevent oral disease and reduce disparities in oral health. The program works with states to establish surveillance systems that provide valuable health information to assess the effectiveness of programs and target them to populations at greatest risk. Grants have been used to support basic state oral health services, including support for program leadership, monitoring oral health risk factors, and developing and evaluating prevention programs such as community fluoridation and school-based sealant programs. Federal funding is essential to maintain these programs.

*\$130 million for the CDC Prevention Block Grant*

\$3.5 million of this amount is for oral health projects. The President's budget eliminates the program completely. The funding is 50 percent of the CDC money

<sup>2</sup>Journal of the American Dental Association (133 JADA 1343).

that flows back to states for oral health programs. It is used by states to purchase and replace fluoridation equipment and to maintain a state dental presence.

\$10 MILLION FOR THE DENTAL HEALTH IMPROVEMENT ACT ENACTED AS PART OF THE  
HEALTH CARE SAFETY NET AMENDMENTS OF 2002 (PUBLIC LAW 107-251)

The Dental Health Improvement Act will help, when funded, to eliminate the disparities in oral health status and assure access to oral health services for low-income children. The law authorized \$50 million over 5 years for innovative state oral health care grants. Congress has not yet provided funding for this important federal-state partnership. The American Dental Association (ADA) and the American Academy of Pediatric Dentists (AAPD) join ADEA in requesting \$10 million for this program in fiscal year 2006.

Grants can be used for a variety of state initiatives including loan forgiveness programs for dentists serving in dental health professions shortage areas (HPSAs); grants or low-interest loans for dentists participating in Medicaid; dental faculty recruitment programs; and establishment or augmentation of a state dental officer position to coordinate oral health and access issues in the state. The program, when funded, will be a shining example of a true federal-state partnership, as states must agree to match at least 40 percent of any federal contributions under this grant.

\$135 MILLION FOR THE MINORITY AND DISADVANTAGED ASSISTANCE PROGRAMS IN THE  
HEALTH PROFESSIONS EDUCATION AND TRAINING PROGRAMS

The infrastructure that has been established by previous federal investment requires sustained and increased support to meet the challenges of diversifying the health care workforce, addressing student indebtedness, eliminating faculty shortages, and eradicating oral health care disparities in underserved communities.

The President's fiscal year 2006 budget eliminates funding for the Centers of Excellence (COE) program, the Health Careers Opportunity Program (HCOP), and the Faculty Loan Repayment Program (FLRP) and reduces by nearly 80 percent the funding for Scholarships for Disadvantaged Students (SDS). These programs are crucial if we are to address concerns with health disparities. The COE, HCOP and SDS programs are essential in assisting economically disadvantaged students enter and graduate from health professions schools. Underrepresented minority recruitment and retention in the health professions is a serious problem. In 2004, the first-year enrollment of underrepresented minority students in dental school was just 11.3 percent of the total first year dental student enrollment. In 1990, the percentage of underrepresented minority students in the first year class was 13.8 percent of the total first year enrollment. While the FLRP assists in recruiting and retaining faculty, it is of particular importance to academic dentistry as there is currently a faculty shortage. ADEA strongly urges Congress to continue investing in HCOP, COE, SDS, and FLRP so that the health professions can make strides in diversifying the future health care workforce.

\$213 MILLION FOR THE NATIONAL HEALTH SERVICE CORPS (NHSC)

The National Health Service Corps Scholarship and Loan Repayment Programs assist students with financing their health professions education while promoting primary care access to underserved areas. It is critical that the NHSC receive increased funding to meet the growing health care needs in the nation's rural and underserved communities. The President's budget proposal cuts \$5 million from the NHSC budget at a time when it is crucial to maintain a pipeline of health providers in health professions shortage areas.

\$108 MILLION FOR THE INDIAN HEALTH SERVICE (IHS) DENTAL PROGRAMS

Maintaining the health care infrastructure and supporting the health care workforce that provides care to the Alaska Native/American Indian (AN/AI) population is essential in meeting the needs of Indian people. The IHS Loan Repayment Program makes payments on health care worker's student loans while they provide care at one of 280 hospital sites located around the country. The IHS Scholarship program provides both hope and financial support to AN/AI students pursuing careers in the health professions. Without these programs access to care as well education for the AN/AI population will surely worsen.

\$1 MILLION FOR A MEDICAID COMMISSION TO STUDY AND RECOMMEND CHANGES TO  
MEDICAID

ADEA supports the amendment in the Senate's fiscal year 2006 Budget Resolution that halts further cuts to Medicaid and instead establishes a reserve fund of



\$1 million to establish a Medicaid Commission to study and recommend changes needed in Medicaid. While expenditures on dental care account for less than 1 percent of all Medicaid expenditures, 25 million children enrolled in Medicaid are eligible for needed dental care under the program. Medicaid accounts for almost a quarter of all dental expenditures for children under age 6 and provides the only guarantee of relief from dental pain and infections, restoration of teeth and dental health for millions of children on Medicaid. The Medicaid program is the only access that many of the poorest and sickest adults have to critical emergency oral health care.

In conclusion, the American Dental Education Association appreciates consideration of our fiscal year 2006 budget recommendations for dental education and research. A sustained federal commitment is needed to help meet the challenges oral disease poses among the nation's most vulnerable citizens including children. So too is the development of a partnership between the federal government and dental education programs to implement a national oral health plan that guarantees access to dental care for everyone, ensures continued dental health research, eliminates disparities, and eliminates workforce shortages.

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PREPARED STATEMENT OF THE AMERICAN GEOLOGICAL INSTITUTE

To the Chairman and Members of the Subcommittee: Thank you for this opportunity to provide the American Geological Institute's perspective on fiscal year 2006 appropriations for the Department of Education's Mathematics and Science Partnership program.

In 1999, the Third International Math and Science Study found that the longer U.S. students are in school, the farther they fall behind in math and science proficiency in international comparisons. That prompted President Bush to propose the National Math and Science Partnership (MSP) program as part of No Child Left Behind. The goal of the partnership program is to strengthen K-12 science and math education by promoting a vision of education as a continuum that begins with the youngest learners and progresses through adulthood with teacher training. Among its activities, the program supports partnerships that unite K-12 schools, institutions of higher education and private industry.

Congress took the president's suggestion and authorized an MSP program at the National Science Foundation (NSF) and another partnership program at the Department of Education in 2002. These two acts of Congress were meant to fund two different types of partnerships to achieve the overall goal of highly qualified math and science teachers ensuring that all students have the basic knowledge to compete in the ever changing and competitive job market. The funds allocated for the NSF's MSPs go to the highest quality proposals chosen through a competitive peer-reviewed grant program. The program focuses on modeling, testing and identification of effective math-science activities. The funds allocated for the Department of Education MSPs go directly to the states as formula grants, providing funds to all states to replicate and then implement the best of the NSF partnerships throughout the country. Once states receive the money, they make competitive grants to local partnerships.

At a hearing in October 2003, the House Science Committee found that these new partnership programs are "on the right track toward improving math and science education." Testifying before the committee, M. Susana Navarro, executive director of the El Paso Collaborative for Academic Excellence MSP, said: "What the MSP now provides is an opportunity to bring together partners across the community, K-16, toward the shared development and implementation of high quality math and science content and instructional practices aimed at improving student achievement among all students."

Just 3 months after that hearing, President Bush released his budget proposal for fiscal year 2005, which phased out the NSF partnership programs and shifted the funding to the MSP companion program at the Department of Education. However, the \$120 million increase requested for 2005 was not slated to fund additional MSPs on the local level; instead it would have financed a new program focused on accelerating the math education of secondary-school students, especially those who are at risk of dropping out of school because they lack basic skills in math.

The Senate Labor, Health and Human Services and Education did not go along entirely with the President's plan last year. The MSPs would have received \$200 million, 4.5 percent less than the President requested but \$51 million or 34 percent more than fiscal year 2004 funding in the Senate version of the bill. The report stated, "These funds will be used to improve the performance of students in the areas of math and science by bringing math and science teachers in elementary and sec-

ondary schools together with scientists, mathematicians, and engineers to increase the teachers' subject-matter knowledge and improve their teaching skills.”

We applauded the Subcommittee because it did not choose to fund math over science and, ultimately, Congress did not choose to fund math over science. In last year's omnibus bill, the Math and Science Partnership budget increased 16 percent over fiscal year 2004 levels to \$179 million and none of those funds were set-aside for one subject.

This year, the President has proposed something similar. The fiscal year 2006 budget proposal increases the MSPs to \$269 million, an increase of \$90.4 million, or 51 percent, over the fiscal year 2005 level. Although a large increase has been proposed, the President's plan restricts \$120 million for the Secondary Education Mathematics Initiative, a competitive grant program to be administered by the Department of Education. This creates a net decrease in funding available to the states in fiscal year 2006 compared to the fiscal year 2005 allocations.

The \$120 million in funds for Secondary Education Mathematics Initiative is part of the overall High School Initiative, which will expand the application of No Child Left Behind principles to improve high school education and raise achievement, particularly the achievement of students most at risk of failure. This new initiative combines a number of categorical programs in order to give states and districts more flexibility and contains stronger accountability mechanisms.

AGI believes the two MSPs are the most effective approach to rapidly improving the abilities of all students to enhance their future prospects regardless of their ultimate career goals. The two programs, designed and authorized by Congress, are complementary. AGI supports funding at NSF for competitive grants for teaching tools and teacher training and funding at the Department of Education for formula grants for implementation of these tools in K-12 education. The peer-review process in the NSF program should be safeguarded as should the formula grants for all states as administered by the Department of Education. Moreover, the program within the Department of Education should not suffer a net reduction in funding in order to support a new initiative for mathematics. These funds should serve the Math and Science Partnership with no earmarks or set-asides.

Thank you for the opportunity to present this testimony to the Subcommittee. If you would like any additional information, please contact me at 703-379-2480, ext. 228 voice, 703-379-7563 fax, rowan@agiweb.org, or 4220 King Street, Alexandria VA 22302-1502.

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#### PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

Mr. Chairman and Members of the Subcommittee, on behalf of this Nation's 34 Tribal Colleges and Universities (TCUs), which compose the American Indian Higher Education Consortium (AIHEC), thank you for the opportunity to share our fiscal year 2006 funding requests for programs within the U.S. Department of Education, and the U.S. Department of Health and Human Services—Head Start program.

This statement will cover two areas: (a) background on the tribal colleges, and (b) justifications for our funding recommendations.

##### I. BACKGROUND ON TRIBAL COLLEGES

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. Rapid growth of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the first six tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 34 Tribal Colleges and Universities located in 12 states, which were begun specifically to serve the higher education needs of American Indians. Annually, these institutions serve upwards of 30,000 full-and part-time students from over 250 Federally-recognized tribes.

Currently, all but one of our colleges is accredited by independent, regional accreditation agencies and like all institutions of higher education, must undergo stringent performance reviews on a periodic basis to retain their accreditation status. In addition to college level programming, TCUs provide much needed high school completion (GED), basic remediation, job training, college preparatory courses, and adult education. Tribal colleges fulfill additional roles within their respective reservation communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public-meeting places, and child care centers. Each TCU is committed to improving the lives of its students through higher education and to moving American Indians toward self-sufficiency.

Tribal colleges provide access to higher education for American Indians and others living in some of this Nation's most rural and economically depressed areas. These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally based institutions are best suited to help American Indians succeed in higher education. TCUs combine traditional teachings with conventional postsecondary courses and curricula. They have developed innovative means to address the needs of tribal populations and are successful in overcoming long-standing barriers to higher education for American Indians. Since the first tribal college was established on the Navajo reservation, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to and promoting achievement among students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, tribal colleges remain the most poorly funded institutions of higher education in the country. Persistently inadequate funding remains the most significant barrier to their success. Funding for basic institutional operations of 26 reservation based colleges is provided through Title I of the Tribally Controlled College or University Assistance Act (Public Law 95-471). Funding under the Act was first appropriated in 1981. Almost 25 years later, the funding level is at just 75 percent of the authorized level of \$6,000 per Indian student, which is defined as an enrolled member of a Federally recognized tribe. In fiscal year 2005, these colleges are receiving \$4,447 per full-time equivalent Indian student toward their institutions operating budgets. While mainstream institutions have had a foundation of stable state tax-based support, TCUs must rely on year-to-year Federal appropriations for their basic institutional operating funds. Because TCUs are located on Federal trust territories, states have no obligation to fund them even for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments. Yet, if these same students attended any other public institution in the state, the state would provide basic operating funds to the institution.

Inadequate funding has left many of our colleges with no choice but to continue to operate under severely distressed conditions. Although facilities initiatives of the last few years have resulted in widespread renovation and construction at TCUs, many colleges began in surplus trailers; cast-off buildings; and facilities with crumbling foundations, faulty wiring, and leaking roofs, and therefore have a long way to go. Sustaining quality academic programs is a challenge without a reliable source of facilities maintenance and construction funding.

As a result of more than 200 years of Federal Indian policy—including policies of termination, assimilation and relocation—many reservation residents live in abject poverty comparable to that found in Third World nations. Through the efforts of tribal colleges, American Indian communities receive services they need to reestablish themselves as responsible, productive, and self reliant.

## II. JUSTIFICATIONS

### A. *Higher Education Act*

The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the Nation's Tribal Colleges and Universities (Section 316). Titles III and V programs support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. TCUs clearly fit this definition as they are among the most poorly funded institutions in America, yet they serve some of the most impoverished areas of the country. TCUs are victims of their own success. This year two new tribal colleges are eligible to compete for funding under Title III. Despite the increase in the size of the pool of eligible institutions, the President's fiscal year 2006 Budget recommends level funding for this vital program. We urge the Subcommittee to fund section 316 at \$32 million, an increase of \$8.2 million over fiscal year 2005 and the President's request, and we ask that report language included in since fiscal year 2003 be restated clarifying that funds not needed to support continuation grants or new planning or implementation grants be available for facilities renovation and construction grants.

The importance of Pell grants to our students cannot be overstated. Department of Education figures show that at the majority of all tribal college students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of aid than students at mainstream institutions. 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 mem-

bers of the workforce. We urge Congress to fund this critical program at the highest possible level.

*B. Carl D. Perkins Vocational & Applied Technology Education Act*

*Tribally-Controlled Postsecondary Vocational Institutions.*—Section 117 of the Perkins Act provides basic operating funds for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Crownpoint Institute of Technology in Crownpoint, New Mexico. We urge that Congress fund this program at \$8.5 million. Included in both the House and Senate reauthorization bills, which are being considered in the 109th Congress is language waiving section 117 grantees from having to utilize a restricted indirect cost rate, since the timeline for enactment of the reauthorizing legislation is uncertain, we ask that you reiterate the language that has been included in this appropriations measure since fiscal year 2002 stating that Section 117 Perkins grantees need not utilize restricted indirect cost rate.

The President's fiscal year 2006 budget once again proposes the elimination of the Native American Program Section 116, which reserves 1.25 percent of appropriated funding to support Indian vocational programs. We strongly urge Congress to continue this program, which is vital to the survival of vocational education programs being offered at TCUs.

*C. Greater Support of Indian Education Programs*

*American Indian Adult and Basic Education.*—This section supports adult education programs for American Indians offered by TCUs, state and local education agencies, Indian tribes, institutions, and agencies. Despite a lack of funding, TCUs must find a way to continue to provide basic adult education classes for those Indians that the present K–12 Indian education system has failed. Before many individuals 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 participating students had completed a tribal college GED program before beginning higher education classes at the tribal college. At some schools, the percentage is even higher. Clearly, there is a tremendous need for basic educational programs, and TCUs need funding to support these crucial activities. Tribal colleges respectfully request that Congress appropriate \$5 million to meet the ever increasing demand for basic adult education and remediation program services.

*American Indian Teacher Corps.*—American Indians are severely under-represented in the teaching and school administrator ranks nationally. These competitive programs, aimed at producing new American Indian teachers and school administrators for schools serving American Indian students, support the recruitment, training, and in-service professional development programs for Indians to become effective teachers and school administrators, and in doing so excellent role models for Indian children. We believe that the TCUs are the ideal catalysts for these initiatives because of our current work in this area and the existing articulation agreements TCUs hold with 4-year degree awarding institutions. We request that Congress support these programs at \$10 million and \$5 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.

*D. Department of Health and Human Services/Administration for Children & Families/Head Start*

*Tribal Colleges and Universities (TCU) Head Start Partnership Program.*—The TCU/Head Start partnership has made a lasting investment in our Indian communities by creating and enhancing associate degree programs in Early Childhood Development and related fields. New graduates of these programs can help meet the mandate that 50 percent of all program teachers earn an associate degree in Early Childhood Development or a related discipline. More importantly, this program has afforded American Indian children Head Start programs of the highest quality. A clear impediment to the ongoing success of this partnership program is the erratic availability of discretionary funding made available for the TCU/Head Start partnership. Since fiscal year 1999, the first year of the program, a total of just 15 tribal colleges have been able to participate in this valuable program. Some colleges were awarded 3-year grants, others 5-year grants, and in fiscal year 2002 there were no new grants funded at all. In fiscal year 2003, funding for eight new grants was made available, but in fiscal year 2004, only two new awards could be made because of the lack of adequate funds. The President's fiscal year 2006 budget includes a total request of \$6.9 billion for Head Start Programs. We request Congress direct the Head Start Bureau to designate a minimum of \$5 million for the TCU/Head Start Partnership program, to ensure that this critical program can be continued

and be expanded so that all TCUs might participate in the TCU- Head Start partnership program.

### III. CONCLUSION

Tribal colleges and universities are bringing education to thousands of American Indians. The modest Federal investment in the TCUs has paid great dividends in terms of employment, education, and economic development, and continuation of this investment makes sound moral and fiscal sense. Tribal colleges need your help if they are to sustain and grow their programs and achieve their missions.

Thank you again for this opportunity to present our funding recommendations. We respectfully ask the Members of this Subcommittee for their continued support of the Nation's tribal colleges and universities and full consideration of their fiscal year 2006 appropriations needs and recommendations.

#### PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Mr. Chairman, thank you very much for the opportunity to present the views of the Association of Minority Health Professions Schools (AMHPS). I am Dr. John E. Maupin, President of Meharry Medical College in Nashville, Tennessee and President of AMHPS.

AMHPS is comprised of the nation's 12 historically black medical, dental, pharmacy, and veterinary. Combined, our institutions have graduated 50 percent of African-American physicians and dentists, 60 percent of all the nation's African-American pharmacists, and 75 percent of the African-American veterinarians.

Mr. Chairman, historically black health professions institutions are addressing a pressing national need in carrying out their mission of training minorities in the health professions. While African-Americans represent approximately 15 percent of the U.S. population, only 2–3 percent of the nation's health professions workforce is African-American. Studies have demonstrated that when African Americans and other minorities are trained in minority institutions, they are much more likely to: (1) serve in medically underserved areas, (2) care for minorities, and (3) accept patients who are Medicaid dependent or otherwise poor.

This is important Mr. Chairman because the gap in health status between our nation's minority and majority populations continues to widen due in part to the lack of access to quality health care services in minority communities. As a result, we believe it is imperative that the federal commitment to training African Americans and other minorities in the health professions remains strong.

In spite of our proven success in training health professionals, and the important contribution these professionals make, our institutions continue to face a financial struggle inherent to our mission. The financial challenges facing the majority of our students affect our institutions in numerous ways. For example, we are unable to depend on tuition as a means by which to respond to any discontinuation of federal support. Moreover, the patient populations served by the AMHPS institutions are overwhelmingly poor. As a result, our institutions cannot rely on patient care income at a time when the average medical school gets 40–60 percent of its operating revenue from health care services.

Mr. Chairman, before I present AMHPS's appropriations recommendations for fiscal year 2006, I would like to express my sincere appreciation for your leadership in restoring funding for the Health Resources and Services Administration's health professions training programs in fiscal year 2005. For many of our schools, support from these programs represent the difference between our doors being open or closed. We cannot overstate our gratitude for your leadership in this area.

#### FISCAL YEAR 2006 RECOMMENDATIONS FOR FEDERAL PROGRAMS OF INTEREST TO AMHPS

##### *Health Resources and Services Administration*

##### *Health Professions Training*

The health professions training programs administered by the Health Resources and Services Administration are the only federal initiatives designed to address the longstanding under-representation of minority individuals in health careers. HRSA's Minority Centers of Excellence, Health Careers Opportunity Program, and Scholarships for Disadvantaged Students, support health professions institutions with a historic mission and commitment to increasing the number of minorities in the health professions.

Mr. Chairman, our schools and students greatly appreciate the subcommittee's consistent support of these important programs. However, we are very disappointed

that the administration's budget all but eliminates funding again this year for health professions programs focused on diversity in the workforce. For fiscal year 2006, AMHPS joins with the Health Professions Nursing and Education Coalition in recommending a funding level of at least \$300 million for Title VII health professions training programs.

For the health professions programs specifically focused on enhancing minority representation in the health care workforce AMHPS recommendations are as follows:

*Minority Centers of Excellence*

The purpose of the Minority Centers of Excellence program (COE) is to assist schools that train minority health professionals by supporting programs of excellence in health professions education at those institutions. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty/student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities.

For fiscal year 2006, AMHPS recommends a funding level of \$40 million for Minority Centers of Excellence (an increase of \$6.1 million over fiscal year 2005).

*Health Careers Opportunity Program*

Grants made to health professions schools and educational entities under the Health Careers Opportunity Program (HCOP) enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities and information regarding careers in a primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into the health professions school

For fiscal year 2006, AMHPS recommends a funding level of \$40 million for the Health Careers and Opportunities Program (an increase of \$4.1 million over fiscal year 2005).

*Scholarships for Disadvantaged Students*

The Scholarships for Disadvantaged Students program was established to make scholarship funds available to eligible students from disadvantaged backgrounds who are enrolled (or accepted for enrollment) as full-time students. To be eligible for funding, a school must have in place a program to recruit and retain students from disadvantaged backgrounds (including racial and ethnic minorities) and demonstrate that the program has achieved success based on the number or percentage of disadvantaged students who graduate from the school.

For fiscal year 2006, AMHPS recommends a funding level of \$55 million for the Scholarships for Disadvantaged Students program (an increase of \$7.5 million over fiscal year 2005).

HEALTHY COMMUNITIES ACCESS PROGRAM

Mr. Chairman, as you know, Congress passed legislation last year in 2003 to reauthorize the Community Health Centers program. Included in this important measure was a provision which established a demonstration authority within the Healthy Community Access Program to foster greater collaboration between historically black health professions and federally qualified CHC's. Specifically, this provision:

(1) Establishes a demonstration program for the development of research infrastructure at historically black health professions schools affiliated with federally qualified Community Health Centers.

(2) Establishes joint and collaborative programs of medical research and data collection between historically black health professions schools and federally qualified Community Health Centers with the goal of improving the health status of medically underserved populations.

(3) Supports the cost of patient care, data collection, and academic training resulting from these partnerships.

Mr. Chairman, Meharry Medical College and other members of our Association successfully applied for funding under this new demonstration authority in fiscal year 2005. These funds are making an important contribution at all of our institutions. For fiscal year 2006, we encourage the subcommittee to restore funding for the Health Communities Access Program to \$83 million.

## NATIONAL INSTITUTES OF HEALTH

*The National Center on Minority Health and Health Disparities*

Established in 2000 by the Minority Health and Health Disparities Research and Education Act (Public Law 106–525), the National Center on Minority Health and Health Disparities at NIH is charged with addressing the longstanding health status gap between minority and majority populations. The National Center has the authority to:

- Directly support biomedical research, training, and information dissemination focused on eliminating health status disparities.
- Serve in a leadership capacity in developing a comprehensive plan for minority health research at NIH.
- Participate as an equal when NIH institute and center directors meet to determine research policy.
- Support the enhancement of biomedical research capacity at minority health professions institutions through a “Research Endowment” program.
- Support the development of health professions institutions with a history and mission of serving minority and medically underserved communities through a “Centers of Excellence” program.

For fiscal year 2006, AMHPS recommends a funding level of \$250 million for the National Center. This is an increase of \$53 million. This new funding will enable the Center to support all of its new programs and begin to meet the challenge of eliminating health status disparities within minority and medically underserved communities.

*Extramural Facilities Construction*

Mr. Chairman, if we are to take full advantage of the historic increases in biomedical research funding that Congress has provided to NIH, it is critical that our nation’s research infrastructure remain strong.

Under legislation passed in 2001, the authorization level for the Extramural Facility Construction program at the National Center for Research Resources was increased from \$150 million to \$250 million. In addition, the law maintains the 25 percent set-aside for Institutions of Emerging Excellence (many of which are minority institutions) for funding up to \$50 million and allows the NCRR director to waive the matching requirement for participation in the program.

Unfortunately, funding for the Extramural Facility Construction program was cut from \$119 million in fiscal year 2004 to \$30 million in fiscal year 2005. AMHPS encourages the subcommittee to prioritize support for this important program in fiscal year 2006 by restoring funding to the fiscal year 2004 level.

*Research Centers at Minority Institutions*

The Research Centers at Minority Institutions program (RCMI) at the National Center for Research Resources has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, AMHPS recommends that funding for this important program grow at the same rate as NIH overall in fiscal year 2005.

## STRENGTHENING HISTORICALLY BLACK GRADUATE INSTITUTIONS—DEPARTMENT OF EDUCATION

The Department of Education’s Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to AMHPS institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities.

For fiscal year 2006, AMHPS recommends an appropriation of \$65 million (an increase of \$6.5 million over fiscal year 2005) to continue the vital support that this program provides to historically black graduate institutions.

## HHS OFFICE OF MINORITY HEALTH

The HHS Office of Minority Health (OMH) has the potential to play a critical role in addressing health status disparities throughout the country. Unfortunately, the office does not currently have the authority or resources necessary to support activities that will truly make a difference in closing the health gap between minority and majority populations. For fiscal year 2006, AMHPS recommends a funding level of \$65 million for the Office, with \$10 million designated for the following programs

focused on medically underserved communities and capacity building for the training of minorities in health professions:

(1) OMH sponsored programs to assist medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals;

(2) Assistance to minority institutions in acquiring real property to expand their campuses to increase the capacity to train minorities for medical careers;

(3) Support of conferences for high school and undergraduate students to pursue health professions careers; and

(4) Support for cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

Once again, thank you for the opportunity to present the views of the Association of Minority Health Professions Schools. We look forward to working with you in support of these important programs.

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PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY CENTERS ON  
DISABILITIES

Mr. Chairman, on behalf of the Association of University Centers on Disabilities, I am pleased to submit this written testimony for the record both as a means to thank you for the Committee's support of our Centers in fiscal year 2005, and as a way of alerting you to the exciting developments happening now across the national network of University Centers for Excellence in Developmental Disabilities, Education, Research and Service (UCEDDs). The network of UCEDDs is a showcase for unique and effective models for developing approaches and gathering new knowledge in the field of developmental disabilities and sharing this knowledge both nationally and internationally, as well as in our own states to improve the lives of people with developmental and other disabilities. I am Fred Palmer, Director of the Boling Center for Developmental Disabilities, Tennessee's University Center for Excellence in Developmental Disabilities at the University of Tennessee Health Science Center, and President of the Association of University Centers on Disabilities.

The mission of the UCEDDs is to advance policy and practice, for and with people with developmental and other disabilities, their families and communities. As a network of 61 interdisciplinary Centers across the United States and its Territories, we work to ensure full participation in all aspects of living for individuals with disabilities.

Since the early 1960s, when Congress established a small number of research centers to study mental retardation, we have grown into a national network where each University Center has developed its own area(s) of expertise based on the needs of the local community, state, and evolving expectations of people with disabilities nationwide to be more included in community life. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106-402) we currently focus our work on serving as a national education and training, service and information resource and research entity for our nation.

We are extremely grateful that in fiscal year 2005, the Congress increased funding for the UCEDDs by \$5 million, bringing our current funding to \$31.5 million. This increase has provided us with an opportunity that has not existed in over a decade—the opportunity to increase the number of Centers in our network in order to better serve people with disabilities. With this money, we will establish three new Centers in states where there is a large minority population and/or difficulties reaching people with disabilities due to geographic hardships. The increased funding also provides each current Center with additional dollars to conduct research and provide community supports and services as outlined in the DD Act, essentially funding each current Center at the level authorized in 2000. Additionally, the increased funding allows the Administration on Developmental Disabilities to compete one or two small National Training Initiative grants which allow the grantee to conduct community-based training on a topical area of national significance.

We are respectfully seeking an appropriation of \$37 million for the network of Centers for fiscal year 2006. This increase will allow funding for the three new Centers to be increased to the same funding as the existing 61 Centers, as well as to continue our ability to establish additional Center grants in the five states that currently have unserved and underserved populations, and support for four new Centers that specialize in minority health disparities and education issues.

AUCD believes that all people with disabilities must have the opportunity to maximize their potential, and have equal and meaningful access to all programs that help people be part of community life. We have been honored and pleased to



work with President Bush and his Administration to carry out initiatives established in the New Freedom Initiative. Through Executive Order 12317, "Community-Based Alternatives for Individuals with Disabilities" we are working at the state and national level to implement programs and secure funding to rebalance the system of care for individuals with disabilities and their families. We believe that the country is at a turning point in time that can truly change the way that individuals with disabilities are perceived and treated. By helping states rebalance their service systems to serve people in the community first, as opposed to institutional settings, we are truly working to achieve the President's goals set forward in the Executive Order.

The UCEDDs focus their work in a concerted effort through the areas of education and training at the university and community level; research, both basic and applied; and service provision at the individual and family level. Please allow me this opportunity to provide you with some examples.

*Education.*—Quality of life in the community for individuals with disabilities depends upon well-trained professionals. Positioned within the university, UCEDDs educate professionals-in-training in interdisciplinary approaches and provide continuing education for professionals practicing in multiple fields relating to disabilities. Whether the focus is on leadership, direct service, clinical or other personnel training, these pre-service and continuing education programs are geared to the needs of students, fellows, and practicing professionals and have been essential in raising and defining the educational standards of service across health, education, employment and social service systems. Further, they have increased the capacity of States to be responsive to the needs of individuals with disabilities.

Each year, UCEDDs provide education and training to approximately 500,000 health, education, mental health, and policy-making professionals, as well as people with disabilities and their families. UCEDDs in communities nationwide provide this essential education and training.

For example, one issue that Centers focus on nationally is positive behavioral supports. One UCEDD in Oregon houses the Center on Positive Behavioral Intervention and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that their technical assistance and research has enhanced schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.

Through a partnership with the Centers for Disease Control and Prevention (CDC), the network of UCEDDs are designing and disseminating training materials on Down Syndrome and Spina Bifida. Educational modules are being designed for use in medical schools for training physicians in recognition and recommended treatments for these two conditions. Materials from these efforts will be disseminated to medical schools throughout the country.

*Research.*—UCEDDs engage in cutting edge research on a wide variety of issues related to individuals with developmental disabilities and their families. From basic research to applied research and policy analysis, University Centers work to link research to public policy and professional practice. By studying areas such as brain development, autism spectrum disorders, and early literacy, UCEDD researchers are learning how children and adults learn and how best to teach them. UCEDDs lead in developing and evaluating new ideas and promising practices that improve the lives of children and adults with disabilities and their families and increase their access to quality services. Many participate in federally established research projects to study and disseminate information on the causes and prevention of disabilities and chronic conditions.

One example of how research impacts upon policy and practice is a collaborative effort between one UCEDD and its state Department of Education and Department of Health and Human Services. Together they are studying the issues of access to, and retention in, high quality childcare for all children throughout the state. This multi-year, interdepartmental initiative is studying ways to develop a coordinated system of inclusive childcare and early education for all children, including those who are at risk due to poverty, disability, social-emotional and behavioral challenges, abuse, or language and cultural differences. By implementing and studying various systems of support for childcare providers, the UCEDD will be able to inform policymakers in areas such as staff development and retention of childcare staff, providing childcare support to TANF families, inclusive childcare support for children with disabilities, and supporting children in foster care.

*Service.*—UCEDDs provide direct services and supports to people with developmental and other disabilities, their families, and communities, including state-of-the-art diagnosis, evaluation, and support services for children and adults with dis-

abilities in health care, cognitive development, behavior disorders, education, daily living, and work skills. Moreover, through technical assistance to other providers, they magnify the impact of their programs, reducing disparities among individuals and communities.

In Ohio, one UCEDD is working with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 100 miles to the city for multiple evaluations by individual disciplines. This resulted in a great expense in time and money for the family. The Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluation of children, training for local healthcare providers, and support for the families through a system of rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

UCEDDs also lead in improving the lives of people with disabilities through new technologies. More than 20 UCEDDs including those in Pennsylvania, Iowa, Texas, and Utah provide services that help individuals assess their technology needs and get the equipment they need to read, hear, speak, write, learn, work, play, and fully participate in their communities.

*Responding to National Needs.*—UCEDDs are equipped to respond quickly to emerging national needs. We are currently expanding our work in the area of aging and disability. As we continue to see people with disabilities living longer, aging parents need community support to ensure the safety and well-being of their adult aged children when they can no longer care for them and communities must be prepared. UCEDDs are working in communities on many aging-related projects and working with the White House Conference on Aging to ensure that aging and disability is part of the national dialogue. We continue to work with the federal government on policies and initiatives on emergency preparedness for people with developmental and other disabilities sharing much of our expertise and experience that came with the September 11 disaster. Other national issues that have been addressed by UCEDDs have included treatment and diagnosis of Autism and Related Spectrum Disorders, reading disorders in children, design and dissemination of training programs for direct support personnel in developmental disabilities, provision of training in methods to support employment for individuals with disabilities and improvement of housing options for individuals with disabilities and their families.

I again ask that you consider our request for \$37 million for the network of UCEDDs so that we may expand our network to more adequately serve our nation's growing population of Americans with developmental and related disabilities and to address our nation's health disparities.

Thank you for the opportunity to share this information about the UCEDDs. Your careful consideration of our appropriation requests is appreciated and we are happy to share more detailed information with you at your request.

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PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND  
SCIENCE

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

1. A 6 percent increase for all institutes and centers at the National Institutes of Health (NIH), specifically the National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

2. Urge NCI to continue to support the establishment of collaborative minority health comprehensive cancer centers at historically minority institutions in collaboration with existing NCI cancer centers. Continue to urge NCRR and NCMHD to collaborate on the establishment of a cancer center at a historically minority institution.

3. Urge the Department of Health and Human Services, particularly the Office of Minority Health (OMH), to develop a focused effort on faculty support to address the residency training programs at minority medical institutions.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present you with testimony. Charles R. Drew University is one of four predominantly minority medical schools in the country, and the only one located west of the Mississippi River.

Charles R. Drew University of Medicine and Science is located in the Watts-section of South Central Los Angeles, and has a mission of rendering quality medical education to underrepresented minority students, and, through its affiliation with the University of California Los Angeles (UCLA) at the co-located King-Drew Medical Center, Drew provides valuable health care services to the medically underserved community. Through innovative basic science, clinical, and health services research programs, Drew University works to address the health and social issues that strike hardest and deepest among inner city and minority populations.

The population of this medically underserved community is predominately African American and Hispanic. Many of these people would be without health care if not for the services provided by the King-Drew Medical Center and Charles R. Drew University of Medicine and Science. This record of service has led Charles R. Drew University (in partnership with UCLA School of Medicine) to be designated as a Health Resources and Services Administration Minority Center of Excellence.

#### A RESPONSE TO HEALTH DISPARITIES

Racial and ethnic disparities in health outcomes for a multitude of major diseases in minority and underserved communities continue to plague this nation that was built on a premise of equality. As articulated in the Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care", this problem is not getting better on its own. For example, African American males develop cancer fifteen percent more frequently than white males. Similarly, African American women are not as likely as white women to develop breast cancer, but are much more likely to die from the disease once it is detected. In fact, according to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates. Despite these devastating statistics, we are still not doing enough to try to combat cancer in our communities.

In response to these findings and the high cancer rate in our own community, Charles R. Drew University of Medicine and Science proposes that a Minority Health Comprehensive Cancer Center be built on its campus.

The Center would specialize in providing not only medical treatment services for the community, but would also serve as a research facility, focusing on prevention and the development of new strategies in the fight against cancer.

Mr. Chairman, the support that this subcommittee has given to the National Institutes of Health (NIH) and its various institutes and centers has and continues to be invaluable to our University and our community. The dream of a state of the art facility to aid in the fight against cancer in our underserved community would be impossible without the resources of NIH.

To help facilitate the establishment of a Minority Health Comprehensive Cancer Center at Charles R. Drew University of Medicine and Science, the University is seeking support from the National Institutes of Health's National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

#### ACADEMIC RENEWAL AND CLINICAL FACULTY RECRUITMENT

Some of the major challenges faced in sustaining high quality graduate medical education programs in "safety-net" medical centers with missions focused on the medically underserved, are directly related to the lack of sufficient numbers of clinical faculty highly trained in academic medicine. To address these challenges, a plan for academic enrichment is proposed.

The plan is a strategic initiative to position Charles R. Drew University in the first decade of the 21st Century, as a leader in Urban Academic Health Sciences with an emphasis on training physicians and other health professionals to meet the needs of the medically underserved. The Plan for Academic Enrichment is an opportunity to enhance the impact of Charles R. Drew University as a national center of excellence in meeting the national, state, and local challenge of preparing a diverse complement of excellent physicians and other health professionals to close the health disparity gap by affording culturally sensitive quality care to the medically underserved and economically disadvantaged. A central component of the plan is the enrichment of academic excellence through the recruitment of new, highly qualified clinical teaching faculty, with solid research skills, to be members of the Charles R. Drew College of Medicine faculty to strengthen both the graduate and undergraduate medical education programs.

## CONCLUSION

Despite our knowledge about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the “gap” continues to widen in most instances. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventive care and/or research is completely inaccessible either due to distance or lack of facilities and expertise. This is a critical loss of untapped potential in both physical and intellectual contributions to the entire society.

Even though institutions like Drew are ideally situated (by location, population, and institutional commitment) for the study of conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, this cancer center will facilitate translation of insights gained through research into greater understanding of disparities in cancer incidence, morbidity and mortality and ultimately to improved outcomes.

We look forward to working with you to lessen the burden of cancer for all Americans through greater understanding of cancer, its causes, and its cures. We also look forward to working with the Department of Health and Human Services to address the residency training program issues at Charles R. Drew University.

Mr. Chairman, thank you for the opportunity to present on behalf of Charles R. Drew University of Medicine and Science.

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PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION (CSAVR)

Mr. Chairman and Members of the Senate Appropriations Subcommittee: This testimony is submitted on behalf of the Council of State Administrators of Vocational Rehabilitation (CSAVR) in conjunction with the hearing held on March 2, 2005 before the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

The CSAVR is composed of the chief administrators of the State Vocational Rehabilitation (VR) Agencies serving individuals with physical and/or mental disabilities in the United States, the District of Columbia and the Territories. These agencies constitute the state partners in the State-Federal Program of Rehabilitation Services provided under Title 1 of the Rehabilitation Act of 1973, as amended. State VR agencies provide individualized services and supports to eligible individuals with significant disabilities that are required for them to go to work. These services may include, but are not limited to, counseling and guidance, job training, higher education, physical and mental restoration services, and assistive technology. Over 1 million individuals with disabilities are served annually. In fiscal year 2004, these agencies placed over 213,000 individuals with disabilities into competitive employment.

The CSAVR, founded in 1940 to furnish input into the State-Federal Rehabilitation Program, provides a forum for state administrators to study, deliberate, and act upon matters affecting the rehabilitation and employment of individuals with disabilities. The Council serves as a resource for the formulation and expression of the collective points of view of state rehabilitation agencies on all issues affecting the provision of quality employment and rehabilitation services to persons with significant disabilities.

For fiscal year 2006, CSAVR recommends an increase in the Vocational Rehabilitation (VR) appropriation of \$125 million above the President’s budget request for fiscal year 2006. While the President’s budget proposes a 3.2 percent increase in funding for the Public VR program, an increase of approximately 1.2 percent above the mandated CPI called for in law, this increase is based on the elimination of several smaller programs (Supported Employment (SE), Projects With Industry (PWI), and Migrant and Seasonal Farm Workers (MSFW), with an assumption that VR will continue to provide services, under Title 1 of the Rehabilitation Act, to the individuals previously served under these programs. The President’s budget request for fiscal year 2006 is between \$22 and \$25 million less than the consolidated funding for these three programs; thus, VR would need additional funding for services to accommodate for the elimination of these programs. In addition to the proposed elimination of the SE, PWI, and MSFW programs, which CSAVR does not support, H.R. 27, the House bill to reauthorize the Workforce Investment Act (WIA), expands the requirements for VR to provide transition services to students with disabilities. CSAVR also anticipates that S. 9, the Senate bill to reauthorize the WIA, will include expanded transition requirements, when it is reintroduced as a free-standing bill. Based on the significant internal and external challenges facing the Public VR

Program, (i.e., staffing shortages, state budget shortfalls, increased numbers of consumers seeking services, and increased service expectations, the CSAVR believes that an increased appropriation of \$125 million above the President's budget request for VR, for fiscal year 2006, is an appropriate recommendation.

#### THE PUBLIC VOCATIONAL REHABILITATION PROGRAM

The Public VR Program is one of the most cost-effective programs ever created by Congress. It enables hundreds of thousands of individuals with disabilities to go to work each year and become tax-paying citizens. In fiscal year 2004, the VR Program assisted over 1 million individuals with disabilities who wanted to work, by providing them with the job skills, training and support services they needed to become employed. Of those served, more than 213,000 entered into competitive employment. Funding for the VR Program requires a state match of 21.3 percent, and creates a state-federal partnership that has worked effectively for more than 85 years, and has assisted over 15 million individuals with disabilities to engage in employment and become tax-paying citizens.

The Rehabilitation Act mandates that the annual Federal appropriation for the VR Program grow at a rate at least equal to the change in the Consumer Price Index (CPI) over the previous fiscal year. While the mandate was intended to create a floor for the VR appropriation, Congress has not appropriated funds above the mandated CPI increase since 1999. This is particularly problematic because the formula used to distribute these funds, which is based on a state's per capita income and population, results in significant variations in the increases in individual State's allotments. When the increase is limited to the CPI increase and the formula is applied, not all states receive increases that are equal to the annual rate of inflation. In fiscal year 2005, 30 states did not receive the 1.977 percent required CPI increase in their state allotment.

#### CHALLENGES FACING THE PUBLIC VR PROGRAM

Over the last several years, the Public VR Program has faced a number of external challenges that have been compounded by the minimal increases in Federal funding.

##### *Special Education*

Between 1990 and 2004, the federal appropriation for special education increased by approximately 333 percent. During the same time period, the federal appropriation for the Public VR Program increased by only 22 percent. As a result of these very significant increases in special education funding, an ever-increasing number of special education students are exiting the education system and seeking adult services, including Vocational Rehabilitation, in order to participate in post secondary education, job training, and/or to go to work. In addition, the House passed the Job Training Improvement Act in March 2005, which adds additional responsibilities to State VR agencies for the provision of transition services, beyond those presently required by current law. The Senate bill, S. 9, is also anticipated to add new transition responsibilities for VR when it is reintroduced. These additional requirements, if implemented effectively, will place a tremendous burden on the fiscal and personnel resources of State VR agencies, many of which are already sorely under-funded to meet the needs of adults with significant disabilities who are seeking employment.

##### *Impact of the Workforce Investment Act of 1998 (WIA)*

The Public VR Program is a mandatory partner in the WIA and, as such, is required to contribute significant resources to support the infrastructure and other costs associated with the operation of the One-Stop Centers. While VR's involvement in State Workforce Investment Systems is critically important, WIA has placed yet another financial burden on an already strained program, further reducing the percentage of VR funds that are available to provide services and supports to eligible individuals with disabilities. In addition, the House bill to reauthorize the WIA, H.R. 27, proposes to take significant resources from the Public VR Program far beyond the resources contributed to the One-Stop Centers under current law. The Senate bill, S. 9, also requires additional resources from VR to fund the infrastructure costs and other common costs associated with the operation of One-Stop Centers.

##### *Impact of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA)*

The TWWIIA was designed to address disincentives to work found in the Social Security Disability Insurance Program (SSDI) and the Supplemental Security Income Program (SSI), and to increase employment opportunities for individuals en-

rolled in these programs. Research has shown that less than one-half of one percent of these individuals leaves the Social Security disability rolls each year as a result of paid employment. The provisions in TWWIA that provide extended Medicare and Medicaid coverage to such individuals, when they enter or return to the workforce, are expected to encourage more beneficiaries to seek employment. Despite the establishment of a network of private providers to offer employment services to beneficiaries, the majority of beneficiaries, 90 percent, continue to seek services from State VR Agencies. With only minimal increases in VR funding over the last decade, this situation creates yet another challenge for the Public VR Program.

*Temporary Assistance for Needy Families (TANF)*

Most states have had significant success in reducing their TANF, or welfare to work caseloads. While TANF caseloads have been shrinking, the composition of the remaining caseload has changed. A 2002 General Accounting Office (GAO) report found that individuals with disabilities and their family members represent approximately 44 percent of the remaining TANF population. Since many of these individuals have multiple and significant barriers to employment, state welfare agencies are increasingly turning to State VR Agencies for assistance in serving these individuals. With only minimal increases in funding, and 42 State VR Agencies operating under an Order of Selection, a system of prioritization whereby individuals with the most significant disabilities are served first, it is becoming increasingly difficult, if not impossible, for State VR Agencies to serve the increased numbers of TANF referrals.

As stated earlier, the Public VR Program is one of the most cost-effective programs ever created by Congress. Evidence of its success is further established by:

- A 2002 Longitudinal Study of the Public VR Program which provided evidenced based research that the VR Program is effective in putting people with disabilities to work in good jobs with opportunities for advancement.
- A fiscal year 2005 Program Assessment Rating Tool (PART), developed by the Office of Management and Budget (OMB) to rate program performance, rated the VR Program favorably, and in general, successful in meeting its program goal.
- A report by the Social Security Administration, released annually, that provides detailed information on the funds disbursed to State VR Agencies, based on their successfully serving beneficiaries on Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). In fiscal year 2004 SSA projected a \$470.3 million savings to the Trust Fund by the VR Program, and established that every \$1.00 that SSA spends on VR results in a \$6.00 savings.

In this era of federal and state budget deficits, and an increase in the unemployment rate for individuals with disabilities, we urge you to consider an increase in funding for the Public VR Program, through which you can be assured to have positive outcomes, based on the three factors mentioned above.

Our nation's ability to be competitive in a global economy depends on the quality of our workforce. According to a report released by the Department of Labor, Employment & Training Administration, during the fiscal year 2005 Budget Briefing, the American workforce will be vastly different than it is today, as the 21st century unfolds. Integrating all available workers into the workforce, including workers with significant disabilities, will be required for employers to meet the demands of the 21st century economy. Significant numbers of large and small employers have acknowledged that hiring individuals with disabilities makes good business sense. It provides them with dependable workers and access to a market of individuals with spending power, which has historically been untapped. These same employers also have long-standing, positive relationships with VR, to whom they look to provide them with qualified workers with disabilities. Integrating all available workers into the workforce, including workers with disabilities, will require significant resources. VR's positive relationships with employers, who rely heavily on the Public VR Program to meet their hiring needs, further emphasizes and documents the need for additional resources for VR.

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PREPARED STATEMENT OF THE FLORIDA DEPARTMENT OF EDUCATION

Chairman Specter, and other distinguished members of the Subcommittee: My name is Carlos R. Saavedra. I am the Director of the Adult Migrant Program and Services Section of the Florida Department of Education and submit my testimony for consideration by the Subcommittee regarding the Workforce Investment Act, Title I, Section 167 National Farmworker Jobs Program. The Florida Department of Education is the grantee for the National Farmworker Jobs Program and has op-

erated this program successfully for past years, under the aegis of the Office of Economic Development, the Comprehensive Employment and Training Act, and the Jobs Training Partnership Act.

As you are aware, the President's budget for 2006 proposes to eliminate the National Farmworker Jobs Program. This action appears to be prompted by a reduction in the United States Department of Labor's Employment and Training budget; the conviction that farmworkers will receive similar services through the One-Stop Centers and the local One-Stop Systems; and the belief that the National Farmworker Jobs Program is ineffective and duplicates other programs.

There are many issues that remain to be addressed and resolved first if the One-Stop Centers and the One-Stop Systems are to fulfill the mandate to serve migrant and seasonal farmworkers as part of their universe of clients. At the very least, state and local workforce boards will need to deal with issues of program performance and the manner for reaching farmworkers with services. Farmworkers live and work in the margins of small rural towns, where the One-Stop Systems have limited representation.

As regards performance, local workforce boards and their service providers currently receive few, if any, incentives from the state workforce boards to serve farmworkers and other populations with special needs. Consequently, providers feel obliged to job place many clients in the shortest time possible, with little consideration of their need for remedial education and customized skills training, which farmworkers and other special population with special needs require. Under current conditions, local workforce boards and their providers see little or no benefit to enrolling individuals with extremely low education levels and high mobility rates, as is the case with migrant farmworkers. This is the current state of services to migrant and seasonal farmworkers via the One-Stop Centers and the One-Stop Delivery System in many states where farmworkers are a significant part of the overall workforce.

As regards farmworkers' access to services, the degree and mix of employment, training and supportive services that farmworkers receive in their communities today is possible because of funding by the National Farmworker Jobs Program. The National Farmworker Jobs Program supports customized service strategies with bilingual and bicultural staff that serve as a bridge between the farmworker community and the services and those educational programs offered by community and faith-based organizations and public institutions that are attuned to the needs of youth and adult learners. It is worth noting that the National Farmworker Jobs Program has high performance standards and outcome measures that are consistently met or exceeded. The outcomes for the Farmworker Jobs and Education Program, as Florida's National Farmworker Jobs Program is known, compares very favorably with national, state and local outcomes of other employment and training programs.

In closing, I would like to share with the Subcommittee the story of one individual who benefited from Florida's Farmworker Jobs and Education Program and who was recently recognized by the Florida Department of Education as an "All American Success".

Thank you for the opportunity to address this issue and ask that the Subcommittee consider farmworkers among those for whom continued federal support is essential.

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PREPARED STATEMENT OF GALLAUDET UNIVERSITY

Mr. Chairman and members of the Committee: I would like to express my appreciation to you and to Congress for the generous support that we received in fiscal year 2005 to continue maintaining and enhancing academic programs and salaries at Gallaudet University. I am especially grateful that Congress continues to support us during these challenging times. I would like to provide you with some details concerning our request for fiscal year 2006. In my testimony last year, I discussed ongoing efforts by Gallaudet to diversify our sources of revenue and support, and I also want to bring you up to date on this issue.

It is important to note that the proportion of the Federal appropriation for Gallaudet University as a part of our total budget was 17 percentage points less in 2004 than it was in 1981. During the 1980's and 1990's, we coped with limitations on Federal support by increasing our tuition charges at a rate that exceeded growth in the Consumer Price Index (CPI) during that period. However, in light of concerns expressed by members of Congress and others, we have limited the increase in tuition charges for fiscal year 2006 to 3 percent, commensurate with general inflation. Very significantly, we have also reduced staffing since 1989 by 20 percent. In addi-

tion, we have changed our strategy for funding major construction and renovation projects. When I became President in 1988, every building on the Kendall Green campus had been constructed with 100 percent Federal funding. Since I became President, every major construction or renovation project we have conducted has been supported either by cost-sharing with the Federal government or by private fundraising alone. For example, the buildings constructed here most recently, the Kellogg Conference Hotel at Gallaudet University and the Student Academic Center, were constructed without any additional Federal appropriations. In 2003, we completed a 4-year, \$40 million capital campaign, and much of that funding went to support construction of the Student Academic Center and growth in our endowment. We have begun fundraising for a much-needed new facility to house our language and communication programs, and I am pleased to inform you that in November of last year we received a \$5 million gift for this project from the Sorenson family of Utah. I believe, therefore, that we have been very responsible in our requests for Federal support and that we have done everything we could to seek additional sources of funding during a period when Congress has faced funding limitations.

Because of Congress' ongoing support of Gallaudet in fiscal year 2005, we have been able to maintain a competitive pay structure for our employees while retaining the flexibility to meet the needs of a changing student body. Given the unique student population we serve and the communication skills our employees are expected to possess, retaining skilled employees is very critical to our mission. Gallaudet employees received general pay increases of 2 percent in fiscal year 2003, 3 percent in fiscal year 2004, and 2 percent in fiscal year 2005, increases that are below what Federal employees in the region received during the same timeframe, but in line with increases in the CPI. It will be important for Gallaudet to ensure that our employees receive a 3 percent pay increase in fiscal year 2006, commensurate with current increases in inflation. We are also requesting support for inflationary increases in non-salary areas, especially in the cost of utilities, insurance, and other professional fees.

The administration budget for fiscal year 2006 includes \$104.557 million for Gallaudet, the same as our current year fiscal year 2005 appropriation. I have carefully analyzed our fiscal year 2006 funding needs and have determined that in order to award a 3 percent salary increase to our faculty and staff, and to meet other inflation-driven increases, we need an increase of only \$3.1 million, 3 percent above our current appropriation.

While this minimal increase would allow us to continue with current programs, it would not allow us to invest in programs that the University considers of critical importance. Our three priorities for fiscal year 2006 include the following:

*Initiatives to increase accessibility to information from outside and from within the University campus—\$975,000*

Information technology continues to be the "great equalizer" that levels the playing field for those who are deaf or hard of hearing. Ever-increasing access to visual media and the growing proliferation of text-based communication provides more opportunities for deaf and hard of hearing people in different aspects of society. Therefore, it is essential that Gallaudet continue to invest in information technology that will provide these kinds of opportunities for our students.

This funding will support the replacement of computers used daily by students in the digital learning center at the Student Academic Center, in student services programs, and in classrooms. It will also support upgrades to the University's Web presence and to student e-portfolio systems, which allow students to document their academic progress, receive feedback from their instructors, and present themselves electronically to potential employers.

Finally, Gallaudet owns the largest and most unique collection of deafness-related materials in the world. Support will be given to the digitization of Gallaudet's unique archives. Digitizing these archives will make them more accessible to scholars and students at the University, as well as scholars from outside the Gallaudet community.

*Initiatives to enhance University programs for deaf students from non-traditional and diverse backgrounds—\$300,000*

Gallaudet continues to seek ways to reach out to and create a more positive educational climate for deaf students from non-traditional and diverse backgrounds. Demographic trends point to a growing number of students of color as well as a growing number of deaf students who are placed in educational settings where sign language is not the primary mode of communication.

Gallaudet recognizes that teacher preparation is essential in supporting students of color. In order for the teachers to capitalize on the expertise that Gallaudet has



to offer, we seek to offer a regional distance education degree program that will allow teachers to receive training and earn a degree from Gallaudet without their having to come to Washington, D.C. to earn all their credits.

In public education today, more deaf students are placed in educational settings where sign language is not the primary mode of communication. We believe it is important to have sufficient support for students with such backgrounds who come to Gallaudet to help them make the transition to a direct communication environment. It is also important for those who are undecided about which college to attend to understand that there is a strong program in place to help with such transition. The additional funding will let Gallaudet study optimal ways to enhance real-time captioning. In addition, it will support upgrading of the New Signers Program that provides sign language instruction to new students with weak or no signing skills.

*Improvements to the Theatre Arts Department, including renovations of the Elstad Auditorium and Annex—\$950,000*

Funding will enhance student learning by improving and expanding the Theatre Arts program at Gallaudet and by updating and expanding the Elstad Auditorium and Annex. As an institution that promotes the visual arts, we must provide a solid theatre arts experience to our students. Further, as the world's only university in which all programs and services are specifically designed to accommodate deaf and hard of hearing students, Gallaudet needs a first rate arena to promote direct access for a broad audience.

Changes in technology in the last thirty years have been very significant, and we are falling behind in our technical theatre. Lighting and sound systems are outdated, as are computer programming, costume shop equipment, and the set workshop. The building is not wired for classrooms to have direct access to the information network, and the box office is not wired to enable the use of effective and efficient ticketing programs.

Access to theatre for deaf and hard of hearing people is often limited to one or two interpreted performances in area productions. The improvements to the Gallaudet University Theatre Arts program and facilities would enable direct access by a broader audience, as well as allow for opportunities for us to partner with other theatre companies, such as the nationally acclaimed Arena Stage, to produce unique visual performances. Students would experience "smart" classrooms and learn how to use state-of-the-art theatrical technology. In addition, the deaf and hard-of-hearing community would have direct access to many theatrical performances. Finally, hearing audiences would be attracted to and exposed to deaf theatre.

*Total Program Requests—\$2,225,000*

The total request for Gallaudet University, including these three critical program priorities is \$109.9 million, representing a 5 percent increase from our fiscal year 2005 appropriation. This increase would have a significantly positive impact on the University's ability to meet the increasing and changing needs of our students and those in the field of deaf education.

I appreciate the challenges that Congress faces in making appropriations decisions for fiscal year 2006, but experience has shown that Gallaudet provides an outstanding return on the Federal dollars that are invested here in terms of the educated and productive deaf community that the nation enjoys as a result.

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND THE ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2006

(1) A 6 percent increase for the National Library of Medicine at the National Institutes of Health and support for NLM'S urgent facility construction needs.

(2) Continued support for the Medical Library community's role in NLM'S outreach, telemedicine and health information technology initiatives.

Mr. Chairman, thank you for the opportunity to testify today on behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) regarding the fiscal year 2006 budget for the National Library of Medicine. I am Logan Ludwig, Associate Dean for Library and Telehealth Services at Loyola University Strich School of Medicine in Maywood, Illinois.

Established in 1898, MLA is a nonprofit, educational organization of more than 1,100 institutions and 3,600 individual members in the health sciences information field, committed to educating health information professionals, supporting health information research, promoting access to the world's health sciences information, and working to ensure that the best health information is available to all.

AAHSL is comprised of the directors of libraries of 142 accredited United States and Canadian medical schools belonging to the Association of American Medical Colleges. Together, MLA and AAHSL address health information issues and legislative matters of importance to the medical community through a joint task force.

Mr. Chairman, the National Library of Medicine, on the campus of the National Institutes of Health in Bethesda, Maryland, is the world's largest medical library. The Library collects materials in all areas of biomedicine and health care, as well as works on biomedical aspects of technology, the humanities, and the physical, life, and social sciences. The collections stand at 5.8 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. Housed within the library is one of the world's finest medical history collections of old and rare medical works. The Library's collection may be accessed in the reading room or requested on interlibrary loan. NLM is a national resource for all U.S. health science libraries through a National Network of Libraries of Medicine. Increasingly, it is becoming an international resource for world-wide research collaboration.

With respect to the Library's budget for the coming fiscal year, I would like to touch briefly on four issues: (1) the growing demand for NLM's basic services; (2) NLM's outreach and education services; (3) NLM's telemedicine and informatics activities; and (4) NLM's facility needs.

#### THE GROWING DEMAND FOR NLM'S BASIC SERVICES

Mr. Chairman, it is a tribute to NLM that the demand for its services continues to steadily increase each year. An average of 500 million Internet searches are performed annually on NLM's MEDLINE database, which provides access to the world's most up-to-date health care information. MEDLINEplus, NLM's extensive electronic information resource for the general public, is viewed approximately 200 million times a year. This activity dwarfs previous usage of NLM's bibliographic services, whether electronic or print. Moreover, researchers, scholars, librarians, physicians, healthcare providers from around the world, and the general public rely heavily on NLM and its National Network of Libraries of Medicine to deliver health care information everyday that is necessary to improve the quality of our nation's healthcare system.

NLM also plays a critical role in maintaining the integrity of the world's largest collection of medical books and journals. Increasingly, this current and historical information is in digital form. This has fundamentally changed how the library operates—how and what it collects, how it preserves information, and how it disseminates biomedical knowledge. NLM, as a national library responsible for preserving the scholarly record of biomedicine, is developing a strategy for selecting, organizing, and ensuring permanent access to digital information. Regardless of the format in which the materials are received, ensuring their availability for future generations remains the highest priority of the Library.

Mr. Chairman, simply stated, NLM is a national treasure. I can tell you that without NLM our nation's medical libraries would be unable to provide the quality information services that our nation's healthcare providers, educators, researchers and patients have come to expect.

Recognizing the invaluable role that NLM plays in our health care delivery system, the Medical Library Association and the Association of Academic Health Sciences Libraries join with the Ad Hoc Group for Medical Research Funding in recommending a 6 percent increase for NLM and NIH overall in fiscal year 2006.

#### OUTREACH AND EDUCATION

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities, designed to educate medical librarians, health care professionals and the general public about NLM's services, are an essential part of the Library's mission.

The Library has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. NLM's emphasis on outreach to underserved populations assists the effort to reduce health disparities among large sections of the American public. We were pleased that the Committee again last year recognized the need for NLM to coordinate its outreach activities with the medical library community.

#### *PubMed Central*

The medical library community also applauds NLM for its leadership in establishing PubMed Central, an online repository for life science articles. Introduced in 2000, PubMed Central was created by NLM's National Center for Biotechnology Information and evolved from an electronic publishing concept proposed by former

NIH Director Dr. Harold Varmus. The site houses articles from some 100 journals including the Proceedings of the National Academy of Sciences and Molecular Biology of the Cell.

The medical library community believes that health sciences librarians should continue to play a key role in further development of PubMed Central and we are pleased that medical librarians are members of the NLM PubMed Central Advisory Committee. Because of the high level of expertise health information specialists have in the organization, collection and dissemination of medical literature, we believe our community can assist NLM with issues related to copyright, fair use, and information classification on the PubMed Central site. We look forward to continuing our collaboration with the Library as this exciting project continues to evolve this year.

#### *MEDLINEplus*

NLM estimates that the public conducts 30 percent of all MEDLINE searching. MEDLINEplus [<http://www.nlm.nih.gov/medlineplus/>], a source of authoritative, full-text health information resources from the NIH institutes and a variety of non-Federal sources, has grown tremendously in its coverage of health and its usage by the public. In January 2003, two million unique users searched more than 600 "health topics" that contain detailed consumer-focused information on various diseases and health conditions. Recent additions to MEDLINEplus include illustrated interactive patient tutorials, a daily news feed from the public media on health-related topics, and the NIHSeniorHealth site [<http://nihseniorhealth.gov/>], a collaborative project between NLM and the National Institute on Aging.

#### *Clinical Trials*

Mr. Chairman, I also want to comment on another relatively new service offered by NLM—its clinical trials database [<http://www.clinicaltrials.gov>]. This listing of more than 7,000 federal and privately funded trials for serious or life-threatening diseases was launched in February of 2000 and currently logs more than 2 million page hits per month. The clinical trials database is a free and invaluable resource to patients and families interested in participating in cutting edge treatments for serious illnesses. The medical library community congratulates NLM for its leadership in creating ClinicalTrials.gov and looks forward to assisting the Library in advancing this important initiative.

Mr. Chairman, we applaud the success of NLM's outreach initiatives and look forward to continuing our work with the Library again in fiscal year 2006 on these important programs.

#### TELEMEDICINE AND MEDICAL INFORMATICS

Mr. Chairman, telemedicine continues to hold great promise for dramatically increasing the delivery of health care to underserved communities across the country and throughout the world. NLM has sponsored over 50 innovative telemedicine related projects in recent years, including 21 multi-year projects in various rural and urban medically underserved communities. These sites serve as models for:

- Evaluating the impact of telemedicine on cost, quality, and access to health care;
- Assessing various approaches to ensuring the confidentiality of health data transmitted via electronic networks; and
- Testing emerging health data standards.

It is clear that telemedicine and medical informatics program such as the Visible Human Project [[http://www.nlm.nih.gov/research/visible/visible\\_human.html](http://www.nlm.nih.gov/research/visible/visible_human.html)]  
—male and female data sets consisting of MRI, CT, and photographic cryosection images totaling 50 gigabytes and licenses to scientists at more than 1,700 institutions around the world—will play a major role in the delivery of health care and research in the 21st Century.

We are pleased that NLM has begun a new program to support informatics research that addresses information management problems relevant to disaster management. Medical librarians and health information specialists have an important role to play in supporting these cutting edge technologies, and we encourage Congress and NLM to continue their strong support of telemedicine and other medical informatics initiatives.

#### NLM'S FACILITY NEEDS

Mr. Chairman, over the past two decades NLM has assumed several new responsibilities, particularly in the areas of biotechnology, health services research, high performance computing, and consumer health. As a result, the Library has had tre-

mendous growth in its basic functions related to the acquisition, organization, and preservation of an ever-expanding collection of biomedical literature.

This increase in the volume of biomedical information as well as expansion of personnel (NLM currently houses over 1,100 people in a facility built to accommodate 650) has resulted in a serious shortage of space at the Library. In addition, NLM's National Center for Biotechnology Information [<http://www.ncbi.nlm.nih.gov>] builds sophisticated data management tools for processing and analyzing enormous amounts of genetic information critical to advancing the Human Genome Project.

In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. The medical library community is pleased that Congress appropriated the necessary architectural and engineering funds for facility expansion at NLM in 2003.

We encourage the subcommittee to continue to provide the resources necessary to acquire a new facility and to support the Library's health information programs.

Mr. Chairman, thank you again for the opportunity to present the views of the medical library community.

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#### PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

##### OVERVIEW

The National Association of Children's Hospitals (N.A.C.H.) is pleased to have the opportunity to submit the following statement for the hearing record in support of the Children's Hospitals' Graduate Medical Education (CHGME) Payment Program in the Health Resources and Services Administration (HRSA).

On behalf of the nation's 60 independent children's teaching hospitals, N.A.C.H. very much appreciates the Subcommittee's early and continuing commitment over several years to provide full, equitable GME funding for these hospitals, giving them a level of federal support for their teaching programs that seeks to be comparable to what all other teaching hospitals receive through Medicare.

We also appreciate the Subcommittee's support for level funding of \$303 million for fiscal year 2005—the amount requested by President Bush and recommended by N.A.C.H. Ultimately, this funding was reduced to \$301 million, or less than level funding, by a 0.8 percent across the board reduction in non-defense, non-homeland security discretionary spending programs in the final conference report.

For fiscal year 2006, we respectfully request an adjustment recognizing the cost of inflation for CHGME, which would result in total funding of \$309 million, so that these institutions will have the resources necessary to train and educate the nation's pediatric workforce. Such an adjustment is important for a program with both wage-related and medical teaching costs associated with it. Given the challenges that the Subcommittee faces, we hope that at a minimum the program can at least be maintained at level funding and not lose further ground in fiscal year 2006.

N.A.C.H. is a not-for-profit trade association, representing more than 125 children's hospitals across the country. Its members include independent acute care children's hospitals, acute care children's hospitals organized within larger medical centers, and independent children's specialty and rehabilitation hospitals. N.A.C.H. seeks to serve its member hospitals' ability to fulfill their four-fold missions of clinical care, education, research and advocacy devoted to the health and well being of all children in their communities.

Children's hospitals are regional and national centers of excellence for children with serious and complex conditions. They are centers of biomedical and health services research for children, and they serve as the major training centers for future pediatric researchers, as well as a significant number of our children's doctors. These institutions are major safety net providers, serving a disproportionate share of children from low-income families, and they are also advocates for the public health of all children.

Although they represent less than 5 percent of all hospitals in the country, the three major types of children's hospitals provide 41 percent of the inpatient care for all children, 42 percent of the inpatient care for children assisted by Medicaid, and the vast majority of hospital care for children with serious conditions such as cancer or heart defects.

##### BACKGROUND: THE NEED FOR CHILDREN'S HOSPITALS GME

While they account for less than 1 percent of all hospitals, the independent children's teaching hospitals alone train nearly 30 percent of all pediatricians, half of all pediatric specialists and a majority of future pediatric researchers. They also pro-

vide required pediatric rotations for many other residents. They train about 4,000 residents annually, and the need for these training programs is even more heightened by the growing evidence of shortages in pediatric specialists around the country.

Prior to initial funding of the CHGME program for fiscal year 2000, these hospitals were facing enormous challenges to their ability to maintain their training programs. The increasingly price competitive medical marketplace was resulting in more and more payers failing to cover the costs of care, including the costs associated with teaching.

The independent children's hospitals were essentially left out of what had become the one major source of GME financing for other teaching hospitals, Medicare, because they see few if any Medicare patients. They received only 1/200th (or less than 0.5 percent) of the federal GME support that all other teaching hospitals received under Medicare.

This lack of GME financing, combined with the financial challenges stemming from their other missions, was threatening their teaching programs, as well as other important services.

*Integral Safety Net Institutions.*—In addition to their teaching missions, the independent children's hospitals are a significant part of the health care safety net for low-income children. In fiscal year 2003, children assisted by Medicaid represented, on average, 47 percent of all discharges from free-standing acute care children's hospitals and accounted for about 50 percent of all inpatient days of care. Yet Medicaid, on average, reimbursed 80 percent of the cost of care provided. Without disproportionate share hospital payments, those reimbursements would only cover, on average, 73 percent of the cost of care. The shortfalls in Medicaid payments for outpatient and physician care are even greater. . The independent children's hospitals also are essential providers of care for seriously and chronically ill children. They devote more than 75 percent of their care to children with one or more chronic or congenital conditions. They provide the vast majority of inpatient care to children with many serious illnesses—from children with cancer or cerebral palsy, for example, to children needing heart surgery or organ transplants. In some regions, they are the only source of pediatric specialty care. The severity and complexity of illness and the services and resources that these institutions must maintain to assure access to this quality care for all children are also often inadequately reimbursed.

*Mounting Financial Pressures.*—The CHGME program, and its relatively quick progress to full funding in fiscal year 2002, came at a critical time. In 1997, when Congress first considered establishing CHGME, a growing number of independent children's teaching hospitals had financial losses, and many more faced mounting financial pressures. More than 10 percent had negative total margins, more than 20 percent had negative operating margins, and nearly 60 percent had negative patient care margins. Some of the nation's most prominent children's hospitals were at financial risk. Thanks to the CHGME program, these hospitals have been able to maintain and strengthen their training programs.

Continuing this critical CHGME funding is more important for these hospitals than ever in light of state budget shortfalls in many states and the resulting pressures for significant reductions in state Medicaid spending. Because children's hospitals devote such a substantial portion of their care to children from low-income families, they are especially affected by cutbacks in state Medicaid programs.

*Pediatric Workforce Development.*—The important role the CHGME program plays in the continual development of our nation's pediatric workforce is not lost on the larger pediatric community, including the American Academy of Pediatrics and Association of Medical School Pediatric Department Chairs. The pediatric community supports this program and recognizes that CHGME is critical not only to the future of the individual hospitals, but also to provision of children's health care and advancements in pediatric medicine overall.

Lastly, many of the independent children's hospitals are a vital part of the emergency and critical care services in their communities and regions. They are part of the emergency response system that must be in place for public health emergencies. Expenses associated with preparedness add to their continuing costs in meeting children's needs.

#### CONGRESSIONAL RESPONSE

In the absence of any movement toward broader GME financing reform, Congress in 1999 authorized the Children's Hospitals' GME discretionary grant program to address the existing inequity in GME financing for the independent children's hospitals. The legislation was reauthorized in 2000 through fiscal year 2005 and provided \$285 million through fiscal year 2001 and such sums as may be necessary in

the years beyond.<sup>1</sup> Congress passed the initial authorization as part of the “Healthcare Research and Quality Act of 1999” and the reauthorization as part of the “Children’s Health Act of 2000.”

With the support of this Subcommittee, Congress appropriated initial funding for the program in fiscal year 2000, before the enactment of its authorization. Following enactment, Congress moved substantially toward full funding for the program in fiscal year 2001 and completed that goal, providing \$285 million in fiscal year 2002, \$290 million in fiscal year 2003, \$303 million in fiscal year 2004 and \$301 million in fiscal year 2005. (In the last 2 fiscal years, the funding levels are net of across-the-board reductions in all non-defense, non-homeland security discretionary appropriations.) The annual CHGME appropriations represent an extraordinary achievement for the future of children’s health care as well as for the nation’s independent children’s teaching hospitals.

*Health Resources and Services Administration.*—The CHGME funding appropriated by Congress is distributed through HRSA to 60 children’s hospitals according to a formula based on the number and type of full-time equivalent (FTE) residents trained, in accordance with Medicare rules, as well as the complexity of care and intensity of teaching the hospitals provide. Consistent with the authorizing legislation, HRSA allocates the annual appropriation in bi-weekly periodic payments to eligible independent children’s hospitals.

*“Adequate” Rating From Administration.*—The Office of Management and Budget gave CHGME an “adequate” rating in 2003, using its Program Assessment Rating Tool (PART). The PART review said CHGME has a “clear purpose,” is “effectively targeted,” has specific “long-term performance measures” that focus on outcomes, and holds grantees “accountable for cost, schedule, and performance results.”

#### FISCAL YEAR 2006 REQUEST

N.A.C.H. respectfully requests that the Subcommittee continue equitable GME funding for the independent children’s hospitals by providing \$309 million for the program in fiscal year 2006, which would provide an adjustment for inflation over current funding. We, of course, hope that such an adjustment could be provided, since it is particularly important for a program that includes both wage-related and medical teaching costs. Given the challenges that the Subcommittee faces, we hope that the program at least can be maintained at level funding and not lose further ground in fiscal year 2006.

Adequate, equitable funding for CHGME is an ongoing need. Children’s hospitals continue to train new pediatric residents and researchers every year. Children’s hospitals have appreciated very much the congressional support they have received, including the attainment of the program’s authorized full funding level in fiscal year 2002 and continuation of full funding with an inflation adjustment in fiscal year 2003 and fiscal year 2004. Now, N.A.C.H. asks Congress to maintain this progress by providing \$309 million in fiscal year 2006.

Support for a strong investment in GME at independent children’s teaching hospitals is consistent with the repeated concern the Subcommittee has expressed for the health and well-being of our nation’s children—through education, health and social welfare programs. It also is consistent with the Subcommittee’s repeated emphasis on the importance of enhanced investment in the National Institutes of Health (NIH) overall, and in NIH support for pediatric research in particular, for which we are very grateful.

The CHGME funding has been essential to the ability of the independent children’s hospitals to sustain their GME programs. At the same time, it has enabled them to do so without sacrificing support for other critically important services that also rely on hospital subsidy, such as many specialty and critical care services, child abuse prevention and treatment services, poison control centers, services to low-income children with inadequate or no coverage, mental health and dental services, and community advocacy, such as immunization and motor vehicle safety campaigns.

In conclusion, the Children’s Hospitals GME Payment Program is an invaluable investment in children’s health. The future of the pediatric workforce and children’s access to quality pediatric care, including specialty and critical care services, could not be assured without it. Again, N.A.C.H. and the nation’s independent children’s

<sup>1</sup>The Lewin Group, an independent health policy analysis firm calculated in 1998 that independent children’s teaching hospitals should receive approximately \$285 million in federal GME support for nearly 60 institutions to achieve parity with the financial compensation provided through Medicare for GME support to other teaching hospitals.

teaching hospitals are deeply grateful to the Chairman and the Subcommittee for your continuing leadership on behalf of the teaching missions of children's hospitals.

For further information, please contact Peters D. Willson, vice president for public policy, N.A.C.H., at 703/797-6006 or pwillson@nachri.org.

#### PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

##### SUMMARY OF FISCAL YEAR 2006 RECOMMENDATIONS

1. Increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least \$550 million for fiscal year 2006.

2. Restore funding for Area Health Education Centers (AHECs) to fiscal year 2003 level of \$33.1 million.

3. Restore funding for Health Education Training Centers (HETCs) to fiscal year 2003 level of \$4.3 million.

Mr. Chairman, and members of the subcommittee, I am pleased to present testimony on behalf of the National AHEC Organization.

I am Linda Kanzleiter, and I work for the Pennsylvania Statewide AHEC Program and am a member of the National AHEC Organization (NAO). NAO is the professional organization representing the Area Health Education Centers (AHECs) and Health Education Training Centers (HETCs). Together, we seek to enhance access to quality health care, particularly primary care and preventative care, by improving the supply and distribution of health care professionals through community—academic partnerships

##### PERSISTENT WORKFORCE SHORTAGES

Mr. Chairman, contrary to what may be commonly understood, persistent and severe shortages exist in a number of health professions. Chronic shortages exist for all health professions in many of our nation's underserved communities, and substantial shortages exist in all communities for some professions such as nursing, pharmacy, and certain allied health fields. While the supply of physicians in the non-primary care specialties may well be adequate, supply and distribution problems for primary care physicians, nurses, and many allied health professionals are undermining access and quality in many of our nation's communities.

Historically, the supply of and demand for health care professionals has waxed and waned in a manner that produced cycles of shortage and excess. However, it is reasonable to believe that the current shortages are of a different and more persistent nature. First, the breadth and depth of shortages are greater than at any time in the past. More disciplines are in short supply, more sites of care (hospitals, nursing homes, home care agencies, and clinics) are experiencing shortages, and the duration of vacancies is longer. Second, the demand for health care services is steadily and inexorably increasing due to the aging population and the advances in medical technology. Third, the health care provider population is aging itself. Fourth, the resources with which the health care industry might respond to shortages are inadequate to the challenges. Due to the squeeze of managed care, provider institutions are unable to increase salaries, and due to cuts in government funding, educational institutions are unable to expand class sizes. Finally, the career opportunities available to women, who dominate the health care professions, have expanded greatly.

Health care workforce shortages are occurring in a context of an increasingly aged population with greater needs for health care services. In addition, health technology steadily produces advances that require a higher level of training and sophistication on the part of health care providers. These trends are occurring at time when the number and the level of academic preparedness of students entering the health professions are decreasing.

In addition, minority and disadvantaged populations are egregiously under represented in the health professions. Given the demographic trends in the United States, minority populations constitute a major untapped source of future health care professionals.

##### THE ROLE OF AHECS

Mr. Chairman, the AHEC/HETC network is the federal government's most flexible and efficient mechanism for addressing a wide and evolving variety of health care issues on a local level. Through AHECs and HETCs, national initiatives can be targeted to the areas of greatest need and molded to the particular issues confronting individual communities. Whether the issue is the nursing shortage, bioter-

rorism preparedness, access for the uninsured, or recruiting under-represented minority students into the health professions, AHECs and HETCs, where they exist, can assemble the appropriate local collaboration and apply federal, state, and local resources in a precise and cost-effective manner.

Since our inception almost thirty years ago, AHECs have partnered with local, state, and federal initiatives and educational institutions in providing clinical training opportunities to health professions and nursing students in rural and underserved communities. We bring the resources of academic health centers to bear in addressing the health care needs of these communities. Currently, there are 48 AHEC programs and 180 centers located in 43 states and the District of Columbia. AHEC programs are based at schools of medicine, which are the federal AHEC grant recipients, and are implemented through the regional offices (centers), each of which serves a defined geographic area.

#### AHEC PROGRAMS PERFORM FOUR BASIC FUNCTIONS:

1. They develop and support the community based training of health professions students, particularly in underserved rural and urban areas. Exposing health professions students to underserved communities increases the likelihood that they will return to these communities to practice.

When considering access, Pennsylvania faces some unique challenges. For example, The Pennsylvania Department of Health estimates that about 1,259,441 people in our Commonwealth do not have health insurance of any kind. Of that number, 109,883 are persons within the five counties we serve. The National Association of Community Health Centers estimates that, in Pennsylvania, at least 1,479,087 people are "without a primary care provider". This figure represents more than 12 percent of Pennsylvania's total population (12,281,054). This number is likely higher because eight counties, including Carbon & Lehigh, were not included in their data.

Pennsylvania AHECs have developed a network of over 972 health care training sites, 3,632 students and residents, and 1,045 on-site preceptors providing service to patients at these training centers.

2. They provide continuing education and other services that improve the quality of community-based health care. Improving the quality of care also enhances the retention of providers in underserved communities, particularly community health centers.

A crucial part of our mission in Pennsylvania involves linking fourth year medical students with Medical Preceptors, mentors and teachers in the community. Our goal is to help facilitate the process that allows the students to become familiar with the issues encountered in rural communities. The student can also begin to establish relationships, which will prove beneficial should they decide to practice in a rural area. In this way, Pennsylvania AHECs support the viability and, often, the continued, independent existence of small community hospitals.

The Northeast Pennsylvania Area Health Education Center surveyed physicians in the rural counties it serves to clarify issues surrounding continuing education. The overwhelming response was that there was a desire for more information about bioterrorism, and that it should be accessible online. The Pennsylvania Department of Health subsequently created the Learning Management System (LMS), a web-based system for education and information-sharing regarding bioterrorism and other public health issues. The LMS delivers emergency preparedness training and access to up to date information to the hands of health professionals, day or night. The LMS serves as an information library, a forum for discussion groups, and means of surveying program content online.

3. They recruit under-represented minority students into the health professions through a variety of programs targeted at elementary through high schools. Minority students are grossly under-represented in the health professions and are more likely to practice in underserved communities.

The Northwest Pennsylvania AHEC has developed a program called the Great Hospital Adventure Puppet Presentation. The multi-media presentation includes a live puppet show, video movie, coloring book, classroom poster, and an interactive question and answer session. This program promotes health career awareness and encourages healthy behaviors for children aged four to nine. The classroom materials and activities emphasize non-traditional gender roles and multi-cultural images. The goal of the presentation is to attract children of all genders, backgrounds and cultures to health professions.

The Northeast Pennsylvania AHEC established a summer camp called "Exploring Careers in Health" for high school students who demonstrate a strong interest in medicine or health care. The camp is a weeklong program held on the campus of Keystone College. Students must apply for admission, and the camp provides an in-



depth look at the health care field by participation in workshops with health professionals, hands-on activities, and field trips. Students are encouraged to explore numerous career choices as health professionals.

Additionally, the Northeast Pennsylvania sponsors a program for area teachers and guidance counselors called "Seeds for Success." The program offers an overview of health career opportunities at colleges, universities and post-secondary institutions in the surrounding area. The response to the program was overwhelmingly positive.

4. They facilitate and support practitioners, facilities, and community based organizations in addressing critical local health issues in a timely and efficient manner.

Only 13 percent of primary care physicians in Pennsylvania serve in rural communities. However, 42 of the state's 67 counties are predominantly rural and 7 counties are completely rural. These startling facts are the driving force behind the health care professions workforce development resolution.

#### THE ROLE OF HETCS

The HETC programs were created to address the public health needs of severely underserved populations in border and non-border areas. Currently, HETC programs exist in 12 states and are supported by a combination of federal, state, and local funding, the majority of which comes from non-federal sources.

Because the majority of preventable health problems are due to health behaviors and the environment, HETCs focus on community health education and health provider training programs in areas with severely underserved populations. HETCs target minority groups, disadvantaged communities, and communities with diverse culture and languages.

#### COLLABORATIVE EFFORTS

Virtually all AHEC and HETC programs are collaborative in nature. They routinely partner with a wide variety of federal, state, and locally funded programs. Examples of these collaborations include health professions schools, primary care residency programs, community health centers, primary care associations, geriatric education centers, the National Health Service Corps, public health departments, health career opportunity programs, school districts, and foundations.

Additionally, AHECs and HETCs often go beyond their core functions to undertake a wide variety of innovative programs, tailored to specific health issues affecting the communities they serve. Because health issues vary from community to community, the programs of each AHEC and HETC also vary considerably. AHECs and HETCs respond to changing health and health workforce needs in a flexible and timely manner. Examples of current issues for which we are directing our resources are:

1. *The nursing shortage.*—Currently, AHECs and HETCs are working with schools of nursing, state nursing associations, and others to increase the number of qualified applicants to nursing schools, increase minority enrollment in nursing schools, expand the number of community-based nursing training sites, and re-train nurses who wish to re-enter the profession.

The Northcentral Pennsylvania AHEC facilitated the Nursing Forum, titled *Joining Healing Hands: Communication, Collaboration, and Teambuilding*, to enhance regional nursing recruitment and retention efforts within their 10 county region on Friday, February 27, 2004 in Lewisburg, Union County. Participating nurses, nurse administrators, healthcare representatives, and nursing educators explored ways to strengthen communication, leadership skills, and teamwork to create a shared vision and commitment to quality healthcare. Skill sets encouraged at the forum promoted a shared commitment to quality healthcare, fostered positive outcomes, encouraged inclusion of collaborative educational efforts, and supported the recruitment and retention of a diversified workforce.

2. *Bioterrorism education.*—Currently, AHECs and HETCs are working with public health departments to educate health and public health professionals on surveillance, reporting, risk communication, treatment, and other responses to the threat of bioterrorism.

3. *The National Health Service Corps (NHSC).*—AHECs and HETCs undertake a variety of programs related to the placement and support of NHSC scholars and loan repayment recipients.

The Pennsylvania State University AHEC has actively supported the NHSC "SEARCH" program by interviewing prospective students, recommending community preceptors, and monitoring placements of students each summer in rural and underserved sites.

4. *Expansion of community health centers.*—AHECs and HETCs are collaborating with health professions schools, primary care associations, and community health centers to increase the supply of providers willing and able to work in community health centers. In addition, AHECs/HETCs are working directly with CHC providers to improve the quality of care.

JUSTIFICATION FOR FUNDING RECOMMENDATIONS

Mr. Chairman, I respectfully ask the Subcommittee to support our recommendations to increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least \$550 million for fiscal year 2006. Our recommendations are consistent with those of the Health Professions and Nursing Education Coalition (HPNEC).

The AHEC and HETC programs improve access to primary and preventative care through community partnerships, linking the resources of academic health centers with local communities. AHECs and HETCs have proven to be responsive and efficient models for addressing an ever-changing variety of community health issues.

However, AHECs and HETCs have not yet fully realized their potential to be a nationwide infrastructure for local training and information dissemination. In order to realize that potential additional federal investment is required. That is why we are requesting that in fiscal year 2006, you restore funding to fiscal year 2003 levels of \$33.4 million for AHECs and \$4.3 million for HETCs.

PREPARED STATEMENT OF THE STATE EDUCATIONAL TECHNOLOGY DIRECTORS  
ASSOCIATION (SETDA)

NCLB TITLE II, PART D: ENHANCING EDUCATION THROUGH TECHNOLOGY

On behalf of SETDA representing all fifty states, DC, and American Samoa, we encourage you to restore NCLB Title II, Part D—Enhancing Education through Technology (EETT) program to its fiscal year 2004 funding level of \$692 million. In fiscal year 2005, this program sustained a 28 percent cut, which has not yet been realized in schools across the country due to the grant award cycle. This testimony documents how states leverage EETT funding to ensure the ability of states, districts, and schools to implement all Titles within NCLB, specifically:

- Enhancing data systems to ensure that educators can utilize real-time data to inform sound instructional decisions and ensure that states are able to meet AYP.
- Closing the achievement gap by providing access to software, online resources, and virtual learning aligned to academic standards for instruction and learning.
- Supporting the development of highly qualified teachers by providing online courses, communities of practice, and virtual communication that ensure flexibility and access.

The data and examples illustrate how forty-nine states and DC (representing 99 percent of federal education technology funding) utilize EETT funding. 81 percent of school districts in this country receive and use EETT funding. States maintain 5 percent for technical assistance and administration and disseminate the remaining 95 percent equally between two programs:

1. The Formula Grant Program by which high need districts receive an allotment based upon poverty rates.
2. The Competitive Grant Program through which states establish areas of focus for districts to compete for the grants. Each grantee must include at least one high need district.

THE MYTH OF EETT

Some believe that EETT is utilized primarily to purchase computers or “the boxes in the back of the classroom.” The SETDA National Trends Report and examples provided demonstrate that this is not the case. The majority of this funding supports the purchase of curriculum, provides professional development to ensure teachers are highly qualified, and builds systems for assessment, data and accountability mechanisms. Some grantees may use small amounts of the funding to purchase hardware integral to the students’ education, i.e. laptops that children in rural areas bring home to expand learning opportunities; however the overwhelming majority of the funding is utilized to support the successful implementation of NCLB that is highlighted below.

## MEETING AYP AND IMPROVING STUDENT ACHIEVEMENT THROUGH DATA SYSTEMS

*Key Facts*

Data management and accountability requirements are steadily rising and states have a limited capacity for meeting these requirements. EETT funds are the only source of federal funding for most states to use in developing the data systems needed to report AYP results mandated through NCLB. These funds are being used toward data systems that impact both instructional and administrative aspects of education. On the instructional side, the National Trends Report cites many examples of EETT funds being used to train teachers in understanding how to use data effectively to individualize learning and to make real-time modifications to instruction in order to best meet the needs of every learner. The report also cites multiple examples of state and district-wide data management systems that allow for increased accountability and reporting.

While professional development and student achievement are still extremely important in EETT, the program has seen a tremendous increase in the number of states (78 percent) that are using these technology funds for three other key NCLB priorities—assessment, outreach to parents, and data-driven decision-making.

*Examples*

The Philadelphia Instructional Management System (IMS) is part of the School District of Philadelphia's comprehensive reform effort that includes new resources, a standardized curriculum, after school programs, and professional development. IMS provides teachers and administrators with immediate data on student learning aligned to State and District standards. A benchmark assessment, given every five weeks, allows teachers to differentiate instruction, provide immediate remediation, and identify those students who need additional assistance. Teachers, coaches, and administrators have access to student performance data through an online system. This system also provides suggested resources and strategies teachers can use to meet unique student needs. In 2003, before these technology tools were provided to teachers, only 9 of the 40 initial participating schools had met AYP; and 15 were identified for Corrective Action. At the end of the 2004 school year, 25 schools met their AYP targets, and only 10 remained in Corrective Action II.

In Vermont, school districts are using EETT funds to develop local student data systems or to join the statewide Vermont Data Consortium which is working with the Department of Education to create a statewide Education Data Warehouse. These data efforts support teachers using data to inform instruction and facilitate reporting of AYP data.

States are finding that as they make more and more data available, teachers need help in understanding and using this data to inform their teaching and to help individualize and improve student learning. A good example of this is in the Blackfoot School District in Idaho where EETT funds are used with particular attention to K–12 mathematics. Through this program, teachers use data to identify student needs and then use technology to meet these needs. They are also able to provide ongoing professional development for teachers that otherwise would have been impossible without the Title II D funds.

Maryland is using EETT funds for curriculum management systems. If a child is not mastering certain standards, this provides them with lesson plans and remediation activities to help get them up to par.

## HELPING TO CLOSE THE ACHIEVEMENT GAP

*Key Facts*

The requirement for EETT funds to be targeted to high need districts ensures that students who are most at risk will benefit from additional opportunities. EETT funds are helping to close the achievement gap by providing students with access to software, web courses, and virtual learning opportunities that are aligned to state standards. This is particularly important in areas where teachers in certain disciplines are difficult to find, such as foreign language, Advanced Placement (AP), or higher level science and math courses. With access to online opportunities, students in rural or high need areas have opportunities similar to other students in the state.

Many states have steered EETT funds to core-curricular areas, such as reading, math and science, by establishing content priorities in their competitive grant processes: 74 percent of states created funding priorities in reading or writing, while 38 percent focused on mathematics.

*Examples*

The Missouri eMINTS program provides classrooms with advanced software, intense professional development and Internet access to support standards-based in-

struction. Three years of data from a quasi-experimental evaluation of the eMINTS program showed a significant improvement in third and fourth grade achievement on the Missouri Assessment Program (MAP) test results for African Americans. The study also noted that the achievement gap was closed between those African American students who participated in the program and White students who did not. The success of the eMINTS program is now being replicated in the state of Utah.

Researcher Dale Mann (ASBO, 2003) cited a direct correlation between pupil performance and technology in instruction through West Virginia's Basic Skills/Computer Education program. The study found that while per capita income had not changed between 1991 and 1998, the infusion of technology was the single factor that accounted for the state moving from 33rd among the states for student achievement to 11th.

In Virginia, EETT funds have been used to develop an online Advanced Placement school. This program provides benefits to Virginia's students who are most in need, primarily rural and urban students, who otherwise would not have access to AP teachers or courses. A similar West Virginia project provides foreign language opportunities using online technologies. Preliminary findings through a scientifically-based research evaluation indicate that courses delivered online are as effective as courses delivered face to face—expanding the opportunities for closing the achievement gap between students in remote areas.

In region 4 of New York City, EETT funds have allowed student access to Cyber English, Social Studies, Math and Science classes. High schools are no longer limited by time and space and learning has become a 24/7 activity. This model has improved school attendance, engaged previously uninterested students, allowed students from diverse neighborhoods to collaborate, and finally provided parents a vehicle for becoming involved in their teenager's education.

In North Carolina, the cuts will result in a limitation on nine very successful Community Technology Learning Centers. These centers have offered after-school and weekend programs for needy students and their parents. Most of these centers will either close or drastically scale back their services without EETT funding.

North Dakota has established a rural consortium to implement the "Unified Education Project (UEP), which focuses on creating individualized learning plans for each student based on his or her strengths and weaknesses. Using an electronic portfolio, the UEP helps teachers track needs and provide appropriate instruction and remediation, allows the students to view standards and expectations and assess their own work accordingly, and encourages parent communication. The UEP allows for individualized instruction to ensure that schools and districts can meet AYP.

#### IMPROVING TEACHER TRAINING, RETENTION, AND RECRUITMENT

##### *Key Facts*

EETT requires that at least 25 percent (\$147,000,000) of all EETT funds be used for professional development purposes, although most states use considerably more. EETT funds help to increase the access by providing online options that give teachers anytime, anyplace access to quality professional development. This is critical to ensure that teachers have the opportunity to increase content knowledge, improve instruction, and become highly qualified teachers.

##### *Examples*

Algebra I is often a predictor for success in high school and beyond. Louisiana implemented an on-line Algebra I course to provide additional opportunities for student achievement. Preliminary evaluations indicate that students in the on-line course, with similar pre-test scores are showing more significant achievement gains compared to the control group as indicated below:

Group	Pre-test (fall) mean	Post-test (spring) mean
Algebra I Online Students .....	13.3	17.2
Control Students .....	13.4	15.6

In Nevada, a middle school science partnership is beginning to show evidence of closing the achievement gap in participating schools. The partnerships between the University of Nevada, Reno and five rural Nevada school districts provides professional development to teachers to make them better able to assess their students and use technology to increase student achievement in math. The ability of these teachers to have access to the rigorous university research and the professional development to effectively bring about increases in student achievement in science.

The North Carolina IMPACT Model Schools Grant provides personnel, connectivity, hardware, software, and professional development to impact teaching and learning to improve student achievement in participating elementary or middle schools. One initial finding from this evaluation is that participating schools have dramatically improved their ability to attract and retain teachers. Teachers who are scheduled to retire often choose to stay in these IMPACT schools, others request transfers into them, and new teachers clamor to be hired. "These teachers like the way technology is changing the way they teach, and the enthusiasm with which their students approach learning," says Frances Bryant Bradburn, Director of Instructional Technology for the North Carolina Department of Public Instruction.

In the center of Wyoming, there are many small, rural school districts that do not have the capacity to create aggressive staff development plans. The local Board of Cooperative Education Services formed a partnership between six districts focused on helping teachers to improve instruction through learning environments. For the first time, classes are using smart boards, establishing wireless connections, conducting Internet research, and attending compressed video classes.

In Massachusetts, reports from independent evaluators of the EETT grant projects and the year-end reports submitted by grant recipients show substantial improvement in teacher technology literacy. The use of the state's online interactive Technology Self-Assessment Tool (TSAT) helps in measuring the progress of teachers' technology skills in the different levels. For example, in a Gloucester Public Schools' project, there was an increase from 8.5 percent to 27 percent in the number of educators at the Proficient level and a decrease from 33.5 percent to 20 percent in number at the Early Technology level (the lowest level).

Iowa utilized EETT funds to implement comprehensive professional development programs for teachers targeted at core subject areas. Initial results from one consortium focusing on mathematics demonstrate an increase in student achievement among 4th grade students compared to the control group. Iowa is seeing similar results in reading throughout the state.

#### IMPACT OF CUTTING EETT

Education technology is about more than technology—it's about education. The EETT program supports every tenet and goal of the No Child Left Behind Act. It would be impossible to effectively implement NCLB without the technical expertise and leadership the EETT program brings. As representatives of the states and districts who make the most critical use of educational technology, we urge you to restore the funding to \$692 million, the funding level that was in place before the Omnibus appropriations in November 2004.

Not only does EETT help improve student achievement through technology, it is an efficient use of federal funds. Dale Mann (ASBO, 2003) notes that districts have two options when trying to increase reading scores by one month in grade-level gains: decreasing class size or utilizing technology. Class-size reduction would cost approximately \$636 per student per year compared to \$86 for instructional technology. EETT provides additional opportunities to help increase student achievement.

The targeted funds for educational technology that are available through the EETT program are still very much needed as we work to ensure that all students are ready to compete in the global economy. It is unrealistic to assume that these technology funds and the leadership and innovation that accompany them would be effectively managed through other existing education title programs such as Title I and Title IIA. These Title programs have not received additional funds to pay for the mission critical technology components of their initiatives. Other Title programs, unlike EETT, support narrowly defined student populations and training purposes rather than the broader mission of supporting all students and all programs as EETT currently does. Finally, the leadership and expertise needed to implement successful data driven decision making, curriculum management systems, online professional development, and reporting processes for NCLB would be lost if there was an attempt to subsume educational technology planning and implementation under these already established programs.

About SETDA—<http://www.setda.org>

The State Educational Technology Directors Association (SETDA) is the principal association representing the state directors for educational technology. SETDA's membership includes educational technology directors and staff from the state departments of education of all fifty states, the District of Columbia and American Samoa.

PREPARED STATEMENT OF THE NATIONAL EDUCATION KNOWLEDGE INDUSTRY  
ASSOCIATION

NEKIA appreciates the opportunity to inform the Subcommittee of NEKIA's appropriations proposals for fiscal year 2006. The mission of our association is to advance the development and utilization of research-based knowledge for the improvement of the academic performance of all children. NEKIA's members are committed to finding new and better ways to support and expand high-quality education research, development, dissemination, technical assistance, and evaluation at the federal, regional, state, tribal, and local levels.

Our appropriations proposals seek greater federal investments that will support the use of research-based knowledge in America's K-12 classrooms and spur the implementation of the No Child Left Behind Act and the Education Sciences Reform Act. These two laws ushered in a new era of evidence-based education in which classroom teachers are required to use instructional practices based on scientifically based research. Our proposals for fiscal year 2006 are also designed to address both greater demand for evidence-based education and under-funded supply.

NEKIA'S PROPOSALS ARE BASED ON THREE CRITICAL POINTS

1. *Now is the time to enhance and expand the federal system of education research, development, dissemination, and technical assistance.*—Federally supported programs—specifically the Regional Educational Labs, the R&D Centers, the Comprehensive Centers and Comprehensive School Reform—are playing a vital role in meeting the tremendous needs for research-based practices and technical assistance. Each of these programs fills a unique role in the spectrum of knowledge utilization—from basic research to applied research, from development and dissemination to technical assistance, and ultimately student achievement. Given that more than 20,000 U.S. public schools are not making adequate yearly progress and 10,000 schools are in need of improvement under the No Child Left Behind Act, we must become more aggressive in using research-based education solutions in the classroom.

NEKIA's members are fully supporting the implementation of No Child Left Behind through applied research, development, dissemination, technical assistance, and evaluation programs. For example:

2. *Current federal support for education research, development, dissemination, and technical assistance lags far behind other federal research investments.*—While the No Child Left Behind Act clearly requires educators to use instructional practices and innovations supported by research, the Department of Education spends less than one percent of its budget on research, development, and statistics. Education is a \$745 billion industry representing an estimated 7.2 percent of the gross domestic product. However, only 0.03 percent is spent on research and development. That is only three cents for every hundred dollars spent on education. In comparison, other agencies' R&D budgets as percentage of their discretionary spending: Defense, 17 percent; NASA, 68 percent; Energy, 37 percent; HHS, 42 percent; NSF, 74 percent; and Agriculture, 4.6 percent. In other words, the Department of Education's research budget has been and remains among the smallest of any federal agency.

3. *To address this capacity crisis we urge Congress to double its investments in education knowledge utilization over the next 3 years.*—Not only would increased investments help meet demand, they would also address a number of high priorities such as:

- Improving teacher quality by providing research based information on best practices to teacher training institutions as well as information and technical assistance to schools districts implementing professional development programs.
- Helping special populations of students meet state adequate yearly progress goals. These special populations include English language learners, special needs children, and students in rural areas.
- Working with educators to interpret and manage a variety of data about student performance and classroom instruction.
- Scaling up school improvement efforts at the local level so that reform efforts in single schools can expand to districtwide initiatives.

To adequately respond to the capacity crisis and meet these priorities, NEKIA proposes the following investments:

*Priority Investment.—Fund the Regional Educational Laboratories at \$70 million—an increase of \$3 million over fiscal year 2005*

The Regional Educational Laboratories are the nation's key institutions for applied education research and development that respond to the needs of educators and policy makers. A 2000 Department of Education independent evaluation found

that educators considered the labs among the most trusted institutions in the nation for research support and reported they were highly responsive to customers. They are also highly responsive to local and regional needs. Regional governing boards—representing educators, parents, and businesses from each state of each lab region—set research and development priorities for each lab. The ability to respond to customers in their regions helps keep the laboratories' work focused on real world needs and creating valid research, development, tools and assistance in the successful implementation of the No Child Left Behind Act. Without the Regional Labs, the chain is broken. Without the regional labs, the link between basic research and technical assistance would cease to exist.

Unfortunately, the Regional Education Lab program is at risk. The President's budget for fiscal year 2005 proposes to eliminate funding for the program. Last year, the Administration proposed eliminating the labs. Fortunately, Congress acted in a bipartisan way to fund it. We hope Congress will do so again for fiscal year 2006.

*Priority Investment.—Fund the Research and Development Centers (included in the Research, Development, and Dissemination Line) at \$170 million—an increase of \$5 million over fiscal year 2005*

The centers address enduring issues of national significance in education through sustained and focused research programs. They address specific topics such as early childhood development and learning, student learning and achievement, at-risk students, adult learning, and education policy. The research done by the R&D centers is used by regional labs to develop programs, strategies and assessment tools which in turn are adapted by technical assistance providers (Comprehensive Centers) for the training and tools to implement their own programs to assist districts and schools.

*Priority Investment.—Fund the Comprehensive Regional Assistance Centers at \$60 million—an increase of \$3 million over fiscal year 2005*

The purpose of Title II of the Education Sciences Reform Act (ESRA) and specifically the newly reformed Comprehensive Centers program authorized within it, is to serve as part of a national technical assistance and dissemination system, which provides comprehensive technical assistance services to states, districts, tribes and schools in administering and implementing school reform efforts under No Child Left Behind. Their focus is to help schools and districts improve opportunities for all children to meet content and performance standards. Next year (fiscal year 2006), the 20 new centers will be fully operational. The new centers will include the scope of work of the current Comprehensive Regional Assistance Centers, the Eisenhower Regional Mathematics and Science Consortia, and the Regional Technology in Education Consortia.

*Priority Investment.—Fund the Comprehensive School Reform program at \$233 million—an increase of \$30 million over last year*

Comprehensive School Reform targets the neediest schools. Forty-five percent of CSR schools have poverty rates of 75 percent or greater—almost double the rate of Title I schools. And, almost half (46 percent) of CSR schools are low performing at the time of funding. CSR schools have baseline achievement scores lower than Title I school wide programs (in reading and math) at the time of funding. Finally, CSR Schools address the whole school and are more likely to use research-based models and measurable goals for student performance. Unfortunately, the Comprehensive School Reform program is at risk. The President's budget for fiscal year 2005 proposes to eliminate funding for the program. We hope Congress will act in a bipartisan fashion to preserve it.

NEKIA is very heartened by the continuing interest Congress shows in the work of our member organizations to provide the research-based tools our children and teachers need to succeed. If we are to ensure even greater success for all our children, we must increase the federal investment in knowledge utilization efforts.

Thank you. We appreciate your consideration of our proposals.

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PREPARED STATEMENT OF THE SCIENCE, TECHNOLOGY, ENGINEERING, AND  
MATHEMATICS (STEM) EDUCATION COALITION

On behalf of the science, technology, engineering, mathematics, education and business groups listed here, we thank you for your efforts to secure \$179 million for the fiscal year 2005 Math and Science Partnership program at the U.S. Department of Education (ED). The STEM (Science, Technology, Engineering, and Mathematics) Education Coalition greatly appreciates your continued support to improve STEM education at all levels.

It is imperative that the work continues and additional funding be provided to the ED MSPs so we can ensure that all students receive a world-class education in science and math. We understand in these tight fiscal times, Congress is unable to provide the NCLB authorization of \$450 million for the MSPs, but we do support substantial increases in order to prepare for the science assessments that will be required in 2007. Therefore, we urge you to support the President's request of \$269 million for the fiscal year 2006 Math and Science Partnerships under Title II, Part B of NCLB.

Additionally, we urge you to oppose the creation of a new initiative that would redirect \$120 million of the funds away from the ED state-based MSP programs to create a new federal grant program. This would require a change to the NCLB statute, cut funds to the states, and greatly reduce state flexibility to meet their most critical needs.

Funding for the ED MSPs goes directly to the states as formula block grants. States provide these funds through competitive grants to local partnerships of schools, higher education institutions and others for reform efforts to meet the NCLB math and science education obligations. Most grants go to high-need districts so they can strengthen teacher professional development and increase student performance in science, mathematics, and technology.

In summary, we strongly urge Congress to fund the fiscal year 2006 ED Math and Science Partnerships at \$269 million and to oppose efforts to redirect \$120 million of these funds away from the states.

If we can provide any additional information or answer questions, please contact Patti Curtis at 202.785.7385.

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#### PREPARED STATEMENT OF TEACH FOR AMERICA

Mr. Chairman, Senator Harkin and Members of the Subcommittee: Thank you for the opportunity to submit testimony regarding the President's fiscal year 2006 budget proposal, which includes \$4 million for Teach For America under the Corporation for National and Community Service. Mr. Chairman and Senator Harkin, I applaud your commitment to national service and desire to help AmeriCorps realize its full potential.

I would like to take this opportunity to discuss Teach For America and our current growth plans. I will also focus on the \$4 million line item in the President's fiscal year 2006 budget under the Corporation for National and Community Service and explain why it is critical to Teach For America's ability to grow to scale.

As you know, Teach For America is the national corps of outstanding recent college graduates of all academic majors who commit 2 years to teach in urban and rural public schools and become lifelong leaders in the effort to ensure that all children in our nation have an equal chance in life. We are a private, national non-profit organization, as well as one of the original AmeriCorps programs. Our teachers receive a salary from their local school district as well as education awards through AmeriCorps. These education awards can be used for graduate level education courses necessary to obtain teacher certification, to pay back qualified student loans, or for future education.

Since 1990, when I founded Teach For America, our organization has grown from 500 corps members teaching in 5 regions to what will soon be 3,200 corps members teaching in 22 regions during the 2005–2006 school year. Teach For America corps members are having an impact throughout our nation, from St. Louis to Philadelphia, and from New Mexico's Navajo Nation to the Rio Grande Valley in South Texas.

#### TEACH FOR AMERICA MEETS CRITICAL NEEDS

Our mission is to build a movement to eliminate the educational inequality that exists in our country today. By the age of nine, children in low-income areas are already three grade levels behind in reading ability (Source: National Center of Education Statistics, 2000). As these children progress in the educational system, this achievement gap only widens, to the point that a child who grows up in a low-income community is seven times less likely to graduate from college than a child growing up in a more privileged area (Source: Education Trust, 1998).

Our corps members help close the achievement gap for the students they reach during their 2-year commitment. At the same time, they gain insight and added commitment that shapes them into an important leadership force, working from inside of education and from other sectors, for long-term change.



## OUR PROGRAM

We recruit the most highly sought-after college graduates of all academic majors, career interests, and backgrounds from leading colleges and universities. We then select corps members who demonstrate records of achievement and leadership, as well as a commitment to expanding opportunity for children in low-income areas.

Admission to Teach For America is highly selective, with approximately 12 percent of our applicants gaining admission to the corps. Of our 2004 corps members, 93 percent held leadership positions on their campuses or in their communities. They earned average SAT scores of 1,310 and average GPAs of 3.5. In addition, 31 percent of corps members are people of color.

This year, 17,319 young people applied for only 2,000 slots as first year teachers. At many top schools, Teach For America is considered one of the most prestigious post-graduate opportunities. This year, 12 percent of Spelman's senior class applied to the corps. And at top, larger universities, Teach For America attracted significant portions of the student body: 12 percent of Yale's seniors applied, as did 8 percent of seniors at Princeton and Harvard. All are competing for the opportunity to teach in America's neediest schools.

Corps members are selected into Teach For America if they demonstrate strong leadership characteristics such as achievement orientation, critical thinking, personal responsibility for success, and the ability to influence and motivate others, as well as high expectations for students and families in low-income communities and the desire to work relentlessly toward this particular mission.

Those selected attend a summer training institute where corps members teach in local public summer schools and participate in a full afternoon and evening schedule of professional development activities. We aim to ensure that corps members internalize the overarching approach utilized by the most successful teachers in urban and rural areas; and that they gain skills in instructional planning and delivery; building a strong classroom culture; literacy development; and teaching the specific content-area and grade-level they will be teaching.

Following the institute, corps members assume teaching positions in school districts in 22 urban and rural areas. They are clustered in schools and receive extensive ongoing support and professional development through Teach For America and through local teacher education programs.

Following their 2-year commitments, corps members can remain in teaching (and about 60 percent teach for at least a third year). We expect that they will ask themselves how they can have the greatest possible impact on the challenges they and their students experienced during their 2 years, and we provide a network of resources and support that they can tap into as they continue working in educational and social reform throughout their lives.

## IMMEDIATE IMPACT ON COMMUNITIES AND STUDENT ACHIEVEMENT

Our success in recruiting and preparing exceptional classroom teachers has led education policy makers to highlight our impact on disadvantaged communities. Teach For America corps members impact the academic prospects of their students during their first 2 years in the classroom and continue to impact the quality of education in low-income communities beyond their initial commitments.

A 2004 independent study by Mathematica Policy Research, Inc revealed Teach For America corps members in elementary grades affected greater gains than would typically be expected in a year. The study also showed corps members even outpaced fully certified and veteran teachers in their schools in moving their students ahead academically. To put corps members' value-added in context, Mathematica concludes the impact of having a Teach For America teacher compared to a non-Teach For America teacher (including veteran and certified teachers) is 65 percent of the impact of reducing class size from 23 to 15 students (and is substantially less expensive). The impact of having a corps member versus another novice teacher is greater than the impact of reducing class size by eighty students. This study essentially replicated the results from an earlier study on Teach For America's impact by Stanford's Center for Research in Education Outcomes.

Another way we evaluate corps member impact is through a bi-annual survey of principal satisfaction conducted by Kane, Parsons & Associates, Inc., an independent research firm. In a June 2004 survey by Kane, Parsons & Associates, principals credit Teach For America teachers as having positive effects on their schools and on student achievement. Nearly three out of four principals reported that corps members are more effective than their other beginning teachers. And principals rated corps members as good or excellent on multiple indicators of effective teaching, including:

—90 percent—Instructional planning

- 95 percent—Motivation and dedication to teaching
- 96 percent—Achievement orientation and drive to succeed
- 93 percent—Working with other faculty and administrators
- 92 percent—Having high expectations for students; and
- 93 percent—Assuming responsibility for student achievement.

#### LONG-TERM IMPACT

Teach For America is building a force of leaders and citizens with a lifelong commitment to addressing the issues they witness during their 2 years of service. Education Week, a leading national journal of K–12 education, profiled Teach For America’s alumni in an article titled “Most Likely To Succeed” and called Teach For America a “leader-making machine.”

According to a survey conducted in the fall of 2004, our alumni are deeply influenced by their Teach For America experience:

- Nationally, 63 percent of our alumni are working full-time in education, 39 percent as K–12 teachers and 28 percent as administrators, 4 percent in higher education, and 9 percent in education-related non-profits and other positions in the field of education; and
- Nearly 200 Teach For America alumni have founded a school or a non-profit organization.

Even more striking is the extent to which Teach For America alumni have already assumed leadership in the broader effort to improve education—they are running many of the most highly acclaimed charter schools in the country; they are turning around major urban schools as principals; they are winning some of the highest accolades teachers can win (as state and city teachers of the year); they are serving on school boards and advising Governors and Members of Congress on education policy; and they are leading model education reform, public health and economic development initiatives.

#### TEACH FOR AMERICA NEEDS INCREASED FUNDING TO GROW TO SCALE

Teach For America is in the midst of a 5-year expansion plan to more than double the size of its teacher corps. Currently, Teach For America has over 3,000 teachers in 22 communities and a budget of under \$39 million. In the 2006–2007 school year, Teach For America will have nearly 3,500 corps members and will need to raise a budget in excess of \$50 million. At that scale, Teach For America teachers will reach more than 300,000 public school students every day in this country’s lowest-income neighborhoods.

Seventy-five percent of our funding comes from private sources, much of it from the local communities where our teachers teach. We have a highly diversified base of more than 2,000 private donors from all over the country. Top donors include Don and Doris Fisher’s Pisces Foundation; the Broad Foundation; New Profit; the Atlantic Philanthropies; and Wachovia Corporation.

To raise our expanded budget, we must significantly increase our private funding base while growing our federal funding proportionately. With adequate federal funding, we can expand to reach more communities and engage more recent college graduates while continuing to provide highly qualified teachers for America’s neediest classrooms. The Corporation for National and Community Service’s \$4 million fiscal year 2006 budget line item would allow us to maintain our current ratio of federal to private funding and enable us to execute our growth plan.

#### CONCLUSION

I hope you will agree that we have demonstrated all the characteristics of an exemplary AmeriCorps program: we recruit talented young people into competitive positions in critical areas of public need; we have a significant impact in the communities we serve; we influence the civic commitment and career path of our corps members; and we leverage our public support for significant private resources. As we continue our efforts to more than double in size and reach hundreds of thousands of children each year, we seek your support so that Teach For America can expand its scale and impact. Mr. Chairman and Members of the Subcommittee, we hope you will support the President’s request for \$4 million for Teach for America in the fiscal year 2006 budget.

## PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

## SUMMARY OF REQUEST

For 36 years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from throughout the nation. Our request for fiscal year 2006 funding for tribally controlled postsecondary vocational institutions as authorized under Section 117 of the Carl Perkins Vocational and Applied Technology Act is:

- \$8.5 million under Section 117 of the Perkins Act, which is \$1.1 million over the fiscal year 2005 enacted level of \$7,406,250. This funding is essential to our survival, as we receive no state-appropriated vocational education monies.
- Ensure that the provision that has been included since fiscal year 2002 in the Labor-HHS Education Appropriations Acts that waived the regulatory requirement that we utilize a restricted indirect cost rate is continued.
- Funding for renovation of our facilities, many of which are original to the Fort Abraham Lincoln army installation. A recent study commissioned by the Department of Education shows a facility need for UTTC of \$49 million.
- We support the recommendations of the American Indian Higher Education Consortium, including \$32 million for the Strengthening Developing Institutions Program for tribal colleges (Section 316).

## RESTRICTED INDIRECT COST ISSUE

Beginning in fiscal year 2002 the Labor-HHS-Education Appropriations Act provided that notwithstanding any law or regulation, that Section 117 Perkins grantees are not required to utilize a restricted indirect cost rate. We thank you for taking this action, and ask that it be continued in the fiscal year 2006 Act. We also point out that the pending Perkins reauthorization bills, S.250 and H.R. 366, contain a provision that would exempt Section 117 grantees from the requirement to utilize a restricted indirect cost rate.

In 2001, the Department of Education, for the first time, directed Indian grantees (both Section 116 and 117 grantees) to apply a “restricted indirect cost rate” to their grants. This means each tribal grantee must obtain another indirect cost rate—exclusively for its Perkins Act grant—from its cognizant federal agency (which in most cases is the Inspector General for the Department of the Interior.)

The Department gave two reasons for applying a restricted rate to these Perkins Act Indian programs: (1) The 1998 Amendments to the Perkins Act (Sec. 311(a)) prohibits the use of Perkins Act grant funds to supplant non-federal funds expended for vocational/technical programs. This “supplement, not supplant” limitation previously applied to State grants, only; and (2) A long-standing Department of Education regulation (promulgated years before the 1998 Perkins Amendments) automatically applies the restricted indirect cost rate requirement to any Department of Education grant program with a “supplement, not supplant” provision.

UTTC has no quarrel with the bases and objectives of the “supplement, not supplant” rule and seeks no change to this statutory provision. The primary targets of this rule are States and possibly local government entities that run vocational education programs with State or local funds.

By contrast, however, UTTC has little or no ability to violate this rule, as we have no source of non-federal funds to operate vocational education programs. Unlike States, we have no tax base and no source of non-federal funds to maintain a vocational education program. We depend on federal funding for our vocational/technical education program operations. Despite our inability to violate the supplanting prohibition, we are, nonetheless, being disadvantaged by a Department of Education regulation intended to enforce the prohibition against States who do have the ability to supplant.

—*Impact of new requirement on grantees.*—Under DoEd regulations, a “restricted indirect cost rate” makes unallowable certain indirect costs that are considered allowable by other federal programs. Primarily, these are costs that DoEd believes the grantee would otherwise incur if it did not receive a Perkins grant, such as the cost of the grantee’s chief officer and heads of departments who report to the CEO, as well as the costs of maintaining offices for these personnel.

Prohibiting the Perkins grant from contributing its appropriate share to the grantee’s indirect cost pool will most likely mean that other federal programs operated by the grantee would be expected to pick up a great share of the indirect cost pool. This outcome may well result in objections from the other program agencies that do not want to bear costs properly attributable to the Perkins grant.

We are caught between conflicting federal agency requirements and will find ourselves unable to recover the necessary share of indirect costs attributable to each of the federal programs we operate.

#### UTTC PERFORMANCE INDICATORS

UTTC has:

- An 85 percent retention rate
- A placement rate of 95 percent (job placement and going on to 4-year institutions)
- A projected return on federal investment of 11 to 1 (2003 study comparing the projected earnings generated over a 29-year period of UTTC Associate of Applied Science graduates with the cost of educating them.)
- The highest level of accreditation. The North Central Association of Colleges and Schools has accredited UTTC again in 2001 for the longest period of time allowable—10 years or until 2011—and with no stipulations. We are also the only tribal college accredited to offer on-line associate degrees.

*The demand for our services is growing and we are serving more students.*—For the 2003–2004 school year we enrolled 661 Indian students. For the 2004–2005 school year we enrolled 753 Indian students, for an increase of 13 percent over the prior year. The 753 Indian students we enrolled are from 54 tribes and 22 states. The majority of our students are from the Great Plains states, an area that, according to the 2001 BIA Labor Force Report, has an Indian reservation jobless rate of 75 percent. UTTC is proud that we have an annual placement rate of 95 percent. We hope to enroll 2000 adult students by 2008.

In addition, as of the 2004–2005 year, we have served 257 students in our Theodore Jamerson Elementary school, and 226 children in our infant-toddler and preschool programs.

The total population for whom we provided direct services to in the 2004–2005 academic year is 1,236. This is an increase in our overall total population of 17 percent from the 2003–2004 school year.

*UTTC course offerings and partnerships with other educational institutions.*—We offer 17 AAS degrees, 5 of which have been approved to be offered on-line, and 11 certificate degrees. We are accredited by the North Central Association of Colleges and Schools. Our course which has the highest number of students is the Licensed Practical Nursing program.

We are very excited about the recent additions to our course offerings, and the particular relevance they hold for Indian communities. These programs are: (1) Injury Prevention, (2) On-Line Education, (3) Nutrition and Food Services, (4) Tribal Government Management, (5) Tourism, and (6) Tribal Environmental Science.

*Tribal Environmental Science.*—Our newest course offering is Tribal Environmental Science. It is being established through a National Science Foundation Tribal College and Universities Program grant. The 5-year project will support UTTC in planning and implementing an innovative environmental science program. The program is slated to be developed by this summer, beginning with a three week intense student skill-building program. The course work will lead to a 2-year associate of applied science degree in Tribal Environmental Science.

*Injury Prevention.*—Through our Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the U.S. population. We received assistance through Indian Health Service to establish the only degree-granting Injury Prevention program in the nation. Injuries are the number one cause of mortality among Native people for ages 1–44 and the third for overall death rates.

*On-Line Education.*—We are working to bridge the “digital divide” by providing web-based education and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites and as well as to students on our campus. This semester have 45 students, a number of whom are campus-based, taking on-line courses. We are accredited by the North Central Association of Colleges and Schools to provide on-line associate degrees. This approval is required in order for us to offer federal financial aid to students enrolled in these on-line courses.

On-line courses provide the scheduling flexibility students need, especially those students with young children. Our on-line education is currently provided in the areas of Early Childhood Education, Injury Prevention, Health Information Technology, Nutrition and Food Service and Elementary Education. We are the only tribal college accredited to offer on-line associate degrees.

*Computer Technicians.*—In the second year of implementation, the Computer Support Technician program is at maximum student capacity. In order to keep up with

student demand, we will need more classrooms, equipment and instructors. Our program includes all of the Microsoft Systems certifications that translate into higher income earning potential for graduates.

*Nutrition and Food Services.*—UTTTC will meet the challenge of fighting diabetes in Indian Country through education. As this Subcommittee knows, the rate of diabetes is very high in Indian Country, with some tribal areas experiencing the highest incidence of diabetes in the world. About half of Indian adults have diabetes (Diabetes in American Indians and Alaska Natives, NIH Publication 99-4567, October 1999).

We offer a Nutrition and Food Services Associate of Applied Science degree in an effort to increase the number of Indians with expertise in nutrition and dietetics. Currently, there are only a handful of Indian professionals in the country with training in these areas. Future improvement plans include offering a Nutrition and Food Services degree with a strong emphasis on diabetes education and traditional food preparation.

We also established the United Tribes Diabetes Education Center to assist local tribal communities and our students and staff in decreasing the prevalence of diabetes by providing diabetes educational programs, materials and training. We published and made available tribal food guides to our on-campus community and to tribes.

*Tribal Government Management / Tourism.*—Another of our new programs is tribal government management designed to help tribal leaders be more effective administrators. We continue to refine our curricula for this program.

A recently established education program is tribal tourism management. We developed the core curricula for the tourism program and are partnering with three other tribal colleges (Sitting Bull, Fort Berthold, and Turtle Mountain) in this offering. The development of the tribal tourism program was timed to coincide with the planned activities of the national Lewis and Clark Bicentennial in 2003.

*Job Training and Economic Development.*—UTTTC is a designated Minority Business Center serving Montana, South Dakota and North Dakota. We also administer a Workforce Investment Act program and an internship program with private employers.

Economic Development Administration funding was made available to open a "University Center." The Center is used to help create economic development opportunities in tribal communities. While most states have such centers, this center is the first-ever tribal center.

*Upcoming Endeavors.*—We are seeking to develop a Memorandum of Understanding with the BIA's Police Academy in New Mexico that would allow our criminal justice program to be recognized for the purpose of BIA and Tribal police certification, so that Tribal members from the BIA regions in the Northern Plains, Northwest, Rocky Mountain, and Midwest areas would not have to travel so far from their families to receive training. Our criminal justice program is accredited and recognized as meeting the requirements of most police departments in our region.

We are also interested in developing training programs that would assist the BIA in the area of provision of trust services. We have several technology disciplines and instructors that are capable of providing those kinds of services with minimum of additional training. We also provide training in health records technology that fit within the training needs of the Indian Health Service.

*Department of Education Study Documents our Facility/Housing Needs.*—The 1998 Vocational Education and Applied Technology Act required the Department of Education to study the facilities, housing and training needs of our institution. That report was published in November 2000 ("Assessment of Training and Housing Needs within Tribally Controlled Postsecondary Vocational Institutions, November 2000, American Institute of Research"). The report identified the need for \$17 million for the renovation of existing housing and instructional buildings and \$30 million for the construction of housing and instructional facilities.

We continue to identify housing as our greatest need. We have a current waiting list of 64 families. Some families must wait from 1 to 3 years for admittance due to lack of available housing. In 2003-2004, we were forced to find housing off campus for 52 families. In 2004-2005 we housed 105 families off campus, a 50 percent increase over the prior year. In order to accommodate the enrollment increase, UTTTC partners with local renters and two county housing authorities (Burleigh, Morton).

UTTTC has a new 86-bed single-student dormitory on campus. It is already completely full as are all of our other dormitories and student housing. To build the dormitory, we formed an alliance with the U.S. Department of Education, the U.S. Department of Agriculture, the American Indian College Fund, the Shakopee-Mdewakanton Sioux Tribe and other sources for funding. Our new dormitory has

at the same time created new challenges such as shortages in classroom, office and other support facility space. However, more housing must be built to accommodate those on the waiting list and to meet expected increased enrollment. We also have housing which needs renovation to meet safety codes.

Thank you for your consideration of our request. We cannot survive without the basic vocational education funds that come through the Department of Education's Perkins funds. They are essential to the operation of our campus and essential to the welfare of Indian people throughout the Great Plains region and beyond.

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#### RELATED AGENCIES

##### PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters, I speak on behalf of nearly 257 community radio stations and related organizations across the country. Nearly half our members are rural stations and half are minority controlled stations. In addition, our members include many of the new Low Power FM stations that are putting new local voices on the airwaves. NFCB is the sole national organization representing this group of stations which provide service in the smallest communities of this country as well as the largest metropolitan areas.

In summary, the points we wish to make to this Subcommittee are that NFCB:

- Requests \$430 million in funding for CPB for fiscal year 2008, a \$30 million increase over the fiscal year 2006 advance appropriation;
- Requests \$45 million in fiscal year 2005 for conversion of public radio and television to digital broadcasting. Also supports funding for the Public TV interconnection system;
- Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters;
- Requests report language to ensure that CPB utilizes digital funds it receives for radio as well as television needs;
- Supports CPB activities in facilitating programming and services to Native American and Latino radio stations;
- Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the Subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources.

*Community Radio fully supports \$430 million in federal funding for the Corporation for Public Broadcasting in fiscal year 2008.*—Federal support distributed through 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 and are often in communities with very small populations and limited economic bases, thus the community is unable to financially support the station 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.

For the past 29 years, CPB appropriations have been enacted 2 years in advance. This insulation has allowed public broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most importantly, the insulation that advance funding provides "go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting." (House Report 94-245.)

For the last few years, CPB has increased support to rural stations and committed resources to help public radio take advantage of new technologies such as the Internet, satellite radio and digital broadcasting. We commend these activities which we feel provide better service to the American people but want to be sure that the smaller stations with more limited resources are not left out of this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system utilize the new technologies, particularly rural and minority stations.

NFCB commends CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. For example, *Satélite Radio Bilingüe* provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues in Spanish of particular interest to the Latino population. At the same time, *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.

This year CPB funded the establishment of the Center for Native American Public Radio (CNAPR). Based on a comprehensive assessment of the Native American Radio System, CNAPR will develop new funding sources for stations and programming; provide direct services to the Native Radio System; encourage collaborations; and represent the Native Radio System. These stations are critical in serving local isolated communities (all but one are on Indian Reservations) and in preserving cultures that are in danger of being lost. CPB's assessment recognized that ". . . Native Radio faces enormous challenges and operates in very difficult environments." CPB funding is critical to these rural, minority stations. CPB's funding of the Intertribal Native Radio Summit in 2001 helped to pull these isolated stations together into a system of stations that can support each other. The CPB assessment goes on to say "Nevertheless, the Native Radio system is relatively new, fragile and still needs help building its capacity at this time in its development." The Center for Native American Public Radio promises to leverage additional, new funding to ensure that these stations can continue to provide essential services to their communities.

CPB also funded a Summit for Latino Public Radio which took place in September 2002 in Rohnert Park, California, home of the first Latino Public Radio station. These Summits have expanded the circle of support for Native and Latino Public Radio and identified projects that will improve efficiency among the stations through collaborations and explore new ways of reaching the target audiences.

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 support research so that we have a better understanding of how we are serving listeners. And they provide funding to programming, new ventures, expansion to new listeners, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with new distribution technologies and media consolidation. An example of this support is the grant that NFCB received to update and publish our *Public Radio Legal Handbook* online. This provides easy-to-read information to stations about complying with governmental regulations so that stations can function legally and use their precious resources for programming instead of legal fees.

*Finally, Community Radio supports \$45 million in fiscal year 2006 for conversion to digital broadcasting by public radio and television.*—It is critical that this digital funding be in addition to the on-going operational support that CPB provides. The President's proposal that digital money should be taken from the fiscal year 2006 CPB appropriation would effectively cut stations' grants by more than 25 percent. This would have a devastating impact as stations trying to recover from hard economic times. And it would come at a time when the local voices of community and public radio are especially important to notify and support people during emergency situations and to help communities deal with the loss of loved ones—things that commercial radio is no longer able to do because of media consolidation.

While public television's digital conversion needs are mandated by the FCC, public radio is converting to digital to provide more public service and to keep up with what commercial radio is doing. The Federal Communications Commission has approved a standard for digital radio transmission. CPB has provided funding for 301 transmitters in 42 states to convert to digital, is supporting additional research on AM radio conversion, and is working with radio transmitter and receiver manufacturers to build in the capacity to provide a second channel of programming. Most exciting to public and community radio is the encouraging results of tests that National Public Radio has conducted, with funding from CPB, that indicate that stations can broadcast two high-quality signals, even while they continue to provide the analog signal. The development of second audio channels will potentially double the public service that public radio can provide, particularly in service to unserved and underserved communities. This initial funding still leaves more than 500 radio transmitters that will ultimately need to convert to digital or be left behind.

Federal funds distributed by the CPB should be available to all public radio stations eligible for Federal equipment support through the Public Telecommunications Facilities Program (PTFP) of the National Telecommunications and Information Agency of the Department of Commerce. In previous years, Federal support for pub-

lic radio has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public stations. Stations eligible for PTFP funding and not for CPB funding include small-budget, rural and minority controlled stations and the new Low Power FM service.

Community Radio also supports funding for the public television interconnection system. Interconnection is vital to the delivery of the high quality programming that public broadcasting provides to the American people.

We appreciate Congress' direction 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 fiscal year 2000 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 in general, and Community Radio in particular, more important as a local voice than we have ever been. New Low Power FM stations are providing new local voices in their communities. Community radio is providing essential local emergency information, programming about the local impact of the major global events taking place, culturally appropriate information and entertainment in the language of the native culture, as well as helping to preserve cultures that are dying out.

During this time, the role of CPB as a convener of the system becomes even more important. The funding that it provides will allow the smaller stations to participate along with the larger stations which have more resources, as we move into a new era of communications.

Thank you for your consideration of our testimony. If the Subcommittee has any questions or needs to follow-up on any of the points expressed above, please contact: Carol Pierson, President and CEO, National Federation of Community Broadcasters, Telephone: 510 451-8200 Fax: 510-451-8208 E-mail: carol@nfcfb.org

The NFCB is a 30-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, community participation and support. NFCB's 257 members 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 provide alternative programming to 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 KWSO in Warm Springs, Oregon, you will hear morning drive programs in their Native language; throughout the California farming areas in the central valley, Radio Bilingüe programs five stations targeting low-income farm workers; in Chevak, Alaska, on KCUK you will hear the local weather reports and public service announcements in Cup'ik/Yup'ik 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 and night.

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. 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 THE NATIONAL MINORITY PUBLIC BROADCASTING  
CONSORTIA

- National Asian American Telecommunications Association
- National Black Programming Consortium
- Latino Public Broadcasting Project
- Native American Public Telecommunications
- Pacific Islanders in Communications

The National Minority Public Broadcasting Consortia (Minority Consortia) submits this statement on the fiscal year 2008 appropriation for the Corporation for Public Broadcasting (CPB) and CPB's fiscal year 2006 digital conversion funding. Our primary missions are to bring a significant amount of programming from our communities into the mainstream of PBS and public broadcasting. In summary, we ask the Committee to:

- Encourage CPB to increase its efforts for diverse programming with commensurate increases for minority programming and the Minority Consortia;
- Encourage CPB to continue its support for the Native radio system;
- Reject the Administration's proposal to end advance funding for the Corporation for Public Broadcasting;
- Reject the Administration's proposal to divert \$82 million of already-appropriated fiscal year 2006 funds to digital conversion and satellite interconnection and to rescind an additional \$10 million;
- Recommend at least \$430 million for CPB core funding for fiscal year 2008, a \$30 million increase over fiscal year 2007;
- Support CPB's request of \$45 million in fiscal year 2006 funds for digital conversion, but require that some of it be made available to independent producers. Also support CPB request of \$52 million for the interconnection system for public radio and television.

We are dismayed at the Administration's continued proposals regarding public broadcasting. The quality gap between network television and public television has never been wider, and it continues to grow with each new "reality" show. Administration proposals to end forward funding of CPB and to divert already appropriated funds would dramatically reduce the development of programming for public broadcasting.

*Advance Funding.*—We strongly oppose the Administration's proposal that the advance funding for CPB be eliminated, a proposal that would stop CPB funding for two years. We appreciate that Congress has rejected this proposal each of the last four years. Reasons to continue advance funding for CPB include:

- The production of programming for public broadcasting usually takes several years and substantial lead time is needed for planning.
- Public broadcasting programs are supported by multiple funding sources, and two years advance knowledge of the amount of federal funding allows CPB to better leverage its federal funds to bring in other sources of revenue.
- The Minority Consortia administers a significant amount of CPB programming monies, and elimination of advance funding would negatively affect our organizations' planning and fundraising activities.

*Proposed Diversion of Fiscal Year 2006 CPB Funds.*—We are extremely concerned about the Administration's proposal to rescind \$10 million and divert an additional \$82 million of already appropriated fiscal year 2006 CPB funds to digital conversion and satellite interconnection. Such a rescission/diversion of funds would wreck havoc on our organizations and the independent producers that we help support as well as many radio and television stations. We would be faced with a 25 percent reduction of CPB funds should Congress approve this proposal by the Administration.

*CPB Fiscal Year 2008 Appropriation.*—We support a fiscal year 2008 federal appropriation for CPB of at least \$430 million. This 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 they are held.

Public broadcasting, including PBS and NPR, is particularly important for our nation's growing 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 and radio is universally available.

*Digital Conversion Assistance.*—We support CPB's request for \$45 million in fiscal year 2006 funds for digital conversion funding for CPB.

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 face these new, higher costs.

Part of the equation in bringing more high quality diverse programming to public broadcasting is that independent producers be able to transition to digital production. Federal funding for digital conversion should include assistance for independent producers.

*About the National Minority Public Broadcasting Consortia.*—With primary funding from the Corporation for Public Broadcasting, the Minority Consortia serves as an important component of American public television. By training and mentoring the next generation of minority producers and program managers we are able to ensure the future strength of public television and radio television programming from our communities. Individually, each Consortia organization is engaged in cultivating ongoing relationships with the independent producer 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.

Through our outreach we help bring an awareness of the value of public media among communities which have historically been untapped by public television. Through innovative outreach campaigns, local screenings of works destined for public television, and promotion of web-based information and programming, communities of color are embraced rather than ignored. The Minority Consortia's work in educational distribution further increases the value of public television programming by sharing its works with thousands of students.

While the Consortia organizations work on projects specific to their communities, the five organizations also work collaboratively. One example is our joint effort on the public television four-part series, *Matters of Race* that aired in the Fall of 2003. That series explored the complexity of our rapidly changing multiracial, multicultural society in America. The project resulted in more than television programming. The project was designed so that modules could be pulled out for classroom use. It was also formatted for radio broadcast and for the internet, and included extended interviews. This project provided a great opportunity for extensive and diverse community outreach and collaboration throughout its development, distribution, and use.

We also worked with American Public Television on 6 one-hour programs (named *Colorvision*) featuring the work of Native American, Asian American, Pacific Islander, Latino and African American filmmakers and television producers. It is now in national distribution for all public television stations.

The programming we, both as individual organizations and collaboratively, help bring to public television is beyond the production reach of most local television stations. We support the bill's proposal for increased funding for the production of local programming but believe there is also a great need for increased funding for major programming efforts such as those we and other independent producers undertake.

From 1997 to 2002, the Minority Consortia delivered over 88.5 hours of quality public television programming. Collectively, we have also funded 250 projects and 440 producers/directors. These accomplishments have been recognized with over 123 prestigious national and regional awards, including numerous Emmys. While most of our work is focused on film, of note is that the Native American Public Telecommunications (NAPT) also works in the area of public radio. NAPT developed the Native American public radio satellite network (AIROS) that provides live radio streaming 24 hours a day to over 70 Native American and mainstream public radio stations in the United States (including Alaska).

*CPB Funds for the Minority Consortia.*—The National Minority Public Broadcasting Consortia currently receives funds from two portions of the CPB budget, organization support funds from the Systems Support and programming funds from the Television Programming sections. CPB financial support is critical to the work of our organizations. We believe that we make a major contribution to public broadcasting with a very modest amount of funding, but there is so much more that should be done.

The organizational support funds we receive from CPB are used not only for operations requirements but for also for a broad array of programming support activities and for outreach to our communities. We received \$2 million in fiscal year 2005 CPB funds for organizational support (\$400,000 for each organization). This represents 0.51 percent of the fiscal year 2005 CPB appropriation. We have received only very small increases in operations support funds in the past several years.

The programming funds we receive from CPB are re-granted to producers, used for purchase of broadcast rights and other related programming activities. Each organization solicits applications from our communities for these programming funds.

We received \$3.1 million in fiscal year 2005 CPB funds for programming (\$636,363 for each organization). This represents 0.81 percent of the fiscal year 2004 CPB appropriation. Our CPB programming funds have remained virtually flat over the past nine years, despite increases in CPB appropriations.

The Minority Consortia works closely with CPB. We value our relationship with CPB and appreciate the financial and technical assistance provided to us by that organization. We do not doubt CPB's commitment to increasing the diversity of programming on public television and radio but also believe they can do more with the resources at hand. The oft-stated commitment of CPB and Congress for increased multicultural programming combined with seven years of funding increases should translate into significant progress. We ask this Committee to urge CPB to increase its support for the Minority Consortia as part of an effort to bring more quality multicultural programming to public television.

*Native Radio.*—Native American Public Telecommunications—one of the five Minority Consortia organizations—works with both the radio and television sides of public broadcasting. NAPT operates American Indian Radio on Satellite (AIROS) which distributes programming to Native-owned and other radio stations. Koahnic Broadcasting Corporation, headquartered in Alaska, also produces and distributes Native American programming.

Native-owned radio is the fastest growing area of community radio. There are currently 33 Native-owned stations, all but one of which is located in Indian country. We greatly appreciate CPB's central role in the establishment late last year of the Center for Native American Public Radio (CNAPR), an organization that will provide technical and other services to Native radio stations. CNAPR's mission also includes developing new sources of revenue for the Indian radio system and being an advocate for Native radio. CPB is providing \$1.5 million over a three-year period for CNAPR.

We ask that this Committee urge CPB to continue its support for Native radio.

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 thank you for your long time support of our work on behalf of our communities.



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