FYI from the NHLBI



Public Interest News from the National Heart, Lung, and Blood Institute

Volume 3, Issue 3, December 2002

The NHLBI is one of the National Institutes of Health, an agency of the U.S. Department of Health and Human Services

Organizations Partner with the NHLBI to Spread The Heart Truth

The NHLBI, in partnership with the U.S. Department of Health and Human Services Office on Women's Health, the American Heart Association, WomenHeart: the National Coalition for Women with Heart Disease, and other organizations committed to the health and well-being of women, recently unveiled *The Heart Truth*, a national campaign to improve the heart health of women.

Heart disease is the leading cause of death among women. About one of every three American women dies of heart disease. Heart disease also can lead to lifelong disability. Nonetheless, many women ages 40-60 do not realize that they are at risk. *The Heart Truth* campaign was launched to increase awareness that heart disease is the number one cause of death of women and to motivate women to take heart health seriously, to talk with their doctors about it, and to take steps to reduce their risks.

The campaign includes television, radio, and print public service announcements, which use hard-hitting visuals and testimonials to deliver a wake-up call and encourage women to focus as much attention on their "inner" selves as they do on their "outer" selves. A speaker's kit with a video is being developed, and many of the materials, including a comprehensive *Healthy Heart Handbook for Women* are already available from www.nhlbi.nih.gov/health/hearttruth.

NHLBI Participates in New Jersey Health Forum

An estimated 200 New Jersey residents attended a health forum dedicated to the promotion of heart and circulatory health for senior citizens. Dr. Teri Manolio, Director, Epidemiology and Biometry Program, Division of Epidemiology and Clinical Applications, NHLBI, presented an overview of the NIH and stressed the importance of its activities relative to public health. She provided examples of recent cardiovascular disease research advances and discussed how lifestyle choices can improve health and well-being. The event, which was hosted by Representative Rodney Frelinghuysen (R-NJ) in conjunction with St. Barnabas Medical Center, occurred October 21, 2002.

Public Representatives Attend NHLBI Working Group on Future Directions in Sarcoidosis Research

On August 22 and 23, 2002, investigators with expertise in pulmonary diseases, genetics, identification of infectious agents, immunology, molecular biology, and inflammatory bowel disease gathered at the NHLBI to discuss future directions in sarcoidosis research. As in most working groups, the researchers reviewed the current status of what is known about the disease, identified gaps in research, pinpointed obstacles to progress, and explored other research areas that may be applicable.

Complementing the research focus was a discussion in which representatives from the National Sarcoidosis Networking Society of America, Sarcoid Networking Association, Sarcoidosis Awareness Network, Sarcoidosis Research Institute, Sarcoidosis Research Support, and Sarcoidosis Support Group of Greater Washington expressed their views as patients and family members of patients who have sarcoidosis. They stressed the critical need for improved diagnosis and treatment, and shared experiences from their efforts to increase community awareness of sarcoidosis.

Sarcoidosis is a disease associated with inflammation that can appear in almost any organ, but it most often starts in the lungs or lymph nodes. Its cause is unknown.

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Framingham Heart Study Shows Improved Heart Failure Survival

According to data from the NHLBI's landmark Framingham Heart Study (FHS), the risk of dying of heart failure within ten years after being diagnosed with it dropped by about a third over the past half century. The report, which appeared in *The New England Journal of Medicine*, also shows that new cases of heart failure dropped by about a third for women during the same period. However, the number of new cases for men remained unchanged.

FHS Director Dr. Daniel Levy explained, "The reason that new cases are on the decrease for women but not men may have to do with a gender difference in the causes. Although high blood pressure and heart attack are important causes of heart failure in both men and women, high blood pressure is more prominent as a risk factor for heart failure in women, while heart attack plays a greater role in men.

"Treatment for high blood pressure has improved greatly over the past 50 years and has been shown to dramatically cut the number of new cases of heart failure. This may explain why fewer women are developing the disease," he continued. "Heart attack treatment and survival have improved since 1950 as well. But, many of those who now survive have a damaged heart, which makes them vulnerable to heart failure. A consequence of advances in the treatment of heart attack is a growing group of patients at risk for the occurrence of heart failure." Dr. Levy added that the availability of drugs and other treatments for heart failure may be a key reason survival has improved.

"These findings offer good news about a highly lethal disease," said Dr. Lenfant. "However, heart failure still affects far too many Americans and more than half of those who develop it die within 5 years of diagnosis. Prevention remains the best defense against heart failure. Americans can greatly reduce their chances of developing it by taking steps to prevent or control high blood pressure, heart disease, and other conditions that can lead to heart failure."

Heart failure occurs when the heart loses its ability to pump enough blood through the body. It often develops over many years. About 4.8 million Americans have heart failure, and about 550,000 new cases are diagnosed each year. Heart failure contributes to about 287,000 deaths a year.

News from Capitol Hill

The NIH will be funded under a series of continuing resolutions until Congress passes the Labor, Health and Human Services, Education, and Related Agencies (Labor/HHS/Education) Appropriations Act. The current continuing resolution, which expires January 11, 2003, allows the NHLBI to continue to operate at its fiscal year 2002 spending levels.

The Senate version of the Labor/HHS/Education appropriations bill is awaiting action by the full Senate. The accompanying report language (Sen. Rpt. 107-216) mentions several activities related to the mission of the NHLBI. For example, the committee urges the NHLBI to

- place highest priority on cardiovascular research
- · expand cardiovascular disease research in women
- expand efforts to reduce the shortage of hematologists
- pursue research on whether cholesterol-lowering drugs and antihypertensive medications may protect against cognitive impairment and Alzheimer's disease

On September 17, the House passed the *Women's Health Office Act of 2002 (H.R. 1784)*. It would create in statute the Office on Women's Health (OWH) in the Department of Health and Human Services and also would establish women's health offices in the Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Food and Drug Administration (FDA), and Health Resources and Services Administration.

On October 4, Senator Edward Kennedy (D-MA) introduced the *Research Revitalization Act of 2002 (S. 3060)*. It would require numerous changes to the system for protecting research participants, including the extension of protections to participants in research funded by private sources.

President Bush signed the *Rare Diseases Act (H.R. 4013)* into law as Public Law (P.L.) 107-280. The new law provides statutory authorization for the existing NIH Office of Rare Diseases and establishes Regional Centers of Excellence on Rare Diseases. He also signed into law the *Rare Diseases Orphan Product Development Act (H.R. 4014)* as P.L. 107-281, which authorizes \$25 million to the FDA's existing Orphan Product Research Grant program.

NHLBI Funds Study of Therapy for Obstructive Sleep Apnea Syndrome

In September 2002, the NHLBI awarded \$14 million to Stanford University for a 5-year clinical trial to determine the efficacy of nasal continuous positive airway pressure (CPAP) in treating sleep apnea. Although CPAP therapy is the primary treatment for obstructive sleep apnea syndrome (OSAS), a sleep-related breathing disorder affecting more than 15 million Americans, this is the first large, population-based, randomized clinical trial of long-term CPAP efficacy conducted in the United States. The researchers, led by Dr. William Dement, will assess the long-term effect of CPAP therapy on neurocognitive function, mood, sleepiness, and quality of life; look for specific neurocognitive deficits associated with OSAS in a large, heterogeneous subject population; and determine which deficits in neurocognitive function are reversible and most sensitive to the effects of CPAP.

NHLBI Research Initiatives

From time to time, the NHLBI invites investigators to submit grant applications or contract proposals for specific research programs. We currently are soliciting applications for the following programs. Unless a due date is mentioned, applications are accepted for February 1, June 1, and October 1 deadlines each year. For full descriptions of these and other research initiatives, visit www.nhlbi.nih.gov/funding/inits/index.htm.

Ancillary Pharmacogenetics Studies in Heart, Lung, Blood, and Sleep Disorders (RFA-HL-03-001)

- Applications Due: January 14, 2003
- Objectives: To support collection of DNA from current study participants and the use of these or existing resources for studies of genetic influences on interindividual differences in prescription drug response.

Animal Models of Organ-specific Tolerance for Heart and Lung Transplantation (PA-02-044)

 Objectives: To encourage protocol development using large animal models for heart transplantation and both large and small animal models for lung transplantation.

Biobehavioral Research for Effective Sleep (PA-00-046)

 Objectives: To understand the behavioral, psychosocial, and physiological consequences of acute and chronic partial sleep deprivation and to develop interventions to reduce sleep disturbances.

Cellular and Molecular Mechanisms of Primary Pulmonary Hypertension (PPH) (PA-00-043)

 Objectives: To elucidate the mechanisms involved in the unique vascular remodeling that characterizes PPH and in the regulation of vascular tone during its development.

Clinical Research in Peripheral Arterial Disease (RFA-HL-03-003)

- Applications Due: February 26, 2003
- Objectives: To develop therapeutic and preventive approaches for atherosclerotic arterial diseases of the peripheral vasculature.

Coordination of Vascularization and Lung Development (RFA-HL-03-006)

- Applications Due: March 19, 2003
- Objectives: To understand the mechanisms that coordinate the formation of the lung and its vasculature during normal development or that contribute to arrested or aberrant lung development.

Functional Heterogeneity of the Peripheral, Pulmonary and Lymphatic Vessels (RFA-HL-03-004)

- Applications Due: February 14, 2003
- Objectives: To understand the mechanisms that contribute to functional differences in adult peripheral, pulmonary, and lymphatic vessels.

Functional Tissue Engineering for Heart, Vascular, Lung, Blood, and Sleep Disorders and Diseases (PAR-01-006)

- Applications Due: March 13, 2003 and March 12, 2004
- Objectives: To stimulate development of biological substitutes for damaged tissues and organs.

Highly Active Antiretroviral Therapy (HAART) Cardiovascular Toxicities (RFA-HL-02-028)

- Applications Due: February 19, 2003
- Objectives: To determine how protease and reverse transcriptase inhibitors affect cardiovascular disease development.

Pathogenesis and Treatment of Lymphedema (PA-01-035)

 Objectives: To stimulate research on the biology of the lymphatic system, the underlying developmental, cellular, and molecular mechanisms that cause lymphedema, and new therapies for patients with lymphedema.

Pathophysiology and Treatment of Chronic Fatigue Syndrome (CFS) (PA-02-034)

 Objectives: To understand CFS pathogenesis and pathophysiology with the goal of improving diagnostic and intervention strategies.

Research on Ethical Issues in Human Studies (PA-02-103)

 Objectives: To encourage research on the ethical challenges of involving human participants in research in order to improve protections for human participation in research.

Restless Legs Syndrome and Periodic Limb Movement Disorder (PA-01-086)

 Objectives: To enhance understanding of and develop treatments for restless legs syndrome and periodic limb movement disorder.

Role of Sleep and Sleep-Disordered Breathing in Metabolic Syndrome (RFA-HL-03-008)

- Applications Due: February 11, 2003
- Objectives: To elucidate the relationship of sleep deprivation and sleep-disordered breathing to characteristics of the metabolic syndrome including obesity, high blood pressure, dyslipidemia, insulin resistance, and vascular inflammation.

Specialized Centers of Clinically Oriented Research (SCCOR) Programs

- in Cardiac Dysfunction and Disease
 - (RFA-HL-03-009)
 - Applications Due: September 11, 2003
- in Pediatric Heart Development and Disease
 - (RFA-HL-02-027)
- Applications Due: January 16, 2003
- Objectives: To stimulate clinically relevant, multidisciplinary collaborations leading to clinical and basic science research efforts on important public health problems for individuals with heart diseases.

National Heart, Lung, and Blood Advisory Council Fall Meetings

September 5

Dr. Lenfant called the 207th meeting of the National Heart, Lung, and Blood Advisory Council (NHLBAC) to order and announced that September was National Cholesterol Education Month and Sickle Cell Awareness Month.

The Institute is also celebrating the 30th anniversary of the National Sickle Cell Disease Program, which was created by an Act of Congress in 1972. A booklet describing the accomplishments of the program was distributed to the NHLBAC. Dr. Charles Peterson, Director, Division of Blood Diseases and Resources, described highlights of NHLBI support for sickle cell disease research and gave examples of ongoing and future research programs such as efforts to improve the safety and efficacy of bone marrow transplantation, to identify genetic modifiers, to understand hip and lung complications, and to train clinical investigators.

The National Asthma Education and Prevention Program (NAEPP) Expert Panel recently released an update of the guidelines for the diagnosis and management of asthma. Dr. James Kiley, Director, Division of Lung Diseases, briefly described how the NAEPP update is being disseminated. Dr. Homer Boushey, Professor of Medicine, University of California at San Francisco, described the process of updating the report and gave an overview of how research translates into clinical practice, and Dr. George Rush, Deputy Director, National Center for Primary Care, Morehouse University School of Medicine, explained how the guidelines were being disseminated, especially through NHLBI-funded centers that treat uninsured and underserved patients.

During the closed portion of the meeting, the Council concurred on the award of 144 grants for a total cost of \$63,253,977.

October 24-25

Dr. Lenfant welcomed members of the NHLBAC to the 208th meeting of the Council. He acknowledged the contributions of departing Council members Drs. Allen Cowley, Paul Douglass, Amelie Ramirez, Robert Rosenberg, and Roger Spragg. Newly appointed members Drs. Maria Costanzo and Ngai Nguyen, whose 4-year terms begin November 1, were introduced and welcomed.

30 Years of Sickle Cell Research

Sickle Cell Research for Treatment and Cure, a new publication from the NHLBI. commemorates the 30th anniversary of the National Sickle Cell Anemia Control Act (P.L. 92-294). Since 1972, the NHLBI has committed over \$923 million for research programs to improve the lives of persons with sickle cell disease. The booklet, available online at www.nhlbi.nih.gov/resources/ docs/scd30/, describes results of clinical research supported by the NHLBI. It also provides examples of how basic science advances achieved prior to the 1970s enabled progress against sickle cell disease and describes ongoing studies to develop a cure.

Dr. Lenfant described a Women's Health Initiative Conference to review the outcome of the hormone replacement therapy clinical trial. He explained that the progestin/estrogen arm of the trial was stopped after analysis of the data revealed evidence of increased risk of breast cancer, coronary heart disease, stroke, and pulmonary embolism.

Dr. Herbert Geller, Associate Director for Education in the NHLBI Division of Intramural Research (DIR), spoke about mentoring and training in the DIR. The Office of Education was created in 2002 to assist with recruitment of high-quality trainees, to help trainees acquire the necessary scientific and technical skills, and to promote fellows as they attempt to establish research careers. Dr. Elliot McVeigh, senior investigator, NHLBI Laboratory of Cardiac Energetics (LCE), presented an overview of the research being conducted in the LCE.

The NIH Council of Public Representatives (COPR) released a report last year on Human Research Protection in Clinical Trials. Ms. Rosemary Quigley, a member of the COPR and Assistant Professor at the Center for Medical Ethics and Heart Policy at the Baylor College of Medicine, provided her viewpoint on the report and spoke of the effectiveness of the approaches used in clinical studies.

Twelve initiatives were presented to the Council for their approval. While the Council was supportive of all submitted proposals, members made specific recommendations. Dr. Lenfant will take these recommendations into consideration, along with other budget issues, when determining which proposals will be implemented.

During the closed portion of the meeting, the Council concurred on the award of 162 grants for a total cost of \$ 75,236,132.

The next National Heart, Lung, and Blood Advisory Council (NHLBAC) meeting is scheduled for 8:00 a.m. on February 6, 2003. It is open to the public and will be in NIH Building 31C, Conference Room 10.

The FYI from the NHLBI staff thanks Ms. Sue Byrnes, member of the NHLBAC and director of the LAM Foundation, for preparing these summaries. Full minutes of Council meetings and summaries of the initiatives are available at www.nhlbi.nih.gov/meetings/nhlbac/.

Upcoming Events				
Date	Activity	Details	For Additional Information	
2/1 - 2/28	American Heart Month	The 2003 theme is "Be an American Heartsaver!" Learn CPR, support automatic external defibrillator programs in your community, and help save lives.	www.americanheart.org	
2/6	National Heart, Lung, and Blood Advisory Council	8:00 am - 2:00 pm, NIH Main Campus, Building 31C, Conference Room 10, Bethesda, MD. Open to the public.	www.nhlbi.nih.gov/ meetings/nhlbac	
2/13 - 2/15	28th International Stroke Conference	Phoenix, AZ. The program, for health professionals, will feature advances in the basic sciences of cerebral circulation and brain function, clinical stroke research and outcomes, rehabilitation science, and surgery.	www.strokeconference.	
2/14	Congenital Heart Defect Awareness Day	Join the international coalition of families, nonprofit organizations, support groups, and health professionals in efforts to increase public awareness of congenital heart defects and childhood heart disease.	www.tchin.org/aware	
2/28 - 3/2	6th International Congress on Pediatric Pulmonology (CIPP VI)	Lisbon, Portugal. CIPP VI will offer updates on major aspects of pediatric pulmonology, including issues of special relevance to developing countries.	www.cipp-meeting.com	
4/4 - 4/6	2003 LAM Research Conference	Cincinnati, OH. The conference will integrate the ideas of established lymphangioleiomyomatosis (LAM) investigators with top scientists who have parallel interests in molecular genetics, pathology, smooth muscle biology, lung remodeling and cell biology.	lam.uc.edu/html/ conferences.html	

MEDLINEplus "en Español" - Popular NIH Web Site Now Available in Spanish

If someone contacted your group for health information in Spanish, would you be able to help them? Finding credible medical information in Spanish on the Web is easier than you might think, thanks to a new feature added to MEDLINEplus.gov, the National Library of Medicine's consumer-friendly health Web site. Not only does MEDLINEplus.gov provide credible medical information in both English (at **medlineplus.gov**) and Spanish (at **medlineplus.gov/esp**), but a click on the "Español" link on any English MEDLINEplus.gov page takes the user to its corresponding Spanish page.

"A primary part of NIH's mission is to translate medical advances into health information that the public can use," said Dr. Elias A. Zerhouni, NIH Director. "Making MEDLINEplus information available in Spanish greatly expands NIH's ability to carry out its mission to communicate with the public."

MEDLINEplus and MEDLINEplus "en Español" are available free of charge 24 hours a day. Links to hundreds of topics point users to information from the NIH and other federal agencies, professional medical associations, and health-related organizations. On the medical encyclopedia pages, full-color illustrations and photographs accompany over 4,000 articles on diseases, injuries, tests, and surgeries. The interactive health tutorials -- narrated guides to various health topics -- use animated illustrations and plain language to describe medical procedures, surgeries, and the symptoms and effects of diseases.

Need More Information?

- For health-related questions and publications, please contact the trained information specialists at the NHLBI Information Center
 (NHLBIinfo@rover.nhlbi.nih.gov) or write to the Information Center at P.O. Box 30105, Bethesda, MD 20824-0105.
- For communications pertaining to NHLBI policies and priorities, contact the NHLBI Office of Public Liaison (NHLBI.Listens@nih.gov).
- For additional information regarding NHLBI events, consult the references provided or www.nhlbi.nih.gov/calendar/nhcal.htm. Most other NIH Institutes and Centers also maintain calendars on their Web sites. Links to their Web pages are at www.nih.gov/icd.

Materials Available to Increase Public Awareness of Heart Attack Signs

Now it is even easier to educate your community about the need to act fast when someone may be having a heart attack. As part of the National Heart Attack Alert Program's *Act in Time to Heart Attack Signs* campaign, the NHLBI has produced a Small Group Session Lesson Plan, which includes talking points, reproducible handouts, overhead masters, tips on how to organize and publicize, and more. It can be used for talks at a senior centers, hospitals, churches, adult education classes, worksite health and safety meetings, or community groups. Lesson plan materials, brochures, wallet cards, and a 13-minute video may be ordered by visiting www.nhlbi.nih.gov/actintime.

Constituents' Corner

Space is reserved for you, our readers, to share ideas and broadcast opinions. We invite you to submit your comments, thoughts, and suggestions via email (NHLBI.Listens@nih.gov) or snail mail (Public Interest News, c/o Office of Science and Technology, Building 31, Room 5A03, 31 Center Drive, MSC-2482 Bethesda, MD 20892-2482).

Leader of Public Interest Organization Participates in FDA Review of Medication for COPD

On September 6, Dr. Wlodzimierz (Vlady) Rozenbaum, Moderator of COPD-ALERT, testified before the Pulmonary Allergy Drugs Advisory Committee of the U.S. Food and Drug Administration (FDA) about the drug Spiriva (tiotropium bromide), which has been studied as treatment for chronic obstructive pulmonary disease (COPD). In his testimony, he described the devastating consequences that COPD has for patients and families, as well as its substantial economic costs. He also described the limited treatment options currently available and shared his own experience as a person who has COPD. Dr. Rozenbaum was one of several speakers; representatives from the sponsor of Spiriva. Boehringer Ingelheim, presented data from multiple clinical trials, and other FDA scientists discussed some of the methods used in the studies.

COPD-ALERT is a support and advocacy group for COPD patients, caregivers, and medical professionals; its Web address is www.yahoogroups.com/group/COPD-ALERT. Dr. Rozenbaum, who contributed this article, also manages a Web site containing information about COPD at www.geocities.com/wrozenba/COPD.html.

REMINDER
The Fourth Annual Public
Interest Organization Meeting is
Scheduled for February 5, 2003.
Make Sure Your Group is
Represented.

EFFORTS to Expand Public Outreach Activities

Volunteers from Emphysema Foundation for Our Right to Survive (EFFORTS) have developed a speakers bureau to connect with audiences wishing to learn what it is like to have COPD. Through their stories, speakers tell how they adjusted to living with COPD, learned to communicate with their doctors and families, and used proper nutrition and exercise to live as fully and productively as possible. Speakers who have received lung transplants also share their experiences with the preparation for and rehabilitation following transplant surgery.

Additional information about the EFFORTS speakers bureau and a list of speakers is available at www.emphysema.net/speakers2.html.

Article submitted by: Gary Bain, President, EFFORTS.

Molecular Genetics Enhances Usefulness of Established Registry and Leads to Improvements in Diagnosis and Treatment

In the late 1970s, Drs. Arthur J. Moss from Rochester, New York, and Peter Schwartz from Pavia, Italy, established a registry for patients diagnosed with Long QT Syndrome (LQTS). As is the case with most diseases for which registries are developed, little was known about LQTS. The condition, which causes sudden cardiac death in young people, was known to be an inherited condition, but treatments were limited and diagnosis was often made only after the patient suffered a cardiac arrest.

In 1985, researchers received a grant from the NHLBI to expand the registry to include the families of patients and begin studies of LQTS genetics, natural history, and treatment options. The accumulation of clinical and electrocardiogram (ECG) data on both the first affected individual in a family and family members allowed researchers to make observations about disease similarities within and among families. Meanwhile, the field of molecular genetics was becoming more sophisticated, and researchers began to speculate that family differences may be associated with distinct genetic abnormalities.

Between 1991 and 2001, six LQTS genes and over 200 mutations were identified. When studying patients with mutations in one of three LQTS genes (Iqts1, Iqts2, and lqts3), researchers discovered that patients with mutations in lqts1 or lqts2 respond well to treatment with a class of drugs called beta-blockers. Pacemakers were found to be more useful in treating patients with mutations to lqts3. Discovery of the LQTS genes has had important diagnostic implications, too. Previously, LQTS could be detected only by the presence of a prolonged QT interval as measured by an ECG—a diagnostic approach that was not always accurate. Results of genetic studies help identify people who have LQTS with more certainty than ECGs alone, particularly in asymptomatic family members of patients diagnosed after an unexplained fainting episode (the most common presenting symptom other than cardiac arrest) or during a routine cardiac exam.

The foresight of researchers who launched the registry in 1979, combined with the participation of more than 1,100 enrolled families and the efforts of molecular geneticists who developed the genetic screening techniques, has opened possibilities for understanding LQTS. Much remains to be learned, but the detection of genetic mutations has already demonstrated that molecular understanding of LQTS holds promise for the development of even better diagnostic approaches and treatments.

To learn more about LQTS, contact the Cardiac Arrhythmias Research and Education (C.A.R.E.) Foundation, Inc., at 800-404-9500 or visit their Web site at **www.longqt.org**. **Article submitted by:** Kathy McInerney, Director of Development, C.A.R.E. Foundation.