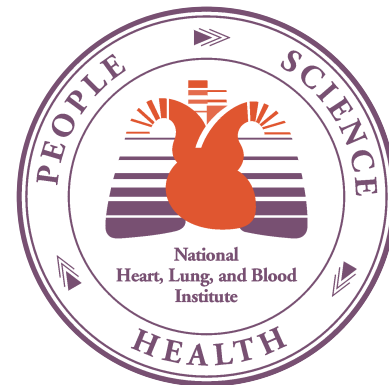


Tyi from the NHLBI



public interest news
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Highlights of the 7th Annual Public Interest Organization (PIO) Meeting

Dr. Elizabeth G. Nabel reported on her first year as NHLBI Director and spoke of how the NHLBI seeks to stimulate discoveries of the causes of disease, speed translation of discoveries to clinical applications, facilitate communication between scientists and physicians, and effectively communicate advances to the public. Focusing on the future of the NHLBI, Dr. Nabel said, “Our vision is based upon a fundamental set of values that must permeate all activities of our Institute and are shared by all our staff.” These include a “commitment to excellence, innovation, integrity, respect, and compassion.” She also stressed the importance of the NHLBI working together with patient advocacy groups to address the needs and concerns within patient communities.

Dr. Elias Zerhouni, NIH Director, described his vision for the NIH and noted that the NIH’s success is measured by its ability to deliver research results and improved health. He remarked that the opportunities for scientific discovery and advancement have never been greater than at the present time. The NIH has developed a new paradigm that emphasizes the “3Ps”: Prediction of pathogenesis; Personalized, precise medicine; and Preemption of disease before it occurs. Dr. Zerhouni elaborated on two key challenges the NIH faces: the flattening of the budget and the need to encourage and develop new investigators. He then discussed the three new initiatives announced under the NIH Roadmap to address these challenges.

Dr. Carl Roth, Director of the Office of Science and Technology, NHLBI, presented an overview of the Institute—its history and mission—and recounted health achievements in which the NHLBI played a leading part. He noted the role of the NHLBI-supported Framingham Heart Study in defining major risk factors for cardiovascular disease—high blood pressure, increased cholesterol, smoking, diabetes, family history, and male gender. Efforts to address modifiable risk factors have contributed to the overall decline in mortality from heart disease and stroke. Overall, life expectancy in the United States has increased

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NHLBI to Launch Framingham Genetic Research Study

A comprehensive genetic research study to identify genes underlying cardiovascular and other chronic diseases will be launched by the NHLBI in collaboration with the Boston University School of Medicine. The new research effort, the Framingham Genetic Research Study, will be part of the NHLBI’s long-running Framingham Heart Study and will involve up to 500,000 genetic analyses of the DNA of 9,000 study participants representing three generations.

Since 1948, the Framingham Heart Study has studied the health of many of the Massachusetts town’s residents. The study has been the source of key research findings regarding the contributions of hypertension, high cholesterol, cigarette smoking, and other risk factors to the development of cardiovascular disease.

“This important study will take genetic research in the Framingham study to the next level—accelerating discoveries on the causes, prevention, and treatment of major chronic diseases,” said Dr. Nabel. “Using the latest technology, researchers will be able to obtain more information about the connection between unique genetic variations in DNA and cardiovascular disease risk factors as well as the genetic basis for heart attack, stroke, and other chronic diseases.”

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Upcoming NHLBI Workshops and Working Groups*

Workshop or Working Group	Date / Location	Contact for More Information
Ontologies for Cardiovascular Research	June 2006 Bethesda, MD	Dr. Jennie Larkin Larkin.J2@nhlbi.nih.gov 301-435-0513
C-Reactive Protein Workshop	July 10-11, 2006 Bethesda, MD	Dr. Denise Simons-Morton SimonsD@nhlbi.nih.gov 301-435-0414
Role of Airway Smooth Muscle in Airway Contraction, Inflammation, and Remodeling: Advancing from Basic Knowledge to Clinical Relevance	September 11-12, 2006 Bethesda, MD	Dr. Susan Banks-Schlegel schleges@nhlbi.nih.gov 301-435-0202
Combined NHLBI/ORD Workshop on Recognition and Treatment of Rare Inherited Arrhythmias	September 14-15, 2006 Bethesda, MD	Dr. Dennis Przywara PrzywaraD@nhlbi.nih.gov 301-435-0504
Working Group: Cardiovascular Consequences of COPD	September 2006 Bethesda, MD	Dr. Thomas Croxton croxtont@nhlbi.nih.gov 301-435-0202
Workshop: Research Needs in Bronchiectasis	September 2006 Bethesda, MD	Dr. Hannah Peavy peavyh@nhlbi.nih.gov 301-435-0222

*PIO representatives will be accommodated on a space-available basis and will be responsible for their own travel expenses.

Highlights of the 7th Annual PIO Meeting

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about 6 years during the 30 year span from 1970 to 2000 and that increase is largely due to the decline in mortality from cardiovascular disease. Dr. Roth also noted the dramatic decline in deaths from neonatal respiratory distress syndrome, the elimination of the risk of post-transfusion hepatitis, and the increased life expectancy for patients with sickle cell disease.

In a session on blood safety, Dr. Harvey Alter, Chief, Infectious Diseases Section, Department of Transfusion Medicine, NIH Clinical Center, discussed the scientific discoveries that led to the elimination of post-transfusion infection from hepatitis C virus. Mr. Carl Weixler, President, Hemophilia Foundation of America, discussed blood supply safety from the perspective of someone living with hemophilia who acquired infections from tainted blood and blood products.

During breakout sessions, NHLBI staff members discussed the NIH grants process, stem cell technology, tissue engineering, and the use of cohort studies for genetic research. Finally, PIO representatives had an opportunity to meet NHLBI staff members in informal discussion groups covering heart development and disease, vascular diseases, lung diseases, airway diseases, blood diseases and resources, and sleep and sleep disorders.

The meeting was held January 30–31, 2006 in Bethesda, Maryland.

Framingham Genetic Research Study

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Additionally, the NIH National Center for Biotechnology Information, part of the National Library of Medicine, will assist in developing a study database that will be made available at no cost to investigators throughout the world, thereby providing opportunities for other experts to search for associations between genes and diseases.

Mark Your Calendar . . .

May: Asthma and Allergy Awareness Month (www.aafa.org)

National High Blood Pressure Education Month
(hin.nhlbi.nih.gov/nhbpep_kit/)

14th to 20th National Women's Health Week
(www.womenshealth.gov)

June: National Men's Health Week
12th to 18th (www.menshealthweek.org)

September National Cholesterol Education Month
(hin.nhlbi.nih.gov/cholmonth)

National Sickle Cell Month
(www.SickleCellDisease.org)

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.

Diet and Physical Activity Assessment Improvement

(Program Announcement with Review PAR-06-104)

Applications/Proposals Due: July 01, 2006

Objective: To improve diet and physical activity measurement through improved instruments, technologies, or statistical/analytical techniques that explore the optimal combinations of objective and self-reported measures that can capture dietary intake and physical activity behaviors in both general and diverse populations.

Transfusion Medicine/Hemostasis Clinical Trials

Network Renewal (RFA Renewal)

Applications/Proposals Due: August 15, 2006

Objective: To continue for a second five-year period a network of interactive clinical research groups to promote the efficient comparison of new management strategies of potential benefit for children and adults with hemostatic disorders and also to evaluate novel as well as existing blood products and cytokines for the treatment of hematologic disorders. The network consists of 17 core clinical centers to perform multiple clinical trials and a Data Coordinating Center.

Non-Viral Systems for Gene Transfer Applications for Heart, Lung, and Blood Diseases: New Approaches (TPA-06-042)

Applications/Proposals Due: September 12, 2006

Objective: To foster the development of efficient non-viral approaches for a broad range of gene- and cell-mediated therapies for heart, lung, and blood diseases in humans. The initiative will use the R21/R33 Phased Innovation Award, allowing projects that are shown to be feasible in the initial R21 period to move forward rapidly.

Network for Cardiothoracic Surgical Investigations in Cardiovascular Medicine (RFA HL-06-005)

Applications/Proposals Due: August 28, 2006

Objective: To conduct multiple, collaborative, proof-of-concept, clinical protocols to evaluate surgical and minimally invasive interventional strategies to improve the treatment of cardiovascular disease in adult populations through the establishment of a cooperative network of academic centers with clinically active cardiothoracic surgeons and their colleagues in allied specialties interested in promulgating the use of evidence-based medicine in surgical practice. The network will include seven clinical centers and a data coordinating center.

Comprehensive Sickle Cell Centers

(RFA - Renewal HL-06-008)

Applications/Proposals Due: September 25, 2006

Objective: To operate a nationwide network of interactive, state-of-the-art, comprehensive centers in basic and translational research focused on the development of cures or significantly improved treatments for sickle cell disease. This is the ninth re-competition of a program that was established by a Presidential initiative and Congressional mandate in 1972. The network will include ten centers and a statistics and data management core.

National High Blood Pressure Education Month

May is National High Blood Pressure Education Month and marks the kickoff of high blood pressure prevention and control activities for the year. The 2006 theme is "Mission Possible: Prevent and Control High Blood Pressure." The NHLBI invites community groups, civic and faith-based organizations, hospital outreach programs, public health departments, and workplaces to join the "Mission" and renew activities to prevent and control high blood pressure.

The NHLBI has created a web site that provides information and tools to help you plan activities in your community. An electronic Planning Kit includes ideas for activities with various groups. The site also includes an activity registry where you can let others know what you are planning and get ideas from others. There are also links to NHLBI fact sheets and other publications. For more information, visit hin.nhlbi.nih.gov/nhbpep_kit/.

National Heart, Lung, and Blood Advisory Council Meeting

February 1, 2006

Dr. Nabel announced the selection of four new Council members: Victor J. Dzau, M.D., Duke University; Helen H. Hobbs, M.D., University of Texas Southwestern Medical Center; Joseph Loscalzo, M.D., Ph.D., Brigham and Women's Hospital; and Jennie R. Joe, Ph.D., M.P.H., University of Arizona.

Dr. Nabel also announced three new staff appointments: Dr. Christopher O'Donnell as Senior Advisor to the Director for Genome Research, Ms. Nancy O'Hanlon as Deputy Ethics Counselor, and Ms. Sheila Pohl as Chief of Staff.

Three additional staff appointments, pending administrative clearances, were announced: Dr. Susan Shurin as Deputy Director of the NHLBI; Dr. Alan Michelson as Associate Director for Basic Research; and Dr. Michael Twery as Acting Director of the National Center on Sleep Disorders Research (NCSDR), which is administered by the NHLBI. Dr. Nabel expressed her appreciation to Dr. Carl Roth for his service as Acting Deputy Director over the past year and to Dr. Carl Hunt for his leadership of the NCSDR.

Dr. Nabel noted that February is American Heart Month and encouraged everyone to wear a Red Dress pin on National Wear Red Day (Friday, February 3rd) to show support for women's heart health awareness.

Dr. Nabel highlighted several recent Institute initiatives, including a solicitation for genome-wide association studies to identify genetic components that relate to heart, lung, and blood disorders; a Request for Proposals (RFP) for research to maximize the scientific value of the biologic specimens from the Women's Health Initiative research studies; and an RFP for large-scale genotyping of NHLBI cohorts.

The Institute has reviewed its policies for distribution of data from clinical trials and epidemiology studies, and released a Request for Information seeking comments on its proposed modifications.

The NHLBI working budget for FY 2006 is \$2.896 million, about \$27 million less than the comparable figure in FY 2005. Dr. Nabel explained in a recent letter to all NHLBI grantees that direct costs for noncompeting renewals of research project grants will be scaled back in FY 2006 to 97.65 percent of their committed levels. This is being implemented across NIH.

Dr. Gregory Morosco, Director, Office of Prevention, Education, and Control (OPEC) reviewed NHLBI efforts to coordinate the translation and dissemination of research findings to health professionals, patients, and the public in order to provide public health benefits to the nation.

Ms. Terry Long, of OPEC, updated the Council on the achievements of *The Heart Truth* Campaign.

Dr. Paolo Sebastiani, Associate Professor in the Department of Biostatistics and Adjunct Associate Professor in the Bioinformatics Program in Boston University's School of Public Health, discussed her research about complex genetic diseases, which are caused by the interplay of several genes and which can be modulated by exposure to environmental factors. Dr. Nabel emphasized the need to have guidelines in place for the many genome-wide association studies that are on the immediate horizon. She said the first step is the development of data access policies.

News from Capitol Hill

On February 1, the President proclaimed February 2006 as "American Heart Month." In keeping with a heart-health theme, the House and Senate passed H.Res. 629 and S.Con.Res. 69 to acknowledge February 14, 2006, as a Day of Hearts: Congenital Heart Defect Day. Acquired heart diseases also received attention with the introduction of S. 2278 and H.R. 4747, the Heart Disease Education, Analysis, and Research, and Treatment (HEART) for Women Act. The bills would expand screening programs for low-income women at risk for cardiovascular diseases and require that data submitted to the FDA as part of the approval process for devices, biologic products, or drugs be analyzed and reported by gender, race, and ethnicity.

Resolutions

Several resolutions pertaining to health observances in

May 2006 have been introduced, including:

- H.Res. 693, a resolution to recognize May 7th as Childhood Stroke Awareness Day;
- H.Res. 696, introduced in support of National Physical Education and Sports Week (May 1-7) and National Physical Education and Sports Month;
- H.Con.Res. 357, introduced to endorse National Cystic Fibrosis Awareness Month.

Other resolutions introduced this year include H.Res. 716, to support establishment of a National Blood Reserve and S.Res. 423, a resolution passed by the Senate to designate April 8, 2006, as National Cushing's Syndrome Awareness Day.

Upcoming Events

Activity	Date/Location	More Information
US Chronic Obstructive Pulmonary Disease Coalition Spring Meeting	May 24 San Diego, CA	www.uscopd.com/activities/meetings.htm
Vascular Disease Foundation Annual Meeting	June 1-3 Philadelphia, PA	www.vdf.org
COPD Foundation Annual Thomas L. Petty Aspen Lung Conference	June 7-10 Aspen, CO	www.copdfoundation.org
Alpha-1 Advocacy Alliance Living with Alpha-1 Conference	June 10-11 Winchester, VA	www.alpha1advocacy.org
Scleroderma Foundation Sjogren's Syndrome Seminar	June 10 New York, NY	www.scleroderma.org
National Heart, Lung, and Blood Advisory Council 222nd Meeting	June 13 Bethesda, MD	www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Platelet Disorder Support Association ITP Conference 2006	June 23-24 Washington, DC	www.pdsa.org
Pulmonary Hypertension Association 7th International PH Conference and Scientific Sessions: Roadmap to a Cure	June 23-25 Minneapolis, MN	www.phassociation.org/Conference/
Klippel-Trenaunay Support Group 2006 Meeting	July 28-29 Rochester, MN	www.k-t.org
National Heart, Lung, and Blood Advisory Council 223rd Meeting	September 12 Bethesda, MD	www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Adult Congenital Heart Association 2006 National Conference	September 15-17 San Francisco, CA	www.achaheart.org

Research Advances from the NHLBI

Treatment Shows Long-term Benefits for Cystic Fibrosis (CF) Patients

New research suggests that inhaling hypertonic saline, a water-based concentrated salt solution, could provide long-term benefits for lung health in patients with CF—a chronic, progressive, and frequently fatal genetic disease that affects about 30,000 children and young adults in the United States. In a study funded by the NHLBI and the Cystic Fibrosis Foundation, researchers tested the effects of inhaling the saline four times daily for 14 days in 24 adolescent and older patients with CF. The treatment significantly improved mucus clearance and lung function and reduced breathing symptoms.

Investigators believe that the treatment increases mucus volume, which helps the airways to clear bacteria and inhaled debris and could limit the number and severity of lung infections. Repeated infections are thought to contribute to lung damage over time. The study results offer potential for a new and inexpensive treatment of CF and could be particularly important if future research shows that the treatment similarly benefits infants and young children and could ultimately prevent or delay lung damage.



Constituents' Corner



From National Sarcoidosis Society **State Tax Check-off to Help Fight Sarcoidosis**

This year, residents of Illinois will have the opportunity to make donations through their 2006 state tax returns to fund research on sarcoidosis, a little-understood disease that disproportionately affects African Americans and, to a lesser degree, people of Scandinavian descent.

Ms. Glenda Fulton, head of the National Sarcoidosis Society Local Chapter in Chicago, along with State Representative Connie Howard and State Senator Mattie Hunter, were able to get legislation passed and signed by Governor Rod Blagojevich that allows Illinois taxpayers to donate to the sarcoidosis cause via their 2006 Illinois 1040 state tax returns. If the check-off generates at least \$100,000 in donations this year, it becomes eligible to appear again on next year's tax form.

"It is imperative that we spread the word about this tax deduction and significant source of revenue to assist in finding a cure, or at the very least, the cause of a disease that has been affecting people for over 130 years," said Ms. Fulton. For more information on sarcoidosis or the tax check-off, contact Ms. Fulton at 773-536-7754 or sarcoidosis2@hotmail.com.

Submitted by Glenda Fulton, National Sarcoidosis Society

From Barth Syndrome Foundation **Barth Syndrome Conference**

The Barth Syndrome Foundation is presenting the 3rd International Barth Syndrome Foundation Scientific and Medical Conference on July 6-7, 2006, at the Coronado Springs Resort in Buena Vista, Florida. Researchers and clinicians from diverse fields will offer presentations in an innovative, thought-provoking agenda that will address what is now known and what is not yet understood.

Major agenda topics include Functions of the Tafazzin Protein, Cardiac Aspects of Barth Syndrome, Hematological Aspects of Barth Syndrome, and other Clinical and Scientific Issues of Barth Syndrome. More information about the meeting can be found at www.barthsyndrome.org.

Immediately following the conference, on July 8, physician attendees will participate in working sessions to develop the first Barth syndrome treatment guidelines. It is expected that the newly developed guidelines will become a necessary reference tool for every physician who treats a Barth syndrome patient.

Submitted by Shelley Bowen, Barth Syndrome Foundation, Inc.

We invite you to use this space that we reserve for you to share your successes and opinions. You may submit your ideas and articles to nhlbi.listens@nih.gov or Public Interest News, Office of Science and Technology, Building 31, Room 5A03, 31 Center Drive, MSC-2482, Bethesda, MD 20892-2482.

Please send your Constituents' Corner submissions no later than the second week of April, August, or December for inclusion in the May, September, or January issues of FYI from the NHLBI, respectively.



Need More Information?

We are always interested in receiving comments and suggestions from the community. If you or your organization have questions for me or for the Institute, please contact me at nabele@nhlbi.nih.gov or Dr. Carl Roth at rothc@nhlbi.nih.gov.

Elizabeth G. Nabel, M.D.
Director, NHLBI

For information on specific issues, the following contacts may be helpful:

- For health-related questions and publications, please contact the trained information specialists at the NHLBI Information Center (NHLBIinfo@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.