

# Tyi from the NHLBI

## Ninth Annual PIO Meeting Recap

The NHLBI held its Ninth Annual Public Interest Organization (PIO) meeting June 9-10, 2008, in Bethesda, Maryland. The meeting opened Monday afternoon with a presentation by Dr. Robert Balaban, NHLBI Scientific Director, who discussed research occurring on the NIH campus in the NHLBI's Intramural Program, and Dr. Keith Horvath, Director of Cardiothoracic Surgery for the NIH Heart Center at Suburban Hospital. Dr. Horvath described how the NHLBI collaborates with Suburban Hospital in using state-of-the-art technologies to bring the best in cardiac research to the community.

Tuesday's program began with a talk by Dr. Josephine Briggs, Director of the National Center for Complementary and Alternative Medicine. She presented statistics on the use of natural products in the U.S. and some recent findings on the use of practices such as Tai Chi and acupuncture. Dr. Briggs also stressed that patients must discuss with their doctors all of the treatments and therapies they take in order to ensure properly managed care. Judging from the number of questions, her presentation resonated with the attendees.

**"This was my first opportunity to attend the PIO meeting. From start to finish it was a great experience."**

*Leanne Storch, Executive Assistant and Patient Advocate  
The Pulmonary Fibrosis Foundation*

Dr. Elizabeth Nabel, NHLBI Director, discussed the Institute's investment in genomic studies such as the Framingham Heart Study and its related SHARe resource. She explained new NIH policies that make such data-rich studies available to secondary researchers in order to maximize the return on research investments, while implementing proper safeguards to ensure data confidentiality.

A panel presentation convened NIH staff and a PIO representative to discuss the latest NIH resources and the NHLBI budget. The panel gave attendees an opportunity to hear first-hand about new resources available to the public,

such as the NIH Research Portfolio Online Reporting Tool (RePORT), which will make information about the NIH easier to locate, and the Research, Condition, and Disease Categorization (RCDC) resource, which will report more consistent figures on NIH funding patterns. RCDC will be particularly useful to PIOs serving communities with diseases or disorders that are funded by more than one NIH institute or center.

Another panel illustrated the promising research advances in Marfan syndrome and featured basic research, PIO, and NHLBI perspectives. The panel was followed by concurrent sessions: one addressed psychosocial issues faced by patients with heart, lung, blood, or sleep diseases and disorders and the other explored clinical trials experiences from the viewpoints of two PIOs that serve very different patient populations.

The meeting closed with an opportunity for participants to meet with NHLBI staff and to continue to network with other PIO representatives.

**"The networking that goes on during the PIO meeting is invaluable and I always go home with great ideas and the inspiration to make a difference in my organization and community."**

*Robbie Darden, President  
Central Indiana Sarcoidosis Support Group*

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## Upcoming NHLBI Workshops and Working Groups\*

Workshop or Working Group	Date / Location	Contact for More Information
Immunogenetics and Immuno-phenotypes of Chronic Lung Disease: Revealing the Immunological Dysregulations that Characterize Asthma, COPD, and IPF	September 25-26, 2008 Bethesda, MD	Antonello Punturieri, M.D., Ph.D. punturiera@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.

### Dr. Nabel Receives First National Marfan Foundation Scientific Leadership Award

The National Marfan Foundation (NMF) honored NHLBI Director Elizabeth Nabel by naming her the first recipient of the organization's Scientific Leadership Award. During its Awards Dinner, which occurred this year on July 12 as part of the Foundation's Annual Conference, the NMF recognizes individuals for achievements in serving the Marfan syndrome community. The NMF's Annual Conference convenes patients and their families along with leading Marfan syndrome researchers and physicians, allowing individuals to network and learn about new research. Marfan syndrome is a disorder of connective tissue that can cause serious problems in various parts of the body, notably in the aorta and heart valves.

The NMF presented Dr. Nabel with its Scientific Leadership Award "for her visionary leadership in support of the Marfan syndrome and related disorders community." In accepting the award, Dr. Nabel highlighted the work of the Pediatric Heart Network (PHN), which was established in 2001 by the NHLBI to accelerate research to improve the quality of life of children with congenital and acquired pediatric heart disease. The PHN comprises a clinical coordinating center and 8 medical centers that each follow the same study protocols in order to ensure consistent and reliable results. One of the current studies in the PHN involves a potentially new treatment to prevent enlargement of the aorta, a potentially deadly effect of Marfan syndrome.

Dr. Nabel noted the NMF's extraordinary work educating patients and collaborating with the NHLBI to link researchers, clinicians, industry, and patients. The NMF has also helped further the efforts of the Marfan study by

financially helping patients with the logistics associated with participation. The NMF is one of the NHLBI's Public Interest Organizations (PIOs), and the research advances in Marfan syndrome were highlighted in a panel presentation at June's PIO Meeting.

#### *Mark Your Calendar . . .*

<b>September</b>	National Cholesterol Education Month ( <a href="http://hin.nhlbi.nih.gov/cholmonth">hin.nhlbi.nih.gov/cholmonth</a> )
<b>October</b>	Healthy Lung Month ( <a href="http://www.lungusa.org">www.lungusa.org</a> )
<b>4th</b>	Sarcoidosis Awareness Day ( <a href="http://nationalsarcoidosisfriends.org">nationalsarcoidosisfriends.org</a> , <a href="http://tripod.com">tripod.com</a> )
<b>November</b>	Pulmonary Hypertension Awareness Month ( <a href="http://www.phassociation.org">www.phassociation.org</a> )
<b>December 1st-7th</b>	National Aplastic Anemia and MDS Awareness Week ( <a href="http://www.aamds.org">www.aamds.org</a> )

## NHLBI Research Initiatives

From time to time, the NHLBI invites investigators to submit grant applications or contract proposals for specific research programs. We are soliciting applications for the following new programs. Please visit the URL listed with each program to obtain information about important application dates and deadlines. For full descriptions of these and other current research initiatives, visit [www.nhlbi.nih.gov/funding/inits/index.htm](http://www.nhlbi.nih.gov/funding/inits/index.htm).

### **Developmental Origins of Altered Lung Physiology and Immune Function (R01)** (HL-08-009)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-009.html>

*Objective:* Understand how the pre- and post-natal environments affect the developing lung and immune system at the molecular and cellular levels, resulting in sustained changes in lung physiology and immune function and decrements in respiratory health and outcomes.

### **NHLBI Asthma Network (AsthmaNet) -- Clinical Centers and Data Coordinating Center (U10)** (HL-08-010/011)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-010.html>

*Objective:* Develop and conduct multiple clinical trials that address the most important management and new treatment questions in asthma by establishing a network to promote cooperation and coordination, facilitate scientific exchange, and leverage resources across the spectrum of age and disease severity.

### **Collaborative Interdisciplinary Team Science in Diabetes, Endocrinology, and Metabolic Diseases (R24)** (PAR-08-182)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-182.html>

*Objective:* Enable strong investigative teams to do inter- and/or trans-disciplinary research on diabetic cardiomyopathy independent of hypertension and coronary artery disease.

### **Research Supplements to Promote Re-Entry into Biomedical and Behavioral Research Careers** (PA-08-191)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-191.html>

*Objective:* Support individuals with high potential to re-enter an active research career after a qualifying interruption for family or other responsibilities.

### **Research Supplements to Promote Diversity in Health-Related Research** (PA-08-190)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-190.html>

*Objective:* Improve the diversity of the research workforce by recruiting and supporting students, postdoctoral students, and eligible investigators from groups that have been shown to be underrepresented.

### **Geographic and Contextual Influences on Energy Balance-Related Health Behaviors (R01)** (PA-08-192/193)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-192.html>

*Objective:* Explore the influence of the built environment, and other contextual features of where people of all ages live and work, on diet, weight, and physical activity.

### **Impact of Health Communication Strategies on Dietary Behaviors (R01)** (PA-08-239/240)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-239.html>

*Objective:* Develop and implement effective communication strategies related to diet and health.

### **Research on Causal Factors and Interventions that Promote and Support the Careers of Women in Biomedical and Behavioral Science and Engineering (R01)** (RFA-GM-09-012)

<http://grants1.nih.gov/grants/guide/rfa-files/RFA-GM-09-012.html>

*Objective:* Study (1) factors that promote or impede careers of women in biomedical and behavioral science and engineering, and (2) the efficacy of programs designed to eliminate gender disparities and to support the careers of women in these disciplines.

### **Meetings, Conferences, and Networks for Research Partnerships to Improve Functional Outcomes (R13)** (PAR-08-207)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-207.html>

*Objective:* Through meetings, conferences, and networks, create opportunities for forming strong and effective multidisciplinary scientific teams to address basic, translational, and clinical research problems in the management of chronic disease.

### **Methodology and Measurement in the Behavioral and Social Sciences (R01/R21)** (PAR-08-212 (R01), PAR-08-213 (R21))

<http://grants.nih.gov/grants/guide/pa-files/PA-08-212.html>

*Objective:* Improve the quality and scientific power of data collected in the behavioral and social sciences that are relevant to the mission of the NHLBI.

### **Fogarty International Research Collaboration -- Behavioral and Social Sciences (FIRCA-BSS) Research Award (R03)** (PAR-08-223)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-223.html>

*Objective:* Facilitate collaborative behavioral and social sciences research between scientists supported by the NIH and investigators in low- and middle-income countries.

### **Using Systems Science Methodologies to Protect and Improve Population Health (R21)** (PAR-08-224)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-224.html>

*Objective:* Apply one or more specific system science methodologies to "policy resistant" public health and health care systems problems of a behavioral and/or social nature. Systems science methodologies are designed to understand connections between a system's structure and its behavior over time.

### **Ancillary Studies in Clinical Trials (R01)** (RFA-HL-09-001)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-09-001.html>

*Objective:* Use the patient cohorts, data, and biological materials of ongoing Phase II and Phase III clinical trials to carry out ancillary studies related to disease mechanisms, genetics, proteomics, therapeutic response, quality of life, behavioral lifestyle issues, treatment adherence, and/or health economic questions.

# National Heart, Lung, and Blood Advisory Council Meeting

**June 11, 2008**

Dr. Nabel welcomed members to the 230th meeting and introduced a new Council member, Dr. Marlene Rabinovitch from the Stanford University School of Medicine.

Dr. Nabel welcomed Dr. Stephan Bour to the NHLBI as Director of the Center for Biomedical Informatics and announced two other changes in personnel: Dr. Chris O'Donnell, Senior Advisor to the NHLBI Director for Genetics and Genomics, will serve concurrently as Scientific Director of the Institute's SNP Health Association Resource (SHARE) Program and Dr. Keith Hoots will join the Institute in January as Director of the Division of Blood Diseases and Resources. He is currently at the University of Texas Medical School at Houston and the University of Texas M.D. Anderson Cancer Center.

In March 2008, the NHLBI announced a comprehensive restructuring of its research program in sickle cell disease (SCD) based on recommendations from a Council review of the Institute's research and training portfolio in SCD. Dr.

Nabel and Dr. Susan Shurin, NHLBI Deputy Director, published an editorial in the May 15 issue of *Blood*, to explain the new directions envisioned for the SCD research program.

Dr. Nabel addressed the recent effort to study the NIH peer review system and determine ways to enhance it. With regard to a related NHLBI policy issue, Dr. Nabel discussed an effort to reduce the burden currently imposed on applicants, reviewers, and NHLBI staff by the large number of amended applications submitted each year.

Ms. Paula Polite, Council member and Manager of Quality Programs, Division of General Services for the City of Memphis, Tennessee, reported on the ninth annual Public Interest Organization (PIO) meeting. She said that the PIO meetings are always a useful opportunity for attendees to learn how their organizations and the NIH can work together for their mutual benefit. Several PIO representatives attended the Council meeting and Dr. Nabel conveyed to them the Institute's pleasure in hosting members of the PIOs each year.

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## News from Capitol Hill

### President Signs Newborn Screening Legislation

On April 24, the President signed into law the Newborn Screening Saves Lives Act (Public Law 110-204) to establish new programs through the Health Resources and Services Administration for education and outreach on the availability and importance of newborn screening. The new law establishes an Interagency Coordinating Committee on Newborn and Child screening that will include the NIH and authorizes the NIH to continue to work with the Secretary of the Department of Health and Human Services to carry out, coordinate, and expand research in newborn screening.

### President Signs Genetic Information Nondiscrimination Act

On May 21, the President signed into law H.R. 493 (P.L. 110-233), a measure that prohibits employers from requiring genetic tests or using genetic information when making personnel decisions and prohibits insurers from using genetic information to set premiums or make decisions on eligibility for coverage.

### Supplemental Appropriations Act of 2008 Provides Additional Funding for NIH

On June 30, the President signed into law H.R. 2642

(P.L. 110-252), a Supplemental Appropriations Act, which provided additional funds for the 2008 fiscal year to support ongoing military operations as well as some domestic programs. The supplemental appropriation included \$150 million for the NIH.

### Pulmonary Fibrosis Legislation Introduced

On July 22, Representative Brian Baird (D-WA) introduced H.R. 6567, the Pulmonary Fibrosis Research Enhancement Act. The legislation would encourage the NHLBI Director to expand, intensify, and coordinate Institute activities with respect to pulmonary fibrosis (PF) research. It also would require a national summit be held every three years to provide a detailed overview of current PF research activities at the NIH and to discuss potential collaborations related to PF among the NIH, the Centers for Disease Control and Prevention, and other Federal agencies.

### Pulmonary Hypertension Legislation Introduced

On July 22, Representative Kevin Brady (R-TX) introduced H.R. 6568, the Tom Lantos Pulmonary Hypertension Research and Education Act of 2008. The measure would encourage the Secretary of HHS to work with the Directors of NIH and NHLBI to continue research on and expand understanding of the causes of pulmonary hypertension and to find a cure.

## Upcoming Events

Activity	Date/Location	More Information
Pseudoxanthoma Elasticum PXE 2008 International Meeting	September 19-21, 2008 Bethesda, MD	<a href="http://www.pxe.org/english/View.asp?x=1722">http://www.pxe.org/english/View.asp?x=1722</a>
Preeclampsia Foundation Saving Grace: A Night of Hope	September 20, 2008 Washington, DC	<a href="http://www.preeclampsia.org/svgrace.asp">http://www.preeclampsia.org/svgrace.asp</a>
American Autoimmune Related Diseases Association, Inc. 2nd Moscow International Conference	September 26-28, 2008 Moscow, Russia	<a href="http://www.aarda.org/upcoming_events.php">http://www.aarda.org/upcoming_events.php</a>
HHT Foundation International, Inc. National Patient and Family conference	September 26-28, 2008 Chicago, IL	<a href="http://www.hht.org/living-with-hht/patients-and-family-conferences/">http://www.hht.org/living-with-hht/patients-and-family-conferences/</a>
Narcolepsy Network, Inc. 2008 Annual Narcolepsy Network Patient Conference	October 3-5, 2008 Milwaukee, WI	<a href="http://www.narcolepsynetwork.org/08conference.php">http://www.narcolepsynetwork.org/08conference.php</a>
American Obesity Association 2008 Annual Scientific Meeting	October 3-7, 2008 Phoenix, AZ	<a href="http://www.obesity.org/annualmeeting08/2008_annual_meeting.asp">http://www.obesity.org/annualmeeting08/2008_annual_meeting.asp</a>
Fanconi Anemia Research Foundation, Inc. Twentieth Annual Scientific Symposium	October 4-7, 2008 Eugene, OR	<a href="http://www.fanconi.org/research/Symposium/20th5.html">http://www.fanconi.org/research/Symposium/20th5.html</a>
National Heart, Lung, and Blood Advisory Council 232nd Meeting	October 21, 2008 Bethesda, MD	<a href="http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm">http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm</a>

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### Science Advance from the NHLBI: A Common Genetic Variant Is Associated with Abdominal Aortic Aneurysm and Intracranial Aneurysm

Abdominal aortic aneurysm (AAA) is a common condition with potentially lethal consequences. Ruptured AAAs and complications after surgical repair are responsible for at least 15,000 deaths per year in the United States. Most aortic aneurysms are detected incidentally from images created for other purposes or through screening programs. Advanced age, cigarette smoking, male gender, hypertension, whether treated or not, and family history have been the most frequently recognized AAA risk factors. Better methods are needed to identify individuals at risk for AAA who would benefit from screening and possible intervention.

NHLBI-funded investigators found that a common genetic sequence variant, which was previously linked to myocardial infarction, also is associated with risk for AAA and for intracranial aneurysm (IA). The variant was studied in several populations (Iceland, UK, US, Belgium, New Zealand, Canada, Finland, and the Netherlands) and found to be associated with AAAs of all sizes, whether symptomatic or asymptomatic. People who carried one copy of the variant had an increased risk for both AAA and IA of more than 30 percent compared with non-carriers, and risk was elevated more than 70 percent in people with two copies.

This study is the first to demonstrate an association of a common genetic variant with AAA and IA that replicates in several populations. The discovery, if augmented by future identification of additional genetic variants, is expected ultimately to enable better prediction of risk for these conditions.





## Constituents' Corner



*No constituents' submissions were received for this issue.*

*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](mailto:nhlbi.listens@nih.gov) or Public Interest News, Office of Science and Technology, Building 31, Room 5A07, 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.*



### NHLBI Launches New Website about Research in Children

The NHLBI has developed a website about children and clinical studies called *No More Hand-Me-Down Research*.

Children have often had to be treated based on what is known to work in adults, even though they are not simply little adults. This "hand-me-down" approach is now being recognized as ineffective, and efforts are under way to

design research properly for children, in order to find the best treatments, drugs, and devices for them.

The new website explains the importance of research in children and offers information on how to get children involved in clinical trials.

Visit [www.ChildrenAndClinicalStudies.nhlbi.nih.gov](http://www.ChildrenAndClinicalStudies.nhlbi.nih.gov) for more information.

### June 2008 Advisory Council Meeting

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Dr. Susan Old, Acting Deputy Director, Division of Cardiovascular Diseases, NHLBI, reviewed the history and purpose of the NHLBI Proteomics Initiative. In FY 2002, the Institute established a consortium of 10 highly interactive, multi-disciplinary proteomics centers to enhance and develop innovative proteomic technologies and their applications. Directors of three centers — Dr. Jennifer Van Eyk (Johns Hopkins University), Dr. Garry P. Nolan (Stanford

University), and Dr. Thomas Kodadek (University of Texas) — discussed highlights of their research and emphasized that the NHLBI program has revolutionized the field of proteomics.

NHLBI staff presented 18 new initiatives, all of which had been reviewed in May by the Institute's Board of External Experts. The Council was supportive of the initiatives, but made a number of specific recommendations for consideration prior to their release.

### 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](mailto:nabele@nhlbi.nih.gov) or Dr. Carl Roth at [rothc@nhlbi.nih.gov](mailto: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](mailto: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](mailto:nhlbi.listens@nih.gov)).
- For additional information regarding NHLBI events, consult the references provided or [www.nhlbi.nih.gov/calendar/nhcal.htm](http://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](http://www.nih.gov/icd).