

NHLBI Holds Ninth Annual Public Interest Organization Meeting

The NHLBI's Ninth Annual Public Interest Organization (PIO) meeting will be held June 9-10, 2008, at the Bethesda North Marriott Hotel and Conference Center in Bethesda, Maryland. This state-of-the-art conference center is conveniently located near the White Flint station on the Metro system's Red Line. The meeting was moved to June to avoid the winter weather that interrupted last year's February meeting. This year's program will again allow for significant networking time with members of fellow PIOs as well as NHLBI staff.

The meeting starts Monday afternoon, June 9, with registration and a presentation about research conducted on the NIH campus. Activities on Tuesday, June 10, will begin with a presentation by Dr. Elizabeth Nabel, NHLBI Director, on the future of genetic disease mapping with genome-wide association studies. Additionally, Dr. Josephine Briggs, Director of the National Center for Complementary and Alternative Medicine, will speak about how to interpret the array of information available to the public on complementary and alternative medicine.

The program will include a panel discussion on NIH research support. Another session will describe a bench-to bedside case study of Marfan syndrome. Concurrent sessions will be held in the afternoon. One session will give attendees the opportunity to learn about psychosocial issues faced by patients with heart, lung, blood, and sleep disorders (originally scheduled on last year's program), and the other session will explore the logistical struggles two PIOs have encountered with clinical trials. The program will close with an opportunity to meet NHLBI staff members who have expertise in heart development and diseases, vascular diseases, lung diseases, airway diseases, blood diseases and resources, and sleep and sleep disorders.

May Is National High Blood Pressure Education Month

Take this opportunity to adopt a healthy eating plan that can both reduce the risk of developing high blood pressure and lower an already elevated blood pressure. High blood pressure is a major risk factor in the development of cardiovascular disease.

The DASH (Dietary Approaches to Stop Hypertension) study is a clinical trial that tested the effects of nutrients in food on blood pressure. Study results indicated that elevated blood pressures were reduced by the DASH diet, which emphasizes fruits, vegetables, and low-fat dairy foods and is low in saturated fat, total fat, and cholesterol. The DASH eating plan includes whole grains, poultry, fish, and nuts and has reduced amounts of fats, red meats, sweets, and sugared beverages.

A second clinical study, called DASH-Sodium, looked at the effect of a reduced dietary sodium intake on blood pressure as people followed either the DASH eating plan or a typical American diet. Results showed that reducing dietary sodium lowered blood pressure for both the DASH eating plan and the typical American diet. The biggest blood pressure-lowering benefits were for those using the DASH eating plan at the lowest sodium level (1,500 milligrams per day).

DASH and DASH-Sodium show the benefits of diet modification and salt reduction in lowering blood pressure. For more information about the DASH diet, please visit http://www.nhlbi.nih.gov/hbp/prevent/h_eating/h_e_dash.htm.

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Upcoming NHLBI Workshops and Working Groups*

Workshop or Working Group	Date / Location	Contact for More Information
Working Group on Case Finding in COPD	June 9-10, 2008 Bethesda, MD	Thomas Croxton, Ph.D., M.D. croxtont@nhlbi.nih.gov 301-435-0202
Genetics of Sarcoidosis: How Do We Move Forward?	July 2008 Bethesda, MD	Sandra Colombini-Hatch, M.D. hatchs@nhlbi.nih.gov 301-435-0222
Building Partnerships towards a Global Approach to Genetics of Asthma: Establishing a Blueprint for the Future	August/September, 2008 Bethesda, MD	Susan Banks-Schlegel, Ph.D. schleges@nhlbi.nih.gov 301-435-0202
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
Pediatric Respiratory Diseases Strategic Planning Workshop	September 2008 Bethesda, MD	Carol Blaisdell, M.D. blaisdellcj@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.

Science Advance from the NHLBI: Safer Treatment for Sepsis

Sepsis is a systemic response to infection, which can lead to organ failure and in its severe form is fatal in 30 to 50 percent of patients. Treatment with activated protein C (APC) reduces mortality of patients with severe sepsis, but APC also has anticoagulant properties that increase the risk of severe bleeding.

Building upon results from previous studies showing that the mechanisms of APC's anticoagulant activity are partially distinct from the mechanisms of its cell-protective therapeutic activity, NHLBI-funded scientists were able to engineer APC variants that selectively reduced the anticoagulant activity of APC while retaining its therapeutic properties. In a mouse model of severe sepsis, an APC variant that had normal therapeutic activity but 10 percent less anticoagulant activity retained its ability to reduce mortality while also dramatically reducing severe bleeding in comparison with standard APC treatment.

An APC variant with reduced anticoagulant activity may thus provide a safer alternative to standard APC therapy. Clinicians may also be able to give increased doses of APC variants to achieve the desired therapeutic effect against sepsis without risking severe bleeding.

Mark Your Calendar . . .

May	Better Sleep Month (www.bettersleep.org)
	American Stroke Month (www.americanheart.org)
June	National Scleroderma Awareness Month (www.scleroderma.org)
July	Hemochromatosis Awareness Month (www.irondisorders.org)
August 1st	National Minority Donor Awareness Day (www.nationalmottep.org)
September	National Cholesterol Education Month (hin.nhlbi.nih.gov/cholmonth)
30th	World Heart Day (www.worldheart.org)

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.

Research on the Economics of Diet, Activity and Energy Balance (R21/R01) (PA-08-077 and -078)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-077.html>
Objective: Apply the tools of health economics, health services research, and econometric modeling to the study of energy balance in order to better understand the causes of obesity.

The Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery (R01/R21) (PA-08-083 and -084)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-083.html>
Objective: Enhance understanding of the influence of racial and ethnic discrimination and bias in health care delivery systems in the United States and their association with disparities in disease incidence, treatment, and outcomes among disadvantaged racial and ethnic minority groups.

Novel Approaches to Study Polymicrobial Diseases (R01/R21) (PA-08-091 and -092)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-091.html>
Objective: Understand the mechanisms that influence the virulence of infections involving two or more microorganisms or strains of microorganisms (with the exception of HIV).

Rare Diseases Clinical Research Consortia (RDCRC) for the Rare Diseases Clinical Research Network (U54) (RFA-OD-08-001)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-OD-08-001.html>
Objective: Participate in a network of research centers conducting collaborative clinical research in rare diseases, including longitudinal studies of individuals with rare diseases, clinical studies, and/or clinical trials.

Administrative Supplements for Making Knockout Mice (NOT-HG-08-002)

<http://grants.nih.gov/grants/guide/notice-files/NOT-HG-08-002.html>
Objective: Generate knockout mice from mutant embryonic stem cell lines for use in ongoing NHLBI-supported research studies.

Molecular Phenotypes for Lung Diseases (R01) (RFA-HL-08-006)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-006.html>
Objective: Re-define major categories of lung diseases using molecular phenotypes based on RNA and DNA extracted from clinically phenotyped patients and controls.

Small Grants for Lung Tissue Research (R03) (RFA-HL-08-008)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-008.html>
Objective: Use biospecimens and clinical data collected by the NHLBI Lung Tissue Research Consortium in studies that will correlate lung molecular characteristics with phenotypic manifestations of COPD.

Immunomodulatory, Inflammatory, and Vasoregulatory Properties of Transfused Red Blood Cell Units as a Function of Preparation and Storage (R01) (RFA-HL-08-005)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-005.html>
Objective: Improve red blood cell transfusion therapies by conducting basic and translational research to identify the molecular and cellular changes that occur during blood preparation and storage, and evaluate the effects of those changes on the blood vessel wall, host cells, and tissue oxygenation.

New Technologies for Transient Molecular Complex Characterization (SBIR [R43/R44]) (PA-08-110)

<http://grants.nih.gov/grants/guide/pa-files/PA-08-110.html>
Objective: Encourage small businesses to develop technologies, tools, and/or processes for the study of transient molecular complexes by creating new methods or extending existing technologies.

Targeted Approaches to Weight Control for Young Adults (U01) (HL-08-007)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-08-007.html>
Objective: Conduct clinical research studies to develop, refine, and test innovative behavioral and/or environmental approaches for weight control in young adults (18-35 years of age) at high risk for weight gain.

Enhancing Zebrafish Research with Research Tools and Techniques (R01) and Genetic Screens to Enhance Zebrafish Research (R01) (PAR-08-138 and -139)

<http://grants.nih.gov/grants/guide/pa-files/PAR-08-139.html>
Objective: Develop new tools or genetic or genomic resources that will advance the detection and characterization of genes, pathways, and phenotypes of interest in development and aging, organ formation, behavior, sensory processing, normal physiological processes, and disease processes.

National Heart, Lung, and Blood Advisory Council Meeting

February 13, 2008

Dr. Nabel welcomed Council members to the 229th meeting and recognized Dr. Andrew Marks, a member attending his first meeting. Dr. Marks is Professor and Chair of Physiology and Cellular Biophysics and Medicine and Director of the Center for Molecular Cardiology at the College of Physicians and Surgeons, Columbia University. Dr. Nabel also recognized Dr. Marvin Konstam, who officially joined the Institute in January as Senior Advisor to the NHLBI Director in Cardiovascular Diseases, and announced that Dr. Gail Weinmann has been selected as Deputy Director of the Division of Lung Diseases.

Dr. Nabel updated the Council on The Heart Truth — the Institute's successful heart health awareness campaign for women — and on the Institute's role in this year's Combined Federal Campaign.

Dr. Nabel reviewed the Institute's budget. The FY 2009 President's Budget includes \$2,924,942,000 for the Institute, an increase of \$2.8 million (0.1 percent) over the FY 2008 Enacted Budget.

Dr. Francis Collins, Director, National Human Genome Research Institute, presented Dr. Nabel with the "NHGRI Special Recognition Award" for her leadership in areas important to the NHGRI, such as integrating genomics into research about heart, lung, and blood diseases and developing a trans-NIH policy for sharing data obtained in NIH-supported or NIH-conducted genome-wide association studies.

Dr. Christopher O'Donnell, Senior Advisor to the NHLBI Director for Genome Research and Associate Director of the Framingham Heart Study, discussed the Framingham Heart Study SNP Health Association Resource (Framingham SHARe). Framingham SHARe examined 550,000 genetic variants in over 9,000 study participants across three generations. The linked genotype-phenotype data are now stored in a database and are available, with appropriate safeguards for participant confidentiality, to authorized investigators around the world. Since October 2007, twelve applications for Framingham SHARe data have been approved. The NHLBI plans to add data from several of its other large cohorts to SHARe.

Ms. Linda Avey, co-Founder and President of 23andMe, Inc., a privately held personal genetics company, discussed the objectives and services of her company. Customers provide a saliva sample using an at-home kit and can then use web-based interactive tools to learn more about their distant ancestors and family inheritance, and receive an individual risk assessment for various diseases.

Dr. Sonia Skarlatos, Deputy Director, Division of Cardiovascular Diseases, explained the Institute's plan to partner with the National Cancer Institute (NCI) to expand the NCI RAID (Rapid Access to Interventional Development) program for use by NHLBI-supported investigators. The goal of the RAID program is to remove common barriers between laboratory discoveries and clinical trials of new molecular entities.

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News from Capitol Hill

Congress Passes Newborn Screening Legislation

The House and Senate have passed legislation (S.1858) to establish grant programs for education and outreach on newborn screening and follow-up care. If signed into law by the President, the "Newborn Screening Saves Lives Act of 2008" would authorize new programs intended to evaluate and improve newborn screening.

Honoring the Contributions of Clinical Trial Participants

A resolution to honor the contributions of patient participants in clinical trials, H. Res. 248, was introduced in the House by Representative Rick Boucher (D-VA) on March 15, 2008.

Senate Passes the Genetic Information Nondiscrimination Act

On April 24, 2008, the Senate passed S. 358, a bill to prohibit discrimination by health insurers and employers on the basis of predictive genetic information. If signed into law by the President, the bill will prohibit employers from requiring genetic tests or using genetic information when making personnel decisions and will prohibit insurers from using genetic information to set premiums or make decisions on eligibility for coverage.

National Cystic Fibrosis Awareness Month

A resolution supporting the goals and ideals of National Cystic Fibrosis Awareness Month, S. Res. 510, was introduced in the Senate by Senator Patty Murray (D-WA) on April 10, 2008.

Upcoming Events

Activity	Date/Location	More Information
Cooley's Anemia Foundation 22nd Annual Thalassemia Action Group Patient and Family Conference	May 9-11, 2008 Washington, DC	http://www.thalassemia.org/sections.php?sec=357
American Society of Hypertension 23rd Annual Meeting	May 14-17, 2008 New Orleans, LA	http://www.ash-us.org/annual_meeting/index.htm
American Thoracic Society 2008 International Conference	May 16-21, 2008 Toronto, Canada	http://www.thoracic.org/sections/meetings-and-courses/international-conference/2008/index.html
Mended Hearts Annual Convention	May 24-28, 2008 Hartford, CT	http://www.mendedhearts.org/frame-events.htm
National Heart, Lung, and Blood Advisory Council 230th Meeting	June 11, 2008 Bethesda, MD	http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Pulmonary Hypertension Association 8th International Conference and Scientific Session	June 20-22, 2008 Houston, TX	http://www.phassociation.org/Conference/
Platelet Disorder Support Association Immune Thrombocytopenic Purpura Conference 2008	June 20-22, 2008 Lombard, IL	http://www.pdsa.org/itp-conferences/2008-itp-conference/index.html
Barth Syndrome Foundation 4th International Scientific, Medical and Family Conference	July 21-26, 2008 Clearwater, FL	http://www.barthsyndrome.org/english/View.asp?x=1
National Lymphedema Network 8th NLN International Conference	August 27-31, 2008 San Diego, CA	http://www.lymphnet.org/2008conf/2008conf.html
Pseudoxanthoma Elasticum PXE 2008 International Meeting	September 19-21, 2008 Bethesda, MD	http://www.pxe.org/english/View.asp?x=1722

Websites Worth Bookmarking

MedLine Plus is an important source of health information. Developed and maintained by the National Library of Medicine of the NIH, MedLine Plus offers information about numerous diseases, descriptions of drugs and supplements, and listings of sources to help you find doctors, hospitals, and health-related organizations.

Access MedLine Plus at <http://www.nlm.nih.gov/medlineplus/>.

ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted in the United States and around the world. It provides information about a trial's purpose, requirements for participation, locations, and phone numbers for more details.

To get started with ClinicalTrials.gov, visit <http://clinicaltrials.gov/>.



Constituents' Corner



From Barth Syndrome Foundation

4th International Scientific and Medical Conference

The Barth Syndrome Foundation will hold its 4th International Scientific and Medical Conference, "Barth Syndrome: On Track Toward a Cure," on July 24 and 25, 2008, in Clearwater, Florida.

The world's leading researchers and clinicians will give presentations on many topics ranging from advances in understanding the underlying biochemistry, to the latest findings utilizing various model systems, to improving clinical aspects of this disorder.

The conference will bring together basic scientists, clinical researchers, treating physicians, and health professionals to focus on the syndrome through a series of carefully organized sessions.

Major agenda topics include the biochemical role of the tafazzin gene, the roles of cardiolipin and other lipids in Barth Syndrome, the phenotypic consequences of tafazzin dysfunction, the scope of Barth Syndrome, and what is being done for treatment. Numerous issues in all of these areas continue to perplex even the most seasoned investigators, so this will be a very stimulating meeting that looks toward the future. In addition to the formal presentations, there will be a poster session.

The Scientific and Medical Conference is part of the broader Scientific, Medical, and Family Conference that will take place July 21st through 26th.

For more information, visit www.barthsyndrome.org.

Submitted by Lynda Sedefian, Barth Syndrome Foundation

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 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.



February 2008 Advisory Council Meeting

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Dr. Denise Simons-Morton, Chief of the Clinical Applications and Prevention Branch, Division of Prevention and Population Sciences, and ACCORD Project Officer, described the ACCORD trial and summarized the recently reported findings that led to the decision to discontinue the intensive glycemic treatment arm of the study.

Dr. Katherine High, Professor of Pediatrics at the University of Pennsylvania and Chair of the Council Subcommittee for Review of the NHLBI Sickle Cell Disease Program, presented the subcommittee's findings and recommendations for future directions. Dr. Nabel and Council members commended the subcommittee for its valuable contribution and assured that the resulting recommendations will be considered carefully by the Institute.

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.