National Heart Lung and Blood Institute
People Science Health

fyi from the NHLBI

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Eighth Annual Public Interest Organization Meeting

The NHLBI will hold the Eighth Annual Public Interest Organization (PIO) meeting at the Doubletree Hotel in Bethesda on February 12-13, 2007. This year's meeting promises to have a wide range of offerings that are sure to benefit the PIO representatives in attendance.

The meeting will kick off on the afternoon of Monday, February 12, with registration, networking, and a presentation on the "State of the NHLBI: The NHLBI Strategic Plan and the Future" by NHLBI Deputy Director, Dr. Susan Shurin.

Tuesday's activities will begin with a continental breakfast and an agenda overview. Before lunch, attendees will hear presentations on nitrite therapy, pulmonary hypertension, engaging the scientific community in rare disease research, the grants process, and understanding clinical trials.

Afternoon activities include sessions on biomarker development, stem cell technology, and psychosocial issues. In addition, roundtable discussions will provide PIO representatives an opportunity to meet NHLBI staff covering areas of heart disease and development, vascular disease, lung diseases, airway diseases, blood diseases and resources, and sleep and sleep disorders. This year, in response to all the positive comments we received from the last meeting, we have once again set aside plenty of non-structured time to encourage interaction and networking.

Our Logo Gets a Makeover

You probably noticed something different about the front page of this issue. Our NHLBI logo has changed. After almost 30 years of service, the old NHLBI logo has been retired. Our new logo depicts a red heart, surrounded by two white lungs, encased in a red blood cell. This fresh look reflects the Institute's renewed commitment to supporting scientific discovery and improving the nation's health.

OPEC Becomes CARD

Dr. Elizabeth G. Nabel , Director NHLBI, recently announced that the NHLBI Office of Prevention, Education, and Control will become the Center for the Application of Research Discoveries (CARD).

CARD will use new knowledge networks, education programs, community outreach, and conferences and symposia to connect research and practice fields, identify knowledge gaps, manage emergent knowledge for rapid translation, and facilitate knowledge sharing and collaboration.

Dr. Nabel explained, "Our challenge is to narrow the gap from scientific discovery to application. Under the leadership of Dr. Gregory Morosco, this new Center will strengthen the Institute's ability to translate our research findings and educate health professionals, patients, and the public."

Reaching out to people in at-risk, low-income, and minority communities through its community outreach efforts will remain a high priority for CARD. In addition, the Center will continue to provide media relations services for the Institute and operate the NHLBI Health Information Center.

Inside

Upcoming NHLBI Workshops and Working Groups*

Workshop or Working Group	Date / Location	Contact for More Information
Working Group: Pulmonary Networks in the 21st Century	March 2007 Location to be determined	Dr. Robert Smith smithra@nhlbi.nih.gov 301-435-0202
Working Group: Lung Cancer and COPD, Different Outcomes of a Common Etiopathogenetic Pathway	June 2007 Location to be determined	Dr. Antonello Punturieri punturieria@nhlbi.nih.gov 301-435-0202
Workshop: Identifying a Parts List for the Lung	June 2007 Location to be determined	Dr. Herbert Reynolds reynoldh@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.

PIO Meeting: Personal Experiences

The following perspective on the Seventh Annual PIO Meeting, held in 2006, was provided by Ms. Hoxi Jones of the Texas Health and Human Services Commission. Ms. Jones is currently serving as a member of the National Heart, Lung, and Blood Advisory Council.

The Public Interest Organization (PIO) Meeting was invaluable as it provided the opportunity to meet others like me living with a disease. Mine just happens to be sickle cell anemia, but there were folks there with hemophilia, sarcoidosis, restless leg syndrome, and ailments with names I'm not even going to butcher here.

Dr. Elias Zerhouni, Director NIH, and Dr. Elizabeth Nabel, Director NHLBI, opened up the one-and-a-half day session by outlining the goals and objectives of the NHLBI and then fielded questions. What impressed me about Dr. Zerhouni is his frankness. There was one question he didn't have an answer for and he readily admitted it. I don't know many CEOs who have the fortitude to do that.

Dr. Nabel invited the PIO's involvement in the strategic planning process, which will take place over the coming months. Everyone's input will be needed in order to make it a viable endeavor.

There was a great presentation by Mr. Carl Weixler from the Hemophilia Federation of America. Listening to how others struggle and how they surmount their obstacles is always a learning experience for me. You can easily get into the mindset of "this is only happening to me," but that's never the case.

One PIO member requested that the NHLBI consider us in our totality — a whole wellness approach, not limited to just the clinical perspective. The fact is, we struggle daily with the vagaries of our disease but our quality of life is often compromised. There's not much addressing this aspect and to that end she requested the NHLBI to make this a priority. I wholeheartedly agree and encourage the NHLBI to place this on its agenda.

We ended just as we began — on a high note. Attendees met with their respective individual NHLBI division. For me, that meant the Division of Blood Diseases and Resources, led by Dr. Charles Peterson. I found myself sitting across the table from the people I usually speak to by phone. This informal, intimate setting was ideal for soliciting input and exchanging perspectives in a relaxed atmosphere.

All in all it was a most worthwhile day and a half and I look forward to future PIO meetings.

Mark Your Calendar . . .

January:	National Blood Donor Month *(www.aabb.org)*
February:	American Heart Month *(www.americanheart.org)*
2nd	National Wear Red Day 2007 *(www.nhlbi.nih.gov/health/hearttruth)*
16th	National Women's Heart Day *(www.womansheartday.org)*
March:	National Nutrition Month *(www.eatright.org)*
April:	National Donate Life Month *(www.organdonor.gov/)*

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.

Arrhythmia Detection and Treatment: New Approaches (PA-07-031/032)
http://grants.nih.gov/grants/guide/pa-files/PA-07-031.html
Objective: Develop new or improved methods, tools, technologies, and approaches for the detection, treatment, and prevention of arrhythmias. Only United States small business concerns are eligible to apply for this program.

Behavioral and Social Sciences: Methodology and Measurement (PA-07-060 (R01), PA-06-343)
http://grants.nih.gov/grants/guide/pa-files/PA-07-060.html
Objective: Improve the quality and scientific power of data collected in the behavioral and social sciences that are relevant to the missions of the NIH Institutes and Centers.

Biomedical Computational Science and Technology Innovations (PAR-06-088, PAR-06-089)
http://grants.nih.gov/grants/guide/pa-files/PAR-06-088.html
Objective: Promote research and development in biomedical computing and biomedical information science and technology in order to ensure (1) better management and analysis of biomedical data and (2) better modeling of biological processes. Four parallel program announcements for this initiative use the R21, R01, R41/R42, and R43/R44 award mechanisms, respectively.

Demonstration and Dissemination Grants (PA-07-017)
http://grants.nih.gov/grants/guide/pa-files/PA-07-017.html
Objective: Conduct demonstration and dissemination studies to test the effectiveness of extending or adapting to broader populations or settings generally accepted interventions to promote healthful behaviors, prevent disease, or ameliorate disease. Applicants are encouraged to use randomized trial designs with intervention and comparison (control) groups in defined populations, or defined clinical or community settings.

Health Literacy: Understanding and Promoting (PAR-07-018)
http://grants.nih.gov/grants/guide/pa-files/PAR-07-018.html
Objective: Conduct empirical research on health literacy concepts, theory, and interventions as these relate to DHHS public health priorities. Applications should address health promotion, injury or disease prevention, treatment or management of injuries, diseases or health conditions, and/or the improvement of health or health care outcomes within specific populations (e.g., children, the elderly, low income or vulnerable or underserved populations).

Mind-Body Interactions and Health (PA-07-046)
http://grants.nih.gov/grants/guide/pa-files/PA-07-046.html
Objective: Understand the processes underlying the relationships among cognitions, emotions, personality, social relationships, and health and apply this knowledge to interventions and clinical practice that promote health and prevent and treat disease and disabilities.

Obese Patients: Improving Health Care (PA-07-013)
http://grants.nih.gov/grants/guide/pa-files/PA-07-013.html
Objective: Determine the barriers to optimal health care for obese patients and test innovations or modifications in care delivery to improve health outcomes for obese patients independent of weight loss.

Right Heart Function in Health and Chronic Lung Diseases (PA-07-043)
http://grants.nih.gov/grants/guide/pa-files/PA-07-043.html
Objective: Explore the cellular, molecular, and physiological determinants of right ventricular function and dysfunction associated with chronic lung diseases and airway disorders in order to better understand the links between right heart failure and chronic lung diseases. This announcement is intended to promote collaboration between the heart and lung research communities.

Research Advances from the NHLBI

Improving Gene Therapy for People Who Have Hemophilia A

A new gene therapy technique holds promise for some hemophilia patients who have lost the ability to benefit from standard treatment. People who have hemophilia A lack a functional form of factor VIII, a protein that enables the blood to clot in response to injury. Although infusions of replacement protein are effective, 20 to 30 percent of patients eventually develop antibodies that inhibit the protein's clotting activity and render subsequent infusions ineffective. Gene therapy has been viewed as a promising treatment for hemophilia, but most of the gene therapy strategies currently being pursued use liver cells to produce factor VIII protein. Such an approach would not benefit patients with inhibitory antibodies because the liver-produced factor VIII protein would be inactivated before it reached the site of injury.

However, researchers have now developed a strategy for expressing the factor VIII gene in blood platelets instead of in the liver. Because circulating platelets home to the site of injury before releasing their contents, they could deliver factor VIII protein directly to where it is needed for clotting. Using a mouse model of hemophilia A, researchers demonstrated that platelet-produced factor VIII protein stopped bleeding even in mice with circulating inhibitory antibodies. Although much more work is needed before gene therapy is offered as a realistic treatment for hemophilia patients, the latest finding indicates that continued research in this area might benefit more patients than previously thought.

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National Heart, Lung, and Blood Advisory Council Meeting

September 12, 2006

Dr. Nabel welcomed Council members and recognized five members who are retiring: Drs. Gordon Bernard, Kim Eagle, Frances Henderson, Ngai Nguyen, and Maria Costanzo.

Dr. Nabel introduced Dr. Alan Michelson, the Institute's new Associate Director for Basic Research. He comes to the NIH from the Howard Hughes Medical Institute and the Division of Genetics in the Department of Medicine at the Brigham and Women's Hospital, Harvard Medical School. Dr. Michelson will have responsibility for NHLBI basic science policies, development and integration of basic sciences initiatives within the NHLBI, and coordination of these policies and programs with other NIH institutes and federal agencies.

Dr. Nabel highlighted an NIH Request for Information that seeks public input (by October 31) on a proposed new NIH policy designed to facilitate the research community's access to data resulting from NIH-funded genome-wide association studies.

Dr. Nabel explained the recent decline in success rates of NIH grant applications, noting that the number of applications has increased each year since the end of the NIH budget doubling, while the NIH budget has remained almost flat. The FY 2007 President's Budget proposed for the NHLBI is almost $30 million less than the FY 2006 appropriation. However, the Institute expects to be able to support an increased number of competing research project grants in FY 2007 because fewer noncompeting research project grant awards are anticipated.

Dr. Nabel provided an update on the Strategic Plan. She also noted that the NHLBI has a new logo.

The NHLBI has undergone some reorganization. The Institute has a new Division of Extramural Research Activities (DERA) directed by Dr. Stephen Mockrin. In addition to supporting grants management and review, DERA will have a new Office of Staff Training and Communication and a new Office of Strategic and Innovative Programs.

At the request of the NHLBI, a panel of eminent researchers reviewed the organization of the Institute's extramural cardiovascular program. In response, the Institute reorganized its cardiovascular program into two new Divisions: the Division of Cardiovascular Diseases (DCVD) - with five disease-oriented branches; and the Division of Prevention and Population Sciences (DPPS) - with two branches. The new Acting Directors of DCVD and DPPS are Drs. Sonia Skarlatos and Peter Savage, respectively.

Dr. Keith Horvath, Director of the NHLBI intramural Cardiothoracic Surgery Research Program, which works closely with Suburban Hospital in Bethesda, Maryland, discussed his lab's current research interests, and described the facilities and capabilities of the NIH Heart Center at Suburban Hospital.

NHLBI Deputy Director, Dr. Susan Shurin, discussed tracking of clinical trials. She explained that the Institute routinely monitors patient accrual for its clinical studies, reviews the composition of its clinical study populations, and monitors all clinical studies annually. In addition, the Institute is working with the grantee community to help them enhance the accuracy of their enrollment projections, develop mechanisms to aid recruitment, and enhance self-regulation by use of rewards for doing well and consequences for not meeting targets.

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News from Capitol Hill

Continuing Resolution for Fiscal Year (FY) 2007

The Congress passed a continuing resolution (H.J.R. 102) on December 8, 2006, as a short-term measure to continue funding for the NIH at the FY 2006 level. The President signed the resolution into law on December 9, 2006 (P.L. 109-383). The new continuing resolution, which will expire on February 15, 2007, is the third temporary funding resolution passed by the Congress for the 2007 fiscal year, which began on October 1, 2006.

The National Institutes of Health Reform Act of 2006

On December 8, 2006 the Congress passed the National Institutes of Health Reform Act of 2006 (H.R. 6164) to reauthorize the NIH. If signed into law by the President, the measure would create a new Division of Program Coordination, Planning, and Strategic Initiatives within the office of the NIH Director to coordinate trans-NIH activities and develop trans-NIH initiatives. The new law would provide the first reauthorization of NIH since 1993.

Upcoming Events

Activity	Date/Location	More Information
International Association for Chronic Fatigue Syndrome 8th International Conference	January 12-14, 2007 Bahia Mar Beach, FL	www.aacfs.org
American Heart Association International Stroke Conference	February 7-9, 2007 San Francisco, CA	strokeconference.americanheart.org/portal/strokeconference/sc/
National heart, Lung, and Blood Advisory Council 225th Meeting	February 14, 2007 Bethesda, MD	www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Daniella Marie Arturi Foundation: Diamond Blackfan Anemia 8th Annual International Conference	March 17-19, 2007 New York, NY	www.dmaf.org/DMAF/News.asp
American Autoimmune Related Diseases Association 12th International Congress on Antiphospholipid Antibodies	April18-20, 2007 Florence, Italy	www.antiphospholipid.net
LAM Foundation LAM International Research Conference	April 20-22, 2007 Cincinnati, OH	www.thelamfoundation.org/LAM_Conferences.htm
Hereditary Hemorrhagic Telangiectasia Foundation 7th HHT International Conference	April 25-28, 2007 Capri, Italy	www.7th-hhtconference2007.com/
Allergy and Asthma Network Mothers of Asthmatics Asthma Awareness Day Capitol Hill	April 30 - May 2, 2007 Washington, DC	www.aanma.org/cityhall/ch_asthmaaware2007.htm

Research Advances from the NHLBI *Continued from page 3*

Registry Leads to Better Clinical Care

Data collected from the 420 participants in the Diamond-Blackfan anemia (DBA) registry have prompted some physicians to change how they treat patients with DBA.

Although corticosteroids and blood transfusions continue to be the standard therapies for DBA patients, the registry has documented that corticosteroids are likely to cause serious side effects when given to children in the first year of life.

Data from the registry also reveal that more infants are receiving blood transfusions as a first line of treatment, presumably because physicians who care for DBA patients are becoming more cognizant of the risks posed by corticosteroids.

The registry also has led to a new understanding of which patients could benefit from a bone marrow or cord blood transplant.

Because registry participants who received cells from unrelated or mismatched donors were at a higher-than-expected risk of death but those who had a matched sibling donor fared particularly well, investigators are not recommending that DBA patients receive bone marrow or cord blood transplants unless the cells are donated by a well-matched brother or sister.

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Constituents' Corner

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.

Research Advances from the NHLBI *Continued from page 5*

Losartan May Prevent Aortic Aneurysms

New research offers hope that losartan, a drug commonly prescribed to treat hypertension, might also be used to treat Marfan syndrome, a genetic disorder that often causes life-threatening aortic aneurysms. After the discovery that Marfan syndrome is associated with a mutation in the gene encoding fibrillin-1, researchers tried for many years, without success, to develop treatment strategies that involved repair or replacement of fibrillin-1.

Recently, a major breakthrough occurred with the discovery that one of the functions of fibrillin-1 is to bind to another protein, TGF-beta, and regulate its effects. After careful analyses revealed aberrant TGF-beta activity in patients with Marfan syndrome, researchers began to concentrate on treating Marfan syndrome by normalizing the activity of TGF-beta.

Losartan, which is known to affect TGF-beta activity, was tested in a mouse model of Marfan syndrome. The results showed that the drug blocked the development of aortic aneurysms as well as lung defects associated with the disease.

Based on the promising results of the study, the NHLBI Pediatric Heart Network is undertaking a trial of losartan in patients with Marfan syndrome. The effects of losartan on other diseases known to involve abnormal TGF-beta activity are also being explored.

September 2006 Advisory Council Meeting

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Dr. Christopher O'Donnell, Senior Advisor to the Director for Genome Research and Associate Director of the Framingham Heart Study, discussed genome-wide association studies. The Framingham SNP-Health Association Resource (SHARe) will enable studies of connections between genetic variation and common diseases by providing access to genotype information and phenotype data collected from participants of the Framingham Heart Study.

Dr. Charles Friedman, Director of the NHLBI's new Center for Research Informatics and Information Technology (CRIIT), presented the informatics and information technology (IT) goals of the Institute and the plan for reaching them. The long-term goal is to create and maintain an integrated information and knowledge environment for the diverse NHLBI community.

For a more detailed meeting summary, please go to www.nhlbi.nih.gov/meetings/nhlbac/sept06min.htm.

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.