

Tyi from the NHLBI

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12th Annual PIO Meeting Recap

The NHLBI held its Twelfth Annual Public Interest Organization (PIO) meeting on Monday, May 23, and Tuesday, May 24, 2010, in Bethesda, Maryland.

The meeting opened with a presentation by Dr. Lawrence A. Tabak, Principal Deputy Director, NIH. He discussed the NIH budget, noting that despite the doubling of the NIH budget between Fiscal Years 1998 and 2003, the NIH's purchasing power has declined to about what it was in 2001 due to subsequent flat budgets and inflation.

Dr. Tabak briefed the audience on creation of the new National Center for Advancing Translational Sciences (NCATS). The purpose of NCATS is to improve and catalyze the development, testing, and implementation processes for diagnostics and therapeutics. The NCATS will facilitate, but not duplicate, other translational research activities supported by the NIH, complement the private sector, and reinforce commitment of the NIH to basic research.

The program continued with a presentation by Dr. Susan B. Shurin, Acting Director of the NHLBI. She discussed components of the NHLBI strategic plan, specifically how the Institute's priorities are driven by scientific opportunities and public health needs; how basic, clinical, and population research complement each other; and how data from population studies are informing basic science and clinical translational research.

Dr. Shurin also discussed participation by the NHLBI in the NIH Therapeutics for Rare and Neglected Diseases (TRND) Program, a Congressionally mandated effort to speed development of new drugs for rare and neglected diseases that is a collaboration between NIH-intramural and extramural labs with appropriate expertise. Projects can enter TRND at a variety of developmental stages and will be taken to the appropriate phase needed for external organizations to adopt them for clinical development. It will not duplicate PhRMA (Pharmaceutical Research and Manufacturers of America)

projects, but will encourage creative partnerships and novel approaches to intellectual property rights.

Following Dr. Shurin's presentation, PIO representatives had the opportunity to meet NHLBI extramural staff members. This portion of the meeting has always been well received, but this year's version exceeded all expectations because of a new twist: each PIO representative was individually matched to a specific NHLBI staff member with expertise in the disease relevant to the PIO's mission.

Next was a presentation about the NIH Undiagnosed Diseases Program (UDP). The first speaker in this session was Dr. Cynthia Tift, Deputy Clinical Director of the National Human Genome Research Institute. She discussed the UDP, which is a trans-NIH effort focused on diagnosing the most puzzling medical cases referred to the NIH Clinical Center, and highlighted some of the program's intriguing cases. For more information on the UDP, visit <http://www.genome.gov/27544402>.

Following Dr. Tift's remarks, Dr. Robert Balaban, Scientific Director, NHLBI, discussed some of the NHLBI intramural research efforts related to rare and undiagnosed diseases.

A session on dietary supplements was presented by Dr. Paul Coates, Director of the NIH Office of Dietary Supplements, and Ms. Caroline Kruse, Executive Director of the Platelet Disorder Support Association.

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Upcoming NHLBI Workshops and Working Groups*

Workshop or Working Group	Date / Location	Contact for More Information
State of the Science Symposium on Myelodysplastic Syndromes	September 7 – 8, 2011 Bethesda, MD	Dr. Nancy DiFronzo difronzon@nhlbi.nih.gov 301 435-0065
NHLBI Workshop on Transition from Acute to Chronic Pain in Sickle Cell Disease	September 21, 2011 Bethesda, MD	Dr. Harvey Luksenburg luksenburg@nhlbi.nih.gov 301 451-6766
Sickle Cell Disease Advisory Committee Meeting	October 3, 2011 Bethesda, MD	Dr. Keith Hoots, hootswk@nhlbi.nih.gov 301 435-0080

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

12th Annual PIO Meeting Recap

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Dr. Coates gave an overview of his office's mission, which is to strengthen knowledge and understanding of dietary supplements in order to enhance quality of life and health for the U.S. population by evaluating scientific information, stimulating and supporting research, disseminating research results, and educating the public. The Office of Dietary Supplements web site is at <http://ods.od.nih.gov/>.

Ms. Kruse concluded the session on dietary supplements by discussing immune thrombocytopenia (ITP) and the complementary therapies frequently used by patients with ITP and other platelet disorders. For more information about PDSA, please visit <http://www.pdsa.org/>.

The final session, a discussion of collaboration in sharing resources and information, was presented by Mr. James O'Leary, Chief Innovation Officer of Genetic Alliance, Dr. Steve Groft, Director of the NIH Office of Rare Diseases Research (ORDR), and Ms. Audrey Gordon, President and Executive Director of the Progeria Research Foundation.

Mr. O'Leary discussed the activities of his organization, a nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance's network includes more than 1,000 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit <http://www.geneticalliance.org>.

Dr. Groft spoke about collaboration between patient advocacy groups, industry, regulatory agencies, and others in the successful development of therapeutics for rare diseases. He also briefed the audience on the International Rare Diseases Research Consortium, which hopes to develop 200 new

therapies for rare diseases by 2020 and develop diagnostic tests for most rare diseases. For more information, visit <http://rarediseases.info.nih.gov/>.

Ms. Gordon spoke about the progress made in understanding progeria and described her foundation's successful efforts in building a patient registry to enhance research efforts. For more information about the Progeria Research Foundation, visit <http://www.progeriaresearch.org/>.

This year's event drew participants from 20 states and the District of Columbia. In attendance were 81 PIO representatives, representatives of two professional societies, and one National Heart, Lung, and Blood Advisory Council member.

Mark Your Calendar . . .

September National Atrial Fibrillation Awareness Month
(www.stopafib.org)

National Cholesterol Education Month
(hp2010.nhlbihin.net/cholmonth/)

National ITP Awareness Month
(www.pdsa.org/resources/itp-awareness-month.html)

National Sickle Cell Month
(www.sicklecelldisease.org)

30th World Heart Day
(www.worldheart.org)

November COPD Awareness Month
(www.lungusa.org/about-us/our-impact/top-stories/november-is-copd-awareness_1.html)

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 application dates and deadlines. For full descriptions of these and other current research initiatives, visit www.nhlbi.nih.gov/funding/inits/index.htm.

Sleep and Social Environment: Basic Biopsychosocial Processes (R21)

(RFA-HD-12-204)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HD-12-204.html>

Objective: Investigate the interactions of sleep and circadian regulation and function with the behavioral and social environment.

Effects of Secondhand Smoke on Cardiovascular and Pulmonary Disease Mechanisms (R01)

(PA-11-244)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-244.html>

Objective: Characterize the dose-response relationship between secondhand smoke exposure and cardiovascular and pulmonary diseases.

Spatial Uncertainty: Data, Modeling, and Communication (R01)

(PA-11-238 and -239)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-238.html>

Objective: Identify sources of inaccuracy or instability of spatial or geographic information in public health data, adjust for the inaccuracy or instability in statistical methods, and develop novel tools to visualize the nature and consequences of spatial uncertainty.

New Technology for Proteomics and Glycomics (SBIR [R43/R44])

(PA-11-214 and -215)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-214.html>

Objective: Develop broadly applicable research tools that address the core technical challenges in proteomics and glycomics.

Research on Ethical Issues in Biomedical, Social, and Behavioral Research (R01 and R21)

(PA-11-180 and PA-11-182)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-180.html>

Objective: Study high-priority bioethical challenges and issues associated with biomedical, social, and behavioral research.

Ruth L. Kirschstein National Research Service Award (NRSA) Institutional Research Training Grants (Parent T32 and T35)

(PA-11-184 and PA-11-185)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-184.html>

Objective: Enhance research training opportunities for predoctoral and postdoctoral level individuals interested in careers in biomedical, behavioral, and clinical research.

Nutrition and Diet in the Causation, Prevention, and Management of Heart Failure (R21)

(PA-11-165 and PA-11-166)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-165.html>

Objective: Develop nutritional management and preventive measures for patients in various stages of heart failure and for high-risk individuals.

The Effect of Racial and Ethnic Discrimination/Bias on Health Care Delivery (R01 and R21)

(PA-11-162 and PA-11-163)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-162.html>

Objective: Improve the measurement of racial/ethnic discrimination in health-care delivery systems, enhance understanding of its influence, and reduce its prevalence in the United States.

Nanoscience and Nanotechnology in Biology and Medicine (R01 and R21)

(PA-11-148 and PA-11-149)

<http://grants.nih.gov/grants/guide/pa-files/PA-11-148.html>

Objective: Support cutting-edge nanoscience and nanotechnology research for the diagnosis, treatment, and management of an array of diseases and traumatic injuries.

Phase II Clinical Trials of Novel Therapies for Lung Diseases (UM1)

(RFA-HL-12-022)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-12-022.html>

Objective: Test novel interventions that could change significantly the clinical management of a lung disease or a sleep-related cardiopulmonary disorder.

Basic Research in Calcific Aortic Valve Disease (R01)

(RFA-HL-12-015)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-12-015.html>

Objective: Encourage innovative molecular and physiological research leading to early diagnosis or effective medical therapy for calcific aortic valve disease.

Pulmonary Vascular-Right Ventricular Axis Research Program (R01)

(RFA HL-12-021)

<http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-12-021.html>

Objective: Study right ventricular function/dysfunction in order to improve diagnostics and therapeutics.

National Heart, Lung, and Blood Advisory Council Meeting

June 15, 2011

Dr. Shurin welcomed members to the 242nd meeting of the National Heart, Lung, and Blood Advisory Council.

Six new Council members were introduced: Jonathan Alger, J.D., Senior Vice President and General Counsel of Rutgers, The State University of New Jersey; Coletta Barrett, R.N., Vice President of the Mission for Our Lady of the Lake Regional Medical Center, Baton Rouge, LA; Ivor Benjamin, M.D., Professor of Medicine and Biochemistry, University of Utah School of Medicine; Naomi Luban, M.D., Chief of the Division of Laboratory Medicine and Pathology, and Director of the Transfusion Medicine/Donor Center, Children's National Medical Center, Washington, DC; Polly Parson, M.D., Professor of Medicine and Chair of the Department of Medicine, University of Vermont, and Director of the Pulmonary and Critical Care Medicine Unit at the Vermont Lung Center; and Gilbert White, M.D., Executive Vice President for Research and Director of the Blood Research Institute, Blood Center of Wisconsin.

Dr. Shurin updated the Council on formation of the new National Center for Advancing Translational Sciences (NCATS), which will focus on accelerating the development and delivery of new, more effective therapeutics, and formation of an addiction Institute, comprising addiction components of the National Institute on Alcohol Abuse and Alcoholism, National Institute on Drug Abuse, and National Cancer Institute.

Dr. Shurin reported that the NHLBI budget is about 1 percent lower than last year. After adjusting for inflation, the Institute is operating with approximately the same purchasing power it had in 2000-2001. Under the FY 2011 Continuing Resolution, the NHLBI budget is only \$132.1 million more than it was in FY 2008, and the proposed FY 2012 President's Budget for NHLBI is only about \$210.3 million more than the FY 2008 actual budget. NHLBI FY 2011 funding paylines are the same as last year. The Institute continues to emphasize support of investigator-initiated research as much as possible.

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News from Capitol Hill

Pulmonary Fibrosis Legislation Introduced

On July 12, 2011, Senator Christopher Coons (D-DE) and Representative Erik Paulsen (R-MN) introduced the Pulmonary Fibrosis Research Enhancement Act (S. 1350/H.R. 2505) to expand the research, prevention, and awareness activities of the Centers for Disease Control and Prevention (CDC) and the NIH with respect to pulmonary fibrosis (PF). The companion bills would direct the Secretary of the Department of Health and Human Services (DHHS), acting through the Director of CDC, to establish a national PF advisory board, the membership of which would include a representative from the NIH. The bills also would require the CDC to establish a national PF registry. In addition, the legislation would encourage the Director of the NHLBI to expand, intensify, and coordinate activities of the Institute with respect to research on PF.

Hereditary Hemorrhagic Telangiectasia Legislation Introduced

On June 3, 2011, Representative Elton Gallegly (R-CA) introduced H.R. 2123, the Hereditary Hemorrhagic Telangiectasia Diagnosis and Treatment Act of 2011. On June 9, 2011 Senator Tim Johnson (D-SD) introduced a companion measure, S. 1167. The bills would require the DHHS Secretary to establish and implement, in consultation with the Directors of the NIH and the CDC, a hereditary hemorrhagic telangiectasia (HHT) initiative to assist in coordinating activities to improve early detection, screening, and treatment of people who suffer from HHT. The initiative would focus on advancing research and increasing

physician and public awareness of HHT. The bills also would establish an HHT coordinating committee to develop and coordinate implementation of a plan to advance research and understanding of HHT.

Pulmonary Hypertension Legislation Introduced

On May 10, 2011, Representative Kevin Brady (R-TX) introduced H.R. 1810, the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011. Among those provisions related to research, H.R. 1810 would direct the DHHS Secretary, through the NHLBI Director, to continue to encourage basic research on the causes of pulmonary hypertension (PH), including the relationship between scleroderma and sickle cell anemia and PH, clinical research, and training of new clinicians and investigators with expertise in PH. The bill would also require the NIH biennial report to include information on the status of PH research at the NIH. Senator Robert Casey (D-PA) introduced an identical bill, S. 775, on April 8.

Scleroderma Research and Awareness Legislation Introduced

On May 2, 2011, Representative Lois Capps (D-CA) introduced H.R. 1672, the Scleroderma Research and Awareness Act of 2011. The bill would amend the Public Health Service Act to authorize the Director of the NIH to expand, intensify, and coordinate the agency's activities related to scleroderma. The bill also would authorize the DHHS Secretary to carry out a public awareness education campaign. Senator Kristen Gillibrand (D-NY) introduced similar legislation, S.649, on March 17, 2011.

Upcoming Events

Activity	Date/Location	More Information
National Heart, Lung, and Blood Advisory Council 243rd Meeting	September 9, 2011 Bethesda, MD	http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Vascular Disease Foundation Current Issues in Vascular Disease	September 14 – 15, 2011 Washington, DC	http://www.vdf.org/professionals/annualmeeting.php
Nontuberculous Mycobacteria Info & Research, Inc. Patient Conference	September 19 – 20, 2011 Denver, CO	http://ntminfo.org/index.php
Heart Healthy and Stroke Free Society 9th National Forum Meeting	September 22 – 23, 2011 Washington, DC	http://www.cvent.com/events/9th-national-forum-for-heart-disease-stroke-prevention/event-summary-62076c60b50540afb4c19a749bb78806.aspx
Society for the Advancement of Blood Management 2011 Annual Meeting	September 22 – 24, 2011 Philadelphia, PA	http://www.anemia.org/meetings/am2011/
It's My Heart CHD Conference and Family Fun Day	September 23 – 25, 2011 Houston, TX	http://www.itsmyheart.org/get-involved/chd-conference/
Sudden Cardiac Arrest Association 2011 Annual Meeting and Continuing Medical Education Program	September 23 – 25, 2011 Minneapolis, MN	http://associationdatabase.com/aws/SCAA/pt/sp/annualmtg
Aplastic Anemia and MDS International Foundation, Inc. 2011 Patient and Family Conferences	September 24, 2011 Minneapolis, MN October 22, 2011 Tampa, FL	http://www.aamds.org/aplastic/conferences/
Sickle Cell Disease Association of America, Inc. SCDAA 39th Annual Convention	September 27 – October 1, 2011 Memphis, TN	http://www.sicklecelldisease.org/index.cfm?page=annual-convention
Iron Disorders Institute 2011 Conference for the Patient and Physician	October 1 – 2, 2011 Charlotte, NC	http://www.irondisorders.org/2010-iron-conference
Sarcoid Networking Association 19th Annual Conference on Sarcoidosis	October 8, 2011 Portland, OR	http://www.sarcoidosisnetwork.org/
Narcolepsy Network 26th Annual Patient Conference	October 13 – 15, 2011 Las Vegas, NV	http://www.narcolepsynetwork.org/news-and-events/conferences/
Fanconi Anemia Research Fund, Inc. 23rd Annual Scientific Symposium	October 20 – 23, 2011 Barcelona, Spain	http://www.fanconi.org/
American Association for Respiratory Care 57th International Respiratory Congress	November 5 – 8, 2011 Tampa, FL	http://www.aarc.org/education/meetings/
National Hemophilia Foundation 63rd Annual Meeting	November 10 – 12, 2011 Chicago, IL	http://www.hemophilia.org/
Parent Heart Watch 2012 National Conference	January 13 – 15, 2012 New Orleans, LA	http://www.parentheartwatch.org/ActionAdvocacy/Events.aspx

Constituents' Corner

PDSA Announces September as National ITP Awareness Month and September 30th as "Sport Purple for Platelets Day"

The Platelet Disorder Support Association (PDSA) is pleased to announce the inclusion of National ITP Awareness Month and Sport Purple for Platelets Day in the 2011 National Health Observances Calendar. PDSA requested the National ITP Awareness Month designation to increase the public's understanding of ITP and other platelet disorders and to let patients and their families know that there are resources and support available to help them have the best possible outcomes and that they are not alone.

Immune Thrombocytopenia (ITP) is an autoimmune disease in which the body mounts an immune attack toward platelets that are required to maintain integrity of blood vessel walls and for blood to clot. Chronic ITP is perhaps the most common bleeding

disorder. It affects both sexes and all ages and races. The prevalence of adult ITP in the United States is estimated to be as high as 120,000.

PDSA is currently coordinating and promoting ITP Awareness Month initiatives, including *Sport Purple for Platelets Day* on September 30, 2011, PDSA's National Walk/Run: *Pump It Up For Platelets!* - for a world free of ITP, and other awareness events.

For more information, visit our Web site at www.pdsa.org or contact Nancy Potthast at potthast@pdsa.org.

*Submitted by Nancy Potthast, Director of Marketing
Platelet Disorder Support Association*

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.

June 2011 Advisory Council Meeting

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Dr. Eric Green, Director of the National Human Genome Research Institute (NHGRI), NIH, described progress in genomics research that has occurred since the completion of the sequencing of the human genome, and summarized the new NHGRI strategic plan for the future of human genome research, which was published in *Nature* magazine on February 10, 2011. He emphasized the importance of clinical applications of genomics.

Dr. Carl Roth, Acting Deputy Director of the NHLBI and Associate Director for Scientific Program Operation, presented results of an analysis of recent NHLBI participation in the R21 program. The R21 mechanism provides 2 years of funding for exploratory research projects. Dr. Shurin proposed the following NHLBI R21 policy for Council consideration: NHLBI will stop participating in the parent NIH R21 program. Early Stage Investigators, if appropriate and eligible, will be encouraged to explore opportunities to be mentored, such as the NIH Pathway to Independence Award (parent K99/R00). The NHLBI will issue highly targeted RFAs for R21s when scientific opportunities arise, but only established investigators will be eligible for these R21s and

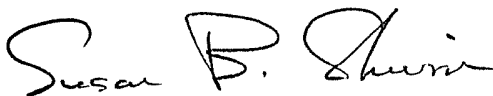
only if the application represents a substantial departure from previous research directions. Council members discussed the proposal and expressed their support.

Dr. Shurin reviewed the elements of the MERIT (Method to Extend Research in Time) program and summarized some recent criticisms. She proposed the following NHLBI MERIT policy for Council consideration: The NHLBI will stop making new MERIT awards, but existing MERIT awards will be extended if eligible. The NHLBI will emphasize participation in existing innovative NIH programs, including the Transformative R01 and EUREKA (Exceptional, Unconventional Research Enabling Knowledge Acceleration) awards (which are being combined), the Pioneer award, and the New Innovator award. Council members discussed the proposal and expressed their support.

NHLBI staff presented 15 new initiatives, 2 renewals, and 1 request for secondary support, all of which had been reviewed in May by the Board of External Experts. The Council was mostly supportive of the initiatives presented, 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 shurinsb@nhlbi.nih.gov or Dr. Carl Roth at rothc@nhlbi.nih.gov.



Susan B. Shurin, M.D.
Acting Director, NHLBI

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

- For health-related questions, information about publications, or communications pertaining to NHLBI policies and priorities, please contact the trained information specialists of the NHLBI Information Center at 301-592-8573, or write to the Information Center at P.O. Box 30105, Bethesda, MD 20824-0105, or email inquiries to nhlbiinfo@nhlbi.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.