

public interest news volume 13, issue 1 May 2012

NHLBI Welcomes New Director

On April 5, 2012, Dr. Francis S. Collins, Director, NIH, announced the selection of Gary H. Gibbons, M.D., as the new director of the National Heart, Lung, and Blood Institute.

Dr. Gibbons is the founder and current director of the Cardiovascular Research Institute, chairperson of the Department of Physiology, and professor of physiology and medicine at the Morehouse School of Medicine in Atlanta. He expects to start his new position about August 1st.

Dr. Gibbons has served as a member of the National Heart, Lung, and Blood Advisory Council (NHLBAC) since 2009, a position he relinquished after being selected to be director of the NHLBI. He was previously a member of the NHLBI Board of Extramural Experts, a working group of the NHLBAC. He has received 15 NHLBI-supported grants since 1997.

Continued on page 2

13th Annual NHLBI PIO Meeting

The NHLBI will hold its 13th annual Public Interest Organization (PIO) meeting on Monday, June 11, and Tuesday, June 12, 2012, at the Bethesda Marriott Hotel in Bethesda, Maryland.

Invitations have already been extended. Due to budget limitations and venue restrictions, this year we can only accommodate one representative per PIO.

The meeting starts Monday with check-in at 4 pm and the keynote address from 5 to 6. On Tuesday, check-in begins at 8 am and presentations will start at 9. A meet-the-staff session will pair each PIO representative with the NHLBI staff member whose expertise is most closely related to the PIO's mission. The meeting is scheduled to conclude at 4:30 pm.

The designated PIO attendee may register online at http://www.nhlbi-piomeeting.org/. Please register by Monday, May 21, 2012.

NIH Launches New Clinical Trials Educational Website

A trans-NIH effort has resulted in the launch of a new NIH website, "Clinical Research Trials and You" (http://www.nih.gov/health/clinicaltrials/index.htm), that is intended to serve as a tool to inform and educate the public and healthcare providers about clinical trials. The site explains to visitors what clinical trials are and identifies some important questions they should ask if considering participation in a clinical trial. Visitors can also review the personal stories of clinical trial participants and researchers who conduct trials. Educational materials specific to children, seniors, and Spanish-speaking audiences are also featured.

A section for healthcare providers explains the importance of educating patients about clinical trials. Additional resources for healthcare providers include printable promotional materials that may be posted and distributed in clinical settings and tips on talking to patients about clinical trials.

The vocabulary of clinical trials can be new, complicated, and confusing to many. The site has a list of commonly used terms to help patients better understand some of the language they may hear when speaking with their healthcare providers and potentially the staff affiliated with a trial. Visitors to the site will also find resources to identify relevant trials.

Inside

NHLBI Workshops and Working Groups	2
NIH Launches Genetic Testing Registry	2
Mark Your Calendar	2
NHLBI Research Initiatives	3
National Heart, Lung, and Blood Advisory Council	
February Meeting	1
News from Capitol Hill	1
Upcoming Events5	5
Constituents' Corner6	3
Need More Information?	3

Upcoming NHLBI Workshops and Working Groups*

Workshop or Working Group

Date / Location

Contact for More Information

Functional Imaging for Regenerative Medicine (A \$100 registration fee is required for this meeting.) May 31 – June 1, 2012 NIST, Gaithersburg, MD NIST is the lead agency for this

workshop.

Dr. Martha Lundberg lundberm@mail.nih.gov

301 435-0513

Annual Sickle Cell Disease Meeting

August 20 - 22, 2012 Bethesda, MD

Dr. Harvey Luksenburg luksenburgh@nhlbi.nih.gov

301 435-0050

Mechanistic Perspectives on How Sex Hormones Induce

Thrombosis in Women

September 13 - 14, 2012

Bethesda, MD

Dr. Jamie Siegel siegelje@nhlbi.nih.gov 301 435-0080

NIH Launches Genetic Testing Registry

On February 29, 2012, the National Institutes of Health launched an online tool to navigate the rapidly changing landscape of genetic tests. The free resource, called the Genetic Testing Registry (GTR), is available at http://www.ncbi.nlm.nih.gov/gtr/.

NIH Director Francis S. Collins, M.D., Ph.D., who unveiled the GTR at the NIH observance of International Rare Disease Day, said, "I'm delighted that NIH has created this powerful, new tool. It is a tremendous resource for all who are struggling to make sense of the complex world of genetic testing. This registry will help a lot of people — from health care professionals looking for answers to their patients' diseases to researchers seeking to identify gaps in scientific knowledge."

Genetic tests currently exist for about 2,500 diseases, and the field continues to grow at an astonishing rate. To keep pace, the GTR will be updated frequently, using data voluntarily submitted by genetic test providers such as the purpose of each genetic test and its limitations, the name and location of the test provider, whether it is a clinical or research test, what methods are used, and what is measured. GTR will contain no confidential information about people who receive genetic tests or individual test results.

To view video tutorials on how to use the new GTR, go to http://www.youtube.com/playlist?list=PL1C4A2AFF811F6F 0B.

NHLBI Welcomes New Director

Continued from page 1

Dr. Gibbons is originally from Philadelphia. He earned his undergraduate degree from Princeton University and graduated magna cum laude from Harvard Medical School. He completed his residency and cardiology fellowship at the Harvard-affiliated Brigham and Women's Hospital. Prior to joining the Morehouse School of Medicine in 1999, Dr. Gibbons was a member of the faculty at Stanford University from 1990 until 1996, and Harvard Medical School from 1996 until 1999.

Throughout his career, Dr. Gibbons has received numerous honors, including election to the Institute of Medicine of the National Academies of Sciences, selection as a Robert Wood Johnson Foundation Minority Faculty Development Fellowship awardee, selection as a Pew Biomedical Scholar by the Pew Charitable Trusts, and recognition as an Established Investigator of the American Heart Association (AHA). He also serves on editorial boards for several journals in cardiovascular medicine, and grant review committees for the Juvenile Diabetes Foundation and the AHA.

Mark Your Calendar . . .

National High Blood Pressure May

Education Month

(http://www.nhlbi.nih.gov/health/ public/heart/hbp/prevhbp/index.htm)

National Asthma and Allergy Awareness Month (http://www.aafa.org)

13 - 19

National Women's Health Week (http://www.womenshealth.gov/whw)

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

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 http://www.nhlbi.nih.gov/funding/inits/index.htm.

Integrative Omics Data Analysis for Discovery in Lung Diseases (R01)

(PAR-12-155)

http://grants.nih.gov/grants/guide/pa-files/PAR-12-155.html

Objective: Generate systems-level models of pulmonary pathobiology through integrative analysis of existing omics (e.g., genomics, transcriptomics, proteomics) data and experimentally test novel predictions of these models using human tissues/cells and/or mammalian animal models.

Short-Term Research Education Program to Increase Diversity in Health-Related Research (R25) (RFA-HL-13-020)

http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-13-020.html

Objective: Promote diversity in undergraduate and health professional participant populations by providing short-term research education support to stimulate career development in cardiovascular, pulmonary, hematologic, and sleep disorders research.

Limited Competition: NHLBI Research Centers at Minority-Serving Institutions - Phase II (P50) (RFA-HL-13-011)

http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-13-011.html

Objective: Solicit applications from investigators funded under Phase I of the NHLBI Research Centers at Minority-Serving Institutions program.

Toward an Improved Understanding of HDL Function (R01)

(PA-12-143)

http://grants.nih.gov/grants/guide/pa-files/PA-12-143.html

Objective: Develop, validate, and standardize assays to measure HDL function and biomarkers for HDL function and identify new pathways and potential HDL targets relevant to HDL function.

Getting from Genes to Function in Lung Disease (R01) (PA-12-110)

http://grants.nih.gov/grants/guide/pa-files/PA-12-110.html

Objective: Characterize the function of genes and their associated variants that are identified by genome-wide association studies, or other genetic approaches, as being involved in lung diseases

Core Clinical Centers for the Cardiothoracic Surgical Trials Network, CTSN (UM1)

(RFA-HL-13-017)

http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-13-017.html

Objective: Solicit applications for participation as a Core Clinical Center in a continuation of the Cardiothoracic Surgical Trials Network, which will evaluate cardiothoracic surgical interventions and related management approaches for the treatment of cardiovascular diseases and conditions in adult patients.

Limited Competition: Data Coordinating Center for Cardiothoracic Surgical Trials Network (CTSN) (U01) (RFA-HL-13-022)

http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-13-022.html

Objective: Support the Data Coordinating Center for the CTSN.

NHLBI Systems Biology Collaborations (R01) (PAR-12-138)

http://grants.nih.gov/grants/guide/pa-files/PAR-12-138.html

Objective: Encourage Research Project Grant applications from institutions/organizations for collaborative systems biology research projects by multi-disciplinary teams to advance our understanding of normal physiology and perturbations associated with heart, lung, blood, and sleep diseases and disorders.

Cardiovascular Risk Reduction in Underserved Rural Communities (R01)

(RFA-HL-13-013)

http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-13-013.html

Objective: Build the evidence base and accelerate the implementation and translation of evidence- or practice-based interventions into practice in rural communities.

National Heart, Lung, and Blood Advisory Council Meeting

February 15, 2012

Dr. Shurin welcomed members to the 245th meeting of the National Heart, Lung, and Blood Advisory Council.

Dr. Shurin welcomed three new Council members: Dr. Pamela Douglas, Ursula Geller Professor of Research in Cardiovascular Diseases, Duke University School of Medicine; Dr. Ron King, Chief Science and Business Officer and Co-Founder, Bio-Accel; and Dr. Barbara Konkle, Director, Translational Research, Puget Sound Blood Center.

Dr Shurin updated the Council on NHLBI leadership appointments: Mr. Ariel Herman is the new Deputy Executive Officer for the Institute and Dr. Jamie Siegel is the new Chief of the Hemostasis and Thrombosis Branch in the Division of Blood Diseases and Resources.

Dr. Shurin announced that beginning in 2013, February Council – like September Council – will be a virtual meeting.

Dr. Kathy Hudson, Deputy Director for Science, Outreach, and Policy at the NIH and Acting Deputy Director of the National Center for Advancing Translational Sciences (NCATS) updated the Council on revising the Common Rule on protection of human subjects. She also noted that the NIH will be devoting \$1 million in bioethics research funding to the development of an evolving, evidence-based approach to ensure effective protection of human subjects.

Dr. Shurin informed the Council of NIH leadership appointments: Dr. Thomas R. Insel, Director, National Institute of Mental Health, has been appointed Acting Director of the NCATS and Dr. M. Roy Wilson has been appointed Deputy

Director, Strategic Scientific Planning and Program Coordination, for the National Institute on Minority Health and Health Disparities.

Dr. Shurin discussed the FY 2013 President's Budget. The proposed NHLBI budget remains relatively flat overall, with a total increase of just over 0.02%, or approximately \$709 thousand. However, the Research Project Grant (RPG) line would decrease slightly, in part due to a mandated increase in Small Business Innovation Research/Small Business Technology Transfer funding from 2.95% in FY 2012 to 3.05% in FY 2013.

The Institute remains committed to the idea that fully-funded strategic investments are more likely to thrive than investments receiving across-the-board cuts. The Institute will also continue to support three main scientific priorities: discovery research (including genomics, systems biology, and modeling), regenerative medicine, and translational research.

Dr. Shurin discussed the Council on the Global Alliance for Chronic Disease, of which she is now the chair.

Dr. Arun Chockalingam, Director of the NHLBI Office of Global Health (OGH), discussed the role of the OGH in facilitating and coordinating global health efforts across the NHLBI; interacting with other NIH Institutes and Centers, the Department of Health and Human Services, and the U.S. Department of State; linking with other national and international organizations; and managing programs in partnership with NHLBI program divisions.

Continued on page 6

News from Capitol Hill

NHLBI Acting Director Speaks at Lung Diseases Congressional Briefing

On February 29, 2012, Dr. Susan Shurin, Acting Director, NHLBI, spoke at a congressional briefing on pulmonary hypertension and pulmonary fibrosis. Other speakers included Representative Kevin Brady (R-TX), NHLBI grantees Dr. Victor Thannickal and Dr. Serpil Erzurum, Ms. Nicole Cooper, Pulmonary Hypertension Association, and Mr. Paul Fogelberg, Pulmonary Fibrosis Advocates. The briefing was sponsored by the NHLBI, the American Thoracic Society, the Pulmonary Hypertension Association, the Coalition for Pulmonary Fibrosis, the Pulmonary Fibrosis Advocates, the Pulmonary Hypertension Clinicians and Researchers, the Pulmonary Fibrosis Foundation, and the Pulmonary Hypertension Professional Network.

NHLBI Acting Director Participates in "Go Red for Women" Congressional Reception

On February 4, 2012, Dr. Shurin provided brief remarks at the "Go Red for Women Reception" sponsored by the American Heart Association to raise awareness about heart disease in women. The reception featured the premiere of Go Red For Women's short film "Just a Little Heart Attack" based on the real stories of women affected by heart disease.

Upcoming Events

Activity	Date/Location	More Information
American Autoimmune Related Diseases Association, Inc. 8th International Congress on Autoimmunity	May 9 – 13, 2012 Granada, Spain	http://www2.kenes.com/autoimmunity/Pages/Home.aspx
Mended Hearts Annual Convention	May 16 – 21, 2012 Dallas, TX	http://mendedhearts.org/events
Aplastic Anemia and MDS International Foundation, Inc. 2012 Patient and Family Conference	May 19, 2012 Atlanta, GA July 28, 2012 New York City Area, NY September 22, 2012 Dallas, TX	http://www.aamds.org/support-and-community/conferences
Alpha-1 Association 21st Annual National Education Conference	June 8 – 10, 2012 Seattle, WA	http://www.alpha1.org/education/nateduconf.php
National Heart, Lung, and Blood Advisory Council 246th Meeting	June 13, 2012 Bethesda, MD	http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Tuberous Sclerosis Alliance 2012 Regional TSC Conference Series	June 15, 2012 Washington, DC June 23, 2012 Houston, TX	http://www.tsalliance.org/pages.aspx?content=696
Pulmonary Hypertension Association 10th International PH Conference and Scientific Sessions	June 22 – 24, 2012 Orlando, FL	http://www.phassociation.org/
Barth Syndrome Foundation 6th International Scientific, Medical, and Family Conference	June 25 – 30, 2012 St. Pete Beach, FL	http://barthsyndrome.org/english/View.asp?x=1670
Parent Project Muscular Dystrophy 2012 Connect Conference	June 28 – July 1, 2012 Ft. Lauderdale, FL	http://www.parentprojectmd.org/site/PageServer?page-name=Connect_conference
Cooley's Anemia Foundation 2012 Patient Family Conference	June 29 – July 1, 2012 Cambridge, MA	http://www.thalassemia.org/
TOPS (Take Off Pounds Sensibly) Club, Inc 2012 International Recognition Days	. July 5 – 7, 2012 San Diego, CA	http://www.tops.org/2012IRDDocs/2012IRD_reg_info.pdf
American Association for Respiratory Care Summer Forum and Meetings	July 12 – 15, 2012 Santa Fe, NM	http://www.aarc.org/education/meetings/summer_forum/
Platelet Support Disorder Association ITP Conference 2012	July 20 – 22, 2012 Denver, CO	http://www.pdsa.org/resources/annual-conference/itp-conference-2012.html?layout=item
Scleroderma Foundation 2012 National Patient Education Conference	July 27 – 29, 2012 e Grapevine, TX	http://www.scleroderma.org/national_conference_2012.htm
National Marfan Foundation 28th Annual Conference	August 2 – 5, 2012 Chicago, IL	http://www.marfan.org/marfan/5346/2011-NMF-Conference:-Main-Page
Fanconi Anemia Research Fund, Inc. Annual Family Meeting	August 10 – 13, 2012 Casco, ME	http://www.fanconi.org/index.php/family_support/annual_family_meeting
Sudden Cardiac Arrest Association 2012 Annual Conference Program	September 13 – 15, 2012 Orlando, FL	http://associationdatabase.com/aws/SCAA/pt/sp/annualmtg
Vascular Disease Foundation Annual Meeting	September 21 – 23, 2012 Tysons Corner, VA	http://www.vdf.org/
PXE (Pseudoxanthoma Elasticum) International 2012 Biennial Conference	September 22 – 23, 2012 Bethesda, MD	http://pxe.org/2012-biennial-conference
Sickle Cell Disease Association of America, Inc. 40th Annual Conference	September 25 – 28, 2012 Baltimore, MD	http://www.sicklecelldisease.org/



Constituents' Corner

TOPS Club Inc. (Take Off Pounds Sensibly) Welcomes Fellow NHLBI-PIOs to Reach Out through its 170,000 Members in Every U.S. State and Canadian Province

TOPS Club Inc., a nonprofit weight-loss organization that has helped millions of people in the United States and Canada to lose weight and develop healthy lifestyles over the last 60+ years, is pleased to share news of its involvement in several recent studies of obesity and its co-morbidities and welcomes fellow NHLBI-PIO members to reach out through its 170,000 membership base in every state and Canadian province.

TOPS has been actively involved in the clinical study of obesity and metabolic research since 1966 and has contributed more than \$8 million to the Medical College of Wisconsin (MCW) in Milwaukee, Wisconsin, in support of these efforts. The TOPS Obesity and Metabolic Research Center was established at MCW in 1994 and has contributed to milestones of obesity research that have resulted in significant progress including:

- The paper entitled "Biology of Regional Body Fat Distribution: Relationship to non-Insulin Dependent Diabetes Mellitus".
 Findings in this study led to the terms "apple shaped" vs. "pear shaped."
- Identification of a gene that plays a significant role in determining blood levels of HDL cholesterol, commonly referred to as "good" cholesterol.
- Over 500 TOPS families participated as research volunteers in those studies, making it one of the largest family studies conducted in the United States.

Findings have been published in more than 200 of the most reputable scientific papers, including the Journal of the American Medical Association and Nature Genetics. In 2011, Dr. Nia Mitchell published a scientific study in Obesity magazine directly assessing the effectiveness of TOPS and found that people who joined TOPS and followed the program for three years were able to lose weight and successfully keep it off.

Because TOPS members and their families are so directly affected by the obesity epidemic and the co-morbidities associated with it, articles on these subjects are frequently included in TOPS News magazine, which is published nine times per year and distributed to more than 170,000 homes and healthcare facilities in North America. TOPS is proud to have been a partner with the NHLBI-PIO group since it was formed, and invites other PIO members to submit articles of interest to the TOPS News magazine by calling 414-482-4620 ext. 41 or by email to wondering@tops.org. TOPS is also interested in other types of outreach and partnership opportunities that promote education and healthy lifestyles. For more information, visit www.tops.org.

Submitted by Barbara Cady, President TOPS Club Inc.



We invite you to use this space that we reserve for you to share your successes and opinions. You may submit your ideas and articles to nhlbi.listens@nih.gov or Public Interest News, Office of Science and Technology, Building 31, Room 5A07, 31 Center Drive, MSC-2482, Bethesda, MD 20892-2482.



February 2012 Advisory Council Meeting

Continued from page 4

Dr. Denise Simons-Morton, Director of the NHLBI Division for the Application of Research Discoveries, presented background and the current approach on development of NHLBI-sponsored clinical practice guidelines. She noted that review and clearance of guideline reports now includes Council review.

Dr. Stephen Daniels, Department of Pediatrics, University of Colorado School of Medicine and Children's Hospital Colorado; and Chair, Expert Panel on Integrated Guidelines for CV Risk Reduction in Children and Adolescents, discussed the guidelines, which were released in December 2011. He noted that guidelines should not be considered a final product, but rather a continuously revised one that evolves along with their evidence base.

Dr. Stephen Mockrin, Director, Division of Extramural Research Activities, NHLBI, presented the delegated authorities to the Council. Delegated authorities allow NHLBI staff to perform specific functions without Council involvement, thereby adding flexibility and decreasing the burden on the Council. The Council agreed to continue the current policy of Delegated Authorities for another year.

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.