

FYI from the NHLBI



Public Interest News from the National Heart, Lung, and Blood Institute

Volume 4, Issue 1, May 2003

The NHLBI is one of the National Institutes of Health (NIH), an agency of the U.S. Department of Health and Human Services

NIH Director and Professional Society Leaders Participate in Annual NHLBI Public Interest Organization Meeting

As in previous years, public interest organization (PIO) representatives convened for a one-day meeting near the National Institutes of Health (NIH) campus to exchange ideas with one another and with NHLBI staff and National Heart, Lung, and Blood Advisory Council members.

The February 5 meeting began with an enthusiastic discussion, led by NIH Director Dr. Elias Zerhouni, about future directions for NIH programs. Participants were especially interested in Dr. Zerhouni's plans to foster multidisciplinary research that transcends a single NIH Institute or Center, his vision of how future research projects will be conducted, and his commitment to involve the public in the NIH research enterprise.

Next, representatives engaged in a round table discussion on the development of workshops and conferences. The session was led by NHLBI staff and Ms. Paula Polite, President, Sarcoidosis Research Institute; Ms. Lorna Stevens, President and Co-founder, Neutropenia Support Association; and Ms. Sue Byrnes, Executive Director, LAM Foundation and a member of the National Heart, Lung, and Blood Advisory Council. Much of the discussion focused on how patients and their families can be involved in scientific conferences and what the PIOs could do to help facilitate their interactions with research and health care professionals at these events.

Later, Ms. Virginia Ladd, President and Executive Director, American Autoimmune Related Diseases Association, presented a case study on how organizations can collaborate to get their messages heard. She described steps her organization has taken to foster relationships with other groups and outcomes that those relationships facilitated.

Dr. Richard Cannon, Clinical Director, NHLBI Division of Intramural Research, described ongoing research activities related to the potential of stem cells for treatment of ischemic heart disease.

The meeting also provided opportunities for PIO representatives to explore collaborations with professional and public groups and with the NHLBI. Much of the afternoon consisted of concurrent community forums

moderated by NHLBI staff and leaders from the American Heart Association, American College of Cardiology, American Thoracic Society, and American Society of Hematology. Both the NHLBI staff and professional society leaders encouraged participants to contact them with follow-up suggestions. Dr. Claude Lenfant, Director, NHLBI, echoed that sentiment in the question-and-answer session at the end of the meeting.

A summary of the meeting is available through the *NHLBI Express* Web site at www.nhlbi.nih.gov/public.

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News from Capitol Hill

Appropriations Hearings

On April 2 and 8, Dr. Zerhouni testified before the House Appropriations Subcommittee on Labor, Health and Human Services, and Education on behalf of all NIH Institutes and Centers, including the NHLBI. The Senate appropriations hearing for the NIH also was held on April 8. At the hearings, Dr. Zerhouni, Dr. Lenfant, and other Directors highlighted specific areas in which the NIH has made progress over the past years and described future opportunities. Representative Wicker (R-MS) asked Dr. Lenfant specifically about the NHLBI-supported Jackson Heart Study, and Senator Specter (R-PA) asked Dr. Lenfant and Dr. Stephen Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, about NIH research on scleroderma. Dr. Lenfant's written testimony for the Senate Subcommittee on Labor-HHS-Education Appropriations and program highlights submitted as part of the FY 2004 budget justification are available through www.nhlbi.nih.gov/funding/fromdir/index.htm.

Selected Legislation Related to the NIH

Representative Kevin Brady (R-TX) introduced the Pulmonary Hypertension Research Act of 2003 (H.R. 1316) to expand NHLBI support of research on pulmonary hypertension. If passed, it would require the NHLBI to develop centers dedicated to research and education efforts on pulmonary hypertension, and a data system for the collection, analysis, and dissemination of information related to pulmonary hypertension research. The bill was referred to the House Energy and Commerce Committee.

Representative Carolyn McCarthy (D-NY) introduced the Diamond-Blackfan Anemia Act (H.R. 894). The bill, which was referred to the House Committee on Energy and Commerce, would require the NIH to expand and intensify research regarding Diamond-Blackfan Anemia.

Representative Stephen Lynch (D-MA) introduced the Women's Autoimmune Diseases Research and Prevention Act (H.R. 370), which also was referred to the House Committee on Energy and Commerce. The bill would require the NIH Autoimmune Diseases Coordinating Committee to expand, intensify, and further coordinate research on autoimmune diseases in women.

In February, the House passed the Human Cloning Prohibition Act of 2003 (H.R. 534). A similar bill, S. 245, was introduced by Senator Sam Brownback (R-KS) and referred to the Senate Committee on Health, Education, Labor, and Pensions. Another bill, the Human Cloning Ban and Stem Cell Research Protection Act of 2003 (S. 303), was introduced by Senator Orrin Hatch (R-UT) and has been assigned to the Senate Judiciary Committee.

Other Bills and Resolutions

Senator Richard Durbin (D-IL) introduced the Donor Outreach, Network, and Timely Exchange (DONATE) Act (S. 376), which was referred to the Senate Committee on Health, Education, Labor, and Pensions. If passed, the bill would promote organ donation and facilitate interstate linkage and 24-hour access to state donor registries.

Representative Jeff Miller (R-FL) introduced H. Con. Res. 45 to emphasize the importance of organ, tissue, bone marrow, and blood donation and support National Donor Day (February 14). The resolution acknowledged the efforts of many professional and patient organizations, several of which — the Juvenile Diabetes Research Foundation International, the Leukemia and Lymphoma Society of America, and the National Minority Organ and Tissue Transplant Education Program — have participated in NHLBI PIO meetings.

Representative Cliff Stearns (R-FL) introduced H. Con. Res. 6 to support the establishment of Chronic Obstructive Pulmonary Disease (COPD) Awareness Month.

Representative Luis Gutierrez (D-IL) and Senator Harry Reid (D-NV) introduced H. Con. Res. 30 and Sen. Con. Res. 33, which include a statement that the NIH should continue to take a leadership role in scleroderma research and should host a symposium to identify research priorities.

Through Sen. Res. 98, Senator Ben Nighthorse Campbell (R-CO) asked President Bush to issue a proclamation designating October 12-18, 2003, as National Cystic Fibrosis Awareness Week.



Spotlight on Our Web Site

Portion Distortion

Portion sizes and the nation's waistlines have increased in the past two decades. A simple measurement will tell you if your waistline has expanded, but do you know the extent to which food portions have increased? Do you know how much exercise it will take to burn the extra calories in those "supersized" fries? Test your knowledge with the NHLBI Obesity Education Initiative Portion Distortion quiz at hin.nhlbi.nih.gov/portion/. When you're done, visit the other patient resources through the Aim for a Health Weight page (www.nhlbi.nih.gov/health/public/heart/obesity/lose_wt/index.htm) for tips to help you order when dining out, a guide to get you started on a physical activity program, a daily food and activity diary, and more.

Reminder — NHLBI Conference Grants are Available

Looking for funding for your next scientific meeting or conference? Interested in learning more about the NIH “R13” conference grants discussed at the fourth annual PIO meeting? The following resources can help you decide if the R13 mechanism is right for you:

- grants.nih.gov/grants/policy/gps/app7.htm, grants.nih.gov/grants/policy/nihgps/part_iii_5.htm, and the surrounding pages describe what groups and events are eligible.
- grants.nih.gov/grants/funding/phs398/phs398.html contains the application forms and instructions. Please read the instructions carefully to determine if additional forms are required. For example, some organizations may need to provide additional information regarding lobbying activities before federal law will allow their applications to be considered.
- grants.nih.gov/grants/guide/notice-files/not98-151.html describes specific NHLBI requirements and lists NHLBI staff whom you should contact BEFORE submitting your application.

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 and proposals 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.

Animal Models of Organ-specific Tolerance for Heart and Lung Transplantation (PA-02-044)

- Objectives: To encourage protocol development using large animal models for heart transplantation and both large and small animal models for lung transplantation.

Biobehavioral Research for Effective Sleep (PA-00-046)

- Objectives: To understand the behavioral, psychosocial, and physiological consequences of acute and chronic partial sleep deprivation and to develop interventions to reduce sleep disturbances.

Functional Tissue Engineering for Heart, Vascular, Lung, Blood, and Sleep Disorders and Diseases (SBIR/STTR) (PAR-01-006)

- Applications due: March 12, 2004
- Objectives: To stimulate development of biological substitutes for damaged tissues and organs.

Hypovolemic Circulatory Collapse: Mechanisms and Opportunities to Improve Resuscitation Outcomes (RFA-HL-03-015)

- Applications due: May 23, 2003
- Objectives: To identify approaches to out-of-hospital resuscitation following severe blood loss and subsequent hypovolemic circulatory collapse.

Lung Tissue Research Consortium (NOT-HL-03-009, RFP-HR-04-08, RFP-HR-04-09, RFP-HR-04-10, RFP-HR-04-11)

- Applications due: May 22, 2003
- Objectives: To support molecular histopathological studies of human lung tissues.

Pathogenesis and Treatment of Lymphedema (PA-01-035)

- Objectives: To stimulate research on the biology of the lymphatic system; the underlying developmental, cellular, and molecular mechanisms that cause lymphedema; and new therapies for patients with lymphedema.

Pathophysiology and Treatment of Chronic Fatigue Syndrome (CFS) (PA-02-034)

- Objectives: To understand CFS pathogenesis and pathophysiology with the goal of improving diagnostic and intervention strategies.

Research on Ethical Issues in Human Studies (PA-02-103)

- Objectives: To encourage studies of ethical challenges related to involving human participants in research (e.g., issues related to participant safety, informed consent, data management, and research oversight).

Restless Legs Syndrome and Periodic Limb Movement Disorder (PA-01-086)

- Objectives: To enhance understanding of and develop treatments for restless legs syndrome and periodic limb movement disorder.

Specialized Centers of Clinically Oriented Research (SCCOR) Program in Cardiac Dysfunction and Disease (RFA-HL-03-009)

- Applications due: September 11, 2003
- Objectives: To stimulate clinically relevant, multidisciplinary collaborations leading to clinical and basic science research efforts on important public health problems for individuals with heart diseases.

Recent Advances from the NHLBI

MRI Provides Better Way To Diagnose Heart Attacks

Advanced magnetic resonance imaging (MRI) technology can detect heart attacks in emergency room patients with chest pain more accurately and faster than traditional methods. Findings of an NHLBI-supported study suggest that more patients who are suffering a heart attack could be identified as candidates for treatment to reduce or prevent permanent damage to the heart if they were assessed with MRI. "Using MRI to detect heart problems in the emergency department will ultimately save lives," said Dr. Lenfant. "Because patients will be diagnosed and treated more quickly, cardiac MRIs might save costs as well."

Low-Dose Warfarin Prevents Recurrence of Blood Clots

A study of long-term, low-dose warfarin to prevent the recurrence of two blood clotting disorders, deep vein thrombosis (DVT) and pulmonary embolism, resulted in such a high degree of benefit to the patients — without significant adverse effects — that the NHLBI stopped the study early. Compared with those taking a placebo, the participants in the Prevention of Recurrent Venous Thromboembolism (PREVENT) trial who received warfarin were 64 percent less likely to experience subsequent episodes of DVT and pulmonary embolism.

Findings Suggest Revised Approach to Therapy for Atrial Fibrillation

The most frequently used initial therapy for patients who have atrial fibrillation is treatment to restore and maintain normal heart rhythm. However, the Atrial Fibrillation Follow-up Investigation of Rhythm Management (AFFIRM) found that the "heart rhythm" strategy prevents no more deaths than treatment to merely control the rate at which the heart beats. Furthermore, researchers found that the "heart rhythm" approach does not result in a lower risk of stroke, nor does it improve the patient's quality of life or cognitive function — all of which had been presumed to be benefits over the "heart rate" strategy. The "heart rate" strategy may also be associated with lower health care costs. Drugs used to control heart rate tend to be less expensive, and as Dr. D. George Wyse, chair of the AFFIRM steering committee, explained, "[investigators] found that patients in the rhythm control group were more likely to be hospitalized, and hospital costs account for the majority of total medical costs."

Hydroxyurea Therapy Improves Survival of Patients Who Have Severe Sickle Cell Anemia

An NHLBI-supported study recently revealed that hydroxyurea therapy not only protects adults who have sickle cell anemia from painful crises and a pneumonia-like illness called acute chest syndrome, but also prolongs their lives. Even the sickest patients — those who suffered three or more crises a year — benefited. Because severely ill patients require more emergency room visits and hospitalizations than those who have less severe disease, the results have important implications both for patient care and for decreasing health care costs. According to lead investigator Dr. Martin Steinberg, Director of the Center of Excellence in Sickle Cell Disease at Boston University School of Medicine, "Presently only a minority of eligible patients are taking hydroxyurea. Our study strongly suggests that adults with sickle cell anemia and clinically significant complications of their disease, like frequent painful episodes and the common pneumonia-like events, should take hydroxyurea under the supervision of a knowledgeable physician. Most people who take this medication will feel better; we now know they will live longer."

Seemingly Unrelated, Fatal Conditions May Share Genetic Defects

Long-QT Syndrome (LQTS), an inherited heart rhythm disorder that causes sudden cardiac death in children and young adults, may not get a lot of attention in the popular press, but researchers familiar with this rare disease have found evidence that associates it with a much more widely known condition — sudden infant death syndrome (SIDS). Scientists led by pediatric cardiologist Dr. Michael J. Ackerman, Director of the LQTS Clinic at the Mayo Clinic, studied a number of infants who died of SIDS and found that approximately 3 percent of them had genetic mutations associated with LQTS. Mutations in a gene encoding a sodium channel that is critical to the heart's electrical system were found in 2 of 58 white babies with SIDS. This study, conducted through the Mayo Clinic, Baylor College of Medicine, University of Wisconsin, and the Arkansas State Crime Laboratory, provides what is perhaps the strongest indicator yet for a genetic role in SIDS. Through a grant from the National Institute of Child Health and Human Development (NICHD), Dr. Ackerman and his team now are investigating whether the other genes involved in LQTS may also cause some cases of SIDS.

For more information on LQTS or other heart rhythm disorders, please contact the Cardiac Arrhythmias Research and Education (C.A.R.E.) Foundation at 800-404-9500 or visit their Web site at www.longqt.org. The National Institute of Child Health and Human Development Web site provides information about SIDS at www.nichd.nih.gov/sids. Submitted by: Ms. Kathy McInerney, Director of Development, C.A.R.E. Foundation.

The NHLBI Holds Workshop at Vascular Disease Foundation Meeting

In January, the Vascular Disease Foundation and 16 national professional societies and health organizations held a 2-day public education strategy meeting to begin a national effort to improve public access to information on peripheral arterial disease (PAD). The program began with a full-day workshop on developing a public awareness campaign, organized by the NHLBI Office of Prevention, Education, and Control (OPEC). Participants learned how to develop campaign strategies, identify key messages and ways to communicate with their intended audiences, and build partnerships.

PAD, which affects over 8 million Americans, is caused by blockages in arteries supplying blood to the limbs, commonly the legs. It usually results from atherosclerosis, the same condition that can lead to heart disease. Advanced age, smoking, high blood cholesterol, and diabetes are risk factors for PAD. Many people with PAD have pain or fatigue in the calf muscles, a symptom called claudication. Early diagnosis and prompt treatment, including reduction of vascular disease risk factors, can slow disease progression, forestall amputation, and decrease the chance of a heart attack or stroke.

Winners of National “How I Get a Heap of Sleep” Contest Announced

Students of the District of Columbia’s Shadd Elementary School met Garfield the Cat and three “How I Get a Heap of Sleep” contest winners at a special ceremony on January 28. The contest, which challenged children to describe what they do before bed to help them sleep, was part of the “Sleep Well. Do Well. Star Sleeper” Campaign to teach children and their parents about the importance of sleep. It was offered to children nationwide through online and classroom promotions, including a lesson plan that was sent to 44,000 second and third grade classrooms.

Dr. Lenfant and Dr. Carl E. Hunt, Director of the National Center on Sleep Disorders Research at the NHLBI—joined by Garfield—awarded prizes to Danielle Wodka, age 7, of Illinois, and Amanda Davol of Massachusetts and Qian Wang of Kentucky, both age 8. Also, six Shadd students were awarded Star Sleeper status for winning a local version of the contest. Among the things the awardees said they did each night to help them get a good night’s sleep was saying “a prayer for my parents, baby sister, and our President Bush” (Wodka); not watching TV (Daval); and finishing his homework early “because then I can get a relaxing evening” (Wang).

The Campaign is cosponsored by Paws, Inc., the corporate entity behind Garfield the Cat. Information about the Star Sleeper Campaign is available at www.nhlbi.nih.gov/health/public/sleep/starslp/index.htm.

National Heart, Lung, and Blood Advisory Council Winter Meeting

Dr. Lenfant welcomed everyone to the 209th meeting of the National Heart, Lung, and Blood Advisory Council. He acknowledged the guests who attended the 4th annual PIO meeting on February 5 and provided time for them and Council members to comment on the meeting.

Dr. Lenfant gave an overview of the President’s proposed budget for fiscal year (FY) 2004. The NIH expects to receive a budget increase of \$549 million, or about 2 percent, between FY 2003 and FY 2004. The NHLBI will receive an additional \$105.6 million in its FY 2004 budget, which corresponds to a 3.8 percent increase.

Dr. Zerhouni, the NIH Director, also discussed the effect of the proposed FY 2004 budget. He reiterated that modest overall budget increases will not have drastic effects on research funding. Due to shifts in funds from infrastructure expenditures to scientific grants, a 7.5 percent increase in research funding is expected for FY 2004. Council members had many questions, several of which focused on training for new scientists. In his replies, Dr. Zerhouni emphasized the need for multidisciplinary training, particularly for clinical researchers.

Dr. Carl Roth, Associate Director for Scientific Program Operation, NHLBI, presented data about the increasing cost of NHLBI Institutional National Research Service Awards (i.e., T32 grants). While the number of grants awarded has not increased significantly in recent years, the grants are becoming more expensive because of rising stipend levels and an increasing number of long-standing T32 awards, which tend to be higher in cost. After the presentation, Dr. Lenfant asked council members to contemplate ways to restructure this program in light of potentially smaller budget increases and increasingly larger grant costs.

Council members also heard a summary of the recent SPARK II working group. At an initial meeting to identify promising research areas for the NHLBI to address over the next few years, the group highlighted five areas of scientific opportunity—regenerative biology and replacement therapy, development and embryogenesis, immunology and inflammation, health promotion, and public health applications of genomics and proteomics. Members of the SPARK II group then met with representatives from the American Heart Association, the American Thoracic Society, and the American Society of Hematology to discuss specific research goals in each area, impediments to achieving them, and resources and technologies that will be needed to address them. The report is available at www.nhlbi.nih.gov/funding/fromdir/spark2web.htm.

During the closed portion of the meeting, the Council concurred on the award of 275 grants for a total cost of \$117,264,000.

The next National Heart, Lung, and Blood Advisory Council meeting is scheduled for 8:00 a.m. on May 29. It is open to the public and will be in NIH Building 31C, Conference Room 10.

Upcoming Events			
Activity	Date	Details	For Additional Information
99th International Conference of the American Thoracic Society	May 16-21	Seattle, WA. The conference will offer the latest information in clinical science, basic science, and behavioral aspects of respiratory disease.	www.thoracic.org
National Heart, Lung, and Blood Advisory Council meetings	May 29, September 4, October 30	8:00 a.m. - 2:00 p.m., NIH Main Campus, Building 31C, Conference Room 10, Bethesda, MD. Meetings are open to the public.	www.nhlbi.nih.gov/meetings/nhlbac/index.htm
Meeting the Challenge of Healthy People 2010: Preventing and Controlling Asthma	June 19-21	Washington, DC. The conference will address how to raise asthma awareness, develop community asthma programs, and implement policies to prevent recurrent exacerbations of asthma and will highlight the latest in asthma diagnosis and management.	www.asthma2003.net/index.asp
From Genome to Disease: A Symposium of High Throughput Biology	July 23-24	Bethesda, MD. The symposium will provide both the novice and experienced investigator an opportunity to explore the application of genomic and proteomic technologies to the study of human disease.	www.nhlbi.nih.gov/meetings/pgai/index.htm
Aplastic Anemia and Myelodysplastic Syndromes International Foundation Patient & Family Conference	August 1-3	San Francisco, CA. Patients and their families will hear the latest medical research findings for treatment of aplastic anemia, myelodysplastic syndromes, and related disorders from expert researchers and clinicians.	www.aamds.org/conferences.shtml
American Heart Association's Annual Scientific Session	November 9-12	Orlando, FL. Scientists and health professionals will learn about recent advances in the diagnosis, treatment, and prevention of cardiovascular disease and stroke.	www.scientificsessions.org/portal/scientificsessions/ss/
National COPD Conference	November 14-15	Arlington, VA. Participants will address challenges related to the Healthy People 2010 program goals for COPD and develop a plan to reduce the proportion of adults whose activity is limited due to chronic lung disease and breathing problems and reduce deaths from COPD.	www.uscopd.com/confer.html

National Stroke Association Launches “Ask Your Doctor” Campaign During National Stroke Awareness Month (May 2003)

Stroke is the third most common cause of death in the United States and the leading cause of adult disability. To improve dialogue between patients and physicians about stroke risk factors and what patients can do reduce their risk (e.g., lower high blood pressure, improve their cholesterol profiles, stop smoking), the National Stroke Association is launching a multi-year “Ask Your Doctor” campaign during National Stroke Awareness Month in May. The campaign’s key component for May 2003 is to get people to ask their doctors “Am I at risk for stroke?”

Submitted by: Kay Wan, Media Relations Manager, National Stroke Association (www.stroke.org or 800-STROKES).

Mission Possible **Opening May 2003 in Communities Everywhere**

Preventing and treating high blood pressure do not need to be daunting tasks. To communicate how simple actions can improve blood pressure, the National High Blood Pressure Education Program selected “Prevent and Treat High Blood Pressure — Mission Possible” as the theme of National High Blood Pressure Education Month 2003.

Your mission ... to improve your heart health and that of your family, friends, and community.

It's possible ... download the tools you need from the NHLBI Web site (www.nhlbi.nih.gov) today.

Coming Attractions...

The *Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure* will be available May 15.

World Asthma Day is May 6, 2003

Join millions of people around the world to increase awareness of the global burden of asthma and the need for improved patient care. The U.S. theme for World Asthma Day 2003 is "Communities Working for Life and Breath," which speaks to the collective effort needed at the national, state, and local levels to lessen the burden of asthma in the United States. Visit the NHLBI World Asthma Day 2003 Web site at www.nhlbi.nih.gov/health/prof/lung/asthma/wad/index.htm for information about how your group can participate.

Updated National Sleep Disorders Research Plan Published Online

The National Center for Sleep Disorders Research recently released the 2003 National Sleep Disorders Research Plan. It provides both an updated and expanded guide for research on sleep and sleep disorders and a summary of progress in sleep research since the release of the first research plan in 1996. The new recommendations, developed by a 14-member task force with input from biomedical researchers, professional societies, and public organizations, address research needs in areas including basic sleep science; neurobehavioral and physiologic consequences of sleep restriction; specific sleep disorders; sex, race, and age differences in sleep needs, health, and disorders; and the interrelationships among sleep, health, and disease. The plan will guide prioritization of future sleep research at the NIH and other Federal and non-Federal entities. Furthermore, it should help to identify research opportunities for new investigators from other scientific and clinical disciplines.

The 129-page plan is available as a PDF file (note: you will need Adobe Acrobat Reader to view it) on the NHLBI Web site at www.nhlbi.nih.gov/health/prof/sleep/sleep-rplan.pdf.

New Summaries of NHLBI Workshops Also Available

- Acute Lung Injury: Future Research Directions Workshop (www.nhlbi.nih.gov/meetings/workshops/ali.htm)
- Clinical Research in Chronic Obstructive Pulmonary Disease: Needs and Opportunities Workshop (www.nhlbi.nih.gov/meetings/workshops/copd_clinical.htm)
- Future Research Directions in Idiopathic Pulmonary Fibrosis Workshop (www.nhlbi.nih.gov/meetings/workshops/ipf_wksp.htm)
- Mobilizing African American Communities to Address Disparities in Cardiovascular Health: The Baltimore City Health Partnership Strategy Development Workshop (www.nhlbi.nih.gov/health/prof/heart/other/balt_rpt.htm)

Need More Information?

- For health-related questions and publications, please contact the trained information specialists at the NHLBI Information Center (NHLBIinfo@rover.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.

Constituents' Corner

Many thanks to all who suggested topics for this issue of the *FYI from the NHLBI*. Because of your generous contributions, this issue contains two extra pages. If you have ideas for our autumn issue, please send them to NHLBI.Listens@nih.gov.

C.A.R.E. Foundation Scientific Advisory Board Member Leads Study on ARVD

From Ms. Kathy McInerney, Director of Development, C.A.R.E. Foundation

Individuals suspected of having arrhythmogenic right ventricular cardiomyopathy/dysplasia (ARVD) can now volunteer to be screened through an NHLBI-supported study at 12 medical centers geographically distributed throughout the United States and Canada. Scientific Board members from the Cardiac Arrhythmias Research and Education (C.A.R.E.) Foundation, a nonprofit organization that promotes education, awareness, and advocacy for people who have inherited life-threatening arrhythmias, will be spearheading the project.

Patients will undergo a series of noninvasive tests. If results are consistent with a diagnosis of ARVD, they will undergo invasive testing (angiography). Those diagnosed as having ARVD will be asked to have first-degree relatives undergo noninvasive screening and submit blood for a genetic study.

This integrative research project will expand clinical knowledge of ARVD and localize genes responsible for this disorder. The C.A.R.E. Foundation is assisting the researchers with patient recruitment by enhancing awareness of the study among the public and medical communities. C.A.R.E. receives inquiries from families across the United States who have been diagnosed with a life-threatening heart rhythm disorder or who have experienced sudden cardiac arrest or sudden death. For more information, contact the C.A.R.E. Foundation at 800-404-9500 or visit www.longqt.org or www.arvd.org.

Turn the page for more Constituents' Corner articles.

Constituents' Corner

(continued from page 7)

Preeclampsia Foundation Gathers Global Health Leaders and Medical Experts to Address Leading Cause of Maternal Mortality

From Eleni Tsigas,
Director of Communications,
Preeclampsia Foundation

The Preeclampsia Foundation hosted the first International Preeclampsia Summit on April 4-6 in Seattle, Washington. Health professionals and researchers from Canada, India, Jamaica, Mexico, Nigeria, South Africa, the United Kingdom, and the United States joined representatives from the World Health Organization, Save the Children, PATH (Program for Applied Technology in Health), the NIH, Family Care International, the Columbia University School of Public Health's Initiative on Averting Maternal Death and Disability, and the Bill and Melinda Gates Foundation to identify and prioritize interventions to reduce maternal and infant illness due to preeclampsia and eclampsia.

The opening session, titled "A Patient's Perspective," featured several preeclampsia survivors and helped ground participants in the real-life stories, rather than just the statistics, of the disease. Later sessions covered the diagnosis and treatment of preeclampsia, the global impact of the disease, and the realities of maternal health care in the developing world. Work groups formed to brainstorm and prioritize interventions. At the close of the meeting, the executive committee drafted an international call to action, citing specific interventions and priority areas supported by the participants.

The Summit was made possible by a grant from the Bill and Melinda Gates Foundation. The Action on Preeclampsia (from the United Kingdom) and the HELLP Syndrome Society also provided financial support.

Preeclampsia occurs in approximately 5 percent of pregnancies and affects both mother and unborn baby. It is characterized by high blood pressure, swelling, and protein in the urine and, if untreated, can lead to stroke, kidney and liver failure, and hemorrhage. For more information, call 800-665-9341 or visit www.preeclampsia.org.

Research Support Comes Full Circle for Investigator

From Ms. Silvana Rodriguez,
Communications Specialist,
Alpha-1 Foundation

Dr. Mark L. Brantly was a researcher in the NHLBI intramural program studying molecular biology when a patient changed the course of his career. This patient urged Dr. Brantly to develop much-needed therapies to help him and others with the same disease. The patient suffered from alpha-1 antitrypsin deficiency, a hereditary disorder that can result in life-threatening liver and lung disease.

After building an impressive career in alpha-1 research, Dr. Brantly became involved with the Alpha-1 Foundation, a nonprofit organization dedicated to improving the quality of life for those diagnosed with alpha-1 disease. In 1998, the Foundation recruited him to direct its new Alpha-1 Antitrypsin Genetics Laboratory at the University of Florida College of Medicine. The Laboratory was the first academic research program of its kind and was created by a unique partnership between the Foundation, the University, and the State of Florida.

Prior to recruiting Dr. Brantly, the Foundation had approached the University of Florida College of Medicine to convince them to develop a research program on alpha-1. Due to widespread support for such a program among university leadership, the governor's office, and university alumni, the Foundation raised \$600,000 for the new laboratory. The University and the State of Florida also made long-term financial commitments to the program totaling \$1.3 million and \$420,000 respectively.

These and other investments allowed Dr. Brantly to build upon the research he conducted at the NIH and create a lab that currently is training 16 researchers interested in studying alpha-1 disease. He is now the recipient of an NHLBI grant that will increase the research and training capabilities at the Alpha-1 Laboratory.

For more information, visit www.alphaone.org or call the Foundation toll free at 877-2CURE-A1.

NECA Develops Collaborations to Empower People Living with Lung Disease

From Dr. Hannah Hedrick,
Vice-President, NECA

Inspired by the 2002 and 2003 PIO meetings, leaders of the National Emphysema/COPD Association (NECA) (www.NECACommunity.org) conducted a series of "Community-Building" meetings, several of which were hosted by the American Lung Association of Metropolitan Chicago (ALAMC). In addition to PIO representatives and individual patients, the meetings have attracted health care providers, educators, researchers, public officials, and others interested in empowering people who have emphysema, chronic obstructive pulmonary disease (COPD), or other lung diseases.

Meeting outcomes include the development of a support group network via the ALAMC and the establishment of NECA Networks to organize collaborative lung health events throughout the United States. Generic and location-specific Lung Support Group Tool Kits are being prepared for distribution at the events. Sessions focusing on support group needs resulted in a project to produce print and electronic publications to help group leaders exchange ideas and update one another about activities.

NECA hopes to work with other PIOs to raise awareness about disease consequences of tobacco use; implement health education, disease prevention, and patient support programs for people who are living in residential facilities or are incarcerated; develop methods to address end-of-life issues; and review materials for the Tool Kits and a Lung Support Group Directory and Resource Guide. Lung diseases and sleep apnea support groups, tobacco-cessation groups, groups to help surviving family members deal with grief and loss, and other interested organizations are urged to contact Ms. Barbara Rogers, NECA president, at BreathEZY@aol.com or Dr. Hedrick at HedrickHNECA@aol.com for more information and to learn how to participate.