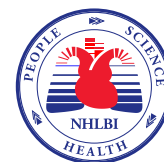


# FYI from the NHLBI



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

Volume 5, Issue 2, September 2004

## NHLBI Listens and Responds



A new booklet titled *From Public Advocacy To Research Priorities, NHLBI Listens And Responds* highlights interactions between public interest organizations (PIOs) and the NHLBI and the positive outcomes that result when PIOs and government work together. To download a

copy, visit [www.nhlbi.nih.gov/public/nhlbi-listens.htm](http://www.nhlbi.nih.gov/public/nhlbi-listens.htm) or request a printed copy from [nhlbi.listens@nih.gov](mailto:nhlbi.listens@nih.gov).

We hope the NHLBI will be the first organization you contact to express your needs and concerns regarding research progress relevant to heart, lung, and blood diseases and sleep disorders.

## Sleep Curriculum Developed

As high school students throughout the country return to their classrooms this fall, many will have to adjust their sleep habits considerably if they hope to make it to school on time. To help parents and their children understand and fully appreciate the importance of sleep, the NHLBI and the NIH Office of Science Education developed a supplemental curriculum for use in high school biology classes. The free curriculum, *Sleep, Sleep Disorders, and Biological Rhythms*, encourages students to explore the scientific processes of sleep, the importance of adequate sleep, and the negative consequences of not getting enough sleep.

Teaching young people about the importance of adequate sleep is an educational priority of the National Center on Sleep Disorders Research (NCSDR), which is part of the NHLBI. Experts recommend at least nine hours of sleep per night for all school-aged children. "Inadequate sleep not only makes us tired, but also can make it difficult for us to concentrate, to learn, and to control our impulses and emotions," said Dr. Carl Hunt, Director, NCSDR.

Additional information on the curriculum supplement is available at <http://science.education.nih.gov/supplements/nih3/sleep/default.htm>. To learn about other curriculum supplements available from the NIH, visit <http://science.education.nih.gov/supplements>.

## Cholesterol Guidelines Updated

A recent update to the National Cholesterol Education Program (NCEP) clinical practice guidelines on cholesterol management advises physicians to consider more intensive treatment options for people at high and moderately high risk for a heart attack. These options include setting lower treatment goals for LDL, or "bad," cholesterol and initiating cholesterol-lowering drug therapy at lower LDL thresholds.

The update is based on a review of five major clinical trials of statin therapy that were conducted since the 2001 release of the NCEP cholesterol guidelines known as the Adult Treatment Panel (ATP) III report.

"The recent trials add to the evidence that when it comes to LDL cholesterol, lower is better for persons with high risk for heart attack," said Barbara Alving, M.D., Acting Director, NHLBI. "These trials show a direct relationship between lower LDL cholesterol levels and reduced risk for major coronary events. So, it is important to consider more intensive treatment for people at very high risk," she added.

Additionally, the importance of using therapeutic lifestyle changes (TLC) to improve cholesterol management was emphasized in the update. Following nutrition guidelines, increasing physical activity, and controlling body weight are examples of TLC.

For a copy of the update and information on the ATP III guidelines visit [www.nhlbi.nih.gov/guidelines/cholesterol](http://www.nhlbi.nih.gov/guidelines/cholesterol).

## What's Inside?

News from Capitol Hill.....	2
Spotlight on Our Web Site .....	2
Need More Information? .....	2
September is National Cholesterol Education Month .....	2
NHLBI Research Initiatives .....	3
National Heart, Lung, and Blood Advisory Council's May Meeting .....	4
Research Findings from the NHLBI .....	4
Upcoming Events .....	5
Constituents' Corner .....	5-6



## News from Capitol Hill

The House of Representatives continues to be interested in legislation addressing stem cell research. On June 24, Representative Mike Castle (R-DE) introduced **H.R. 4682**, the **Stem Cell Research Enhancement Act**. The bill would permit federal support for research using human embryonic stem cells, regardless of the date of derivation, as long as:

- The cell lines were derived from embryos created for fertility treatments.
- The embryos are not needed for fertility treatments and would otherwise be discarded.
- The individuals seeking fertility treatments donated the embryos for research with written informed consent and without receiving any financial or other inducements to make the donation.

The bill, which has 26 cosponsors, was referred to the House Committee on Energy and Commerce.

The 108th Congress also is seeking to facilitate clinical research. On June 21, Representative John Dingell (D-MI) introduced **H.R. 4628**, the **Patient's Bill of Rights Act of 2004**. It is intended to protect consumers in managed care plans and other health coverage, and it includes provisions that would require health care insurers to:

- Allow enrollees to participate in clinical trials funded by the NIH, the Department of Defense, or the Department of Veterans Affairs or approved by the Food and Drug Administration.
- Pay for routine patient costs provided in connection with a trial.

H.R. 4628 was referred to the House Committees on Energy and Commerce, Education and the Workforce, and Ways and Means. A companion measure, **S. 1945**, was introduced by Senator John McCain (R-AZ) on November 24, 2003, and referred to the Senate Committee on Health, Education, Labor, and Pensions.

On July 8, Representative Dave Weldon (R-FL) introduced **H.R. 4779**, the **Clinical Research Act of 2004**. The bill, which was referred to the House Committee on Energy and Commerce, would authorize the NIH to award grants to defray the costs of complying with Federal requirements for the protection of human research subjects (e.g., Public Law 104-191 – the Health Insurance Portability and Accountability Act of 1996) and maintaining institutional review boards. It also would allow for clinical research infrastructure grants to support a variety of activities such as updating information technology systems and creating programs that would increase the supply of qualified clinical investigators. The legislation would also authorize grants to support programs that demonstrate how academic research centers can collaborate with the practicing health care community in clinical research.

## Spotlight on Our Web Site

A new Web resource for health information is available for patients and the public. Developed by the NHLBI, the Diseases and Conditions Index (DCI) provides information on diseases and conditions related to heart, lung, and blood diseases and sleep disorders. New topics are being added and, when completed, the DCI will feature more than 300 diseases and conditions. To explore this easy-to-use resource, visit [www.nhlbi.nih.gov/health/dci](http://www.nhlbi.nih.gov/health/dci).

### Need More Information?

We are always interested in receiving comments and suggestions from the community. If you or your organizations have questions for me or for the Institute, please contact me at [alvingb@nih.gov](mailto:alvingb@nih.gov) or Dr. Carl Roth at [rothc@nih.gov](mailto:rothc@nih.gov).

Barbara Alving, M.D.  
Acting 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](mailto: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](mailto:nhlbi.listens@nih.gov)).
- For additional information regarding NHLBI events, consult the references provided or [www.nhlbi.nih.gov/calendar/nhcal.htm](http://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](http://www.nih.gov/icd).

## September is National Cholesterol Education Month



Invigorate your cholesterol education activities with materials and tools from the 2004 National Cholesterol Education Month Kit. Designed for use by the public and health professionals, the kit is available online at [http://hin.nhlbi.nih.gov/cholmonth/chol\\_kit.htm](http://hin.nhlbi.nih.gov/cholmonth/chol_kit.htm).

## 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](http://www.nhlbi.nih.gov/funding/inits/index.htm).

### **Clinical Centers for a Clinical Research Network for the Treatment of Acute Lung Injury (ALI) and Acute Respiratory Distress Syndrome (ARDS) (RFP-NHLBI-HR-05-04)**

*Proposals due:* October 8, 2004

*Objective:* To develop and conduct clinical trials in the intensive care unit to prevent, treat, and improve the outcome of patients with ALI/ARDS and other related critical illnesses.

### **Community-responsive Interventions to Reduce Cardiovascular Risk in American Indians and Alaska Natives (RFA-HL-04-023)**

*Applications due:* October 22, 2004

*Objective:* To test behavioral interventions for cardiovascular health promotion in Native communities.

### **Exploratory and Developmental Research Grants for Investigations in Rare Diseases (R21) (PA-03-171)**

*Objective:* To encourage new approaches to understanding, treating, and preventing rare heart, lung, and blood diseases and sleep disorders.

### **Improved Therapy for Hemophilia and Hereditary Bleeding Disorders (RFA-HL-04-032)**

*Applications due:* January 14, 2005

*Objective:* To stimulate research to improve therapy and enhance understanding of immune response and safety issues related to new gene transfer, cell-based, or other therapies for bleeding.

### **Mechanisms of HIV-related Pulmonary Complications (RFA-HL-04-031)**

*Applications due:* March 16, 2005

*Objective:* To encourage innovative research on the roles of co-infections, immune factors, and genetic predisposition in the pathogenesis of HIV-related pulmonary diseases.

### **NHLBI Clinical Proteomics Programs (RFA-HL-04-019)**

*Applications due:* October 14, 2004

*Objective:* To promote systematic, comprehensive, large-scale validation of existing and new candidate protein markers that are appropriate for routine use in the diagnosis and management of heart, lung, and blood diseases and sleep disorders.

### **Novel Targets and Therapy Development for Ischemic Stroke (RFA-HL-05-004)**

*Applications due:* January 11, 2005

*Objective:* To develop safe and effective therapies to improve clinical management of stroke patients.

### **Pathogenesis and Treatment of Lymphedema and Lymphatic Diseases (PA-04-071)**

*Objectives:* To identify the developmental, molecular, and cellular mechanisms that contribute to lymphedema and develop effective therapeutic interventions.

### **Prevention and Treatment of Childhood Obesity in Primary Care Settings (RFA-HD-04-020)**

*Applications due:* November 23, 2004

*Objective:* To improve dietary and physical activity behaviors with the goal of preventing excessive weight gain in at-risk children and/or promoting weight loss in obese children.

### **Specialized Centers for Cell-based Therapy for Heart, Lung, and Blood Diseases and Data and Coordinating Center (RFA-HL-04-017)**

*Applications due:* September 21, 2004

*Objective:* To foster multidisciplinary research on cell-based therapies that will enable basic science findings to be more rapidly applied to clinical problems.

### **Specialized Centers of Clinically Oriented Research (SCCOR) in Hemostatic and Thrombotic Diseases (RFA-HL-04-016)**

*Applications due:* September 21, 2004

*Objective:* To foster multidisciplinary research focused on addressing clinical problems in the prevention, diagnosis, and treatment of thrombotic and bleeding disorders.

### **SCCOR in Transfusion Biology and Medicine (RFA-HL-04-018)**

*Applications due:* September 21, 2004

*Objectives:* To support the development and application of new knowledge essential for improved safety, efficacy, and availability of blood, blood components, and plasma derivatives, and to transfer these findings into clinical evaluation and application.

## National Heart, Lung, and Blood Advisory Council's May Meeting

May 13, 2004

Dr. Barbara Alving announced that May is National High Blood Pressure Education Month, Ms. Sandra Gault described the budget report, and Dr. Carl Roth presented new guidelines for program project grants.

Sixteen initiatives, all of which had been reviewed by the Board of Extramural Advisors, were presented by the NHLBI staff. The Council supported all of the initiatives and made several recommendations for consideration.

Dr. Jeffrey Cutler reported on data that showed a significant increase in blood pressure levels among children and adolescents. Dr. Gail Pearson presented an overview of new clinical practice guidelines on high blood pressure in children and adolescents.

The NHLBI plans to collaborate with the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute on Aging (NIA), and the Department of Health and Human Services Office of Public Health and Science (DHHS/OPHS) on stroke research and outreach. Dr. Story Landis, Director, NINDS; Dr. Larry Hodes, Director, NIA; and Dr. Larry Fields, Senior Executive Advisor to the Assistant Secretary for Health, DHHS/OPHS, spoke about the stroke-related activities of their organizations and described areas of research and outreach of relevance to the NHLBI.

Dr. John Fakunding described the Historically Black Colleges and Universities Research Scientist Award, and announced the Institute's plans for a recompetition of the program. Dr. Sonia Skarlatos announced a Request for Applications (RFA) for Specialized Centers of Clinically Oriented Research (SCCOR) in Vascular Injury, Repair, and Remodeling.

During the closed portion of the meeting, the Council concurred on the award of 380 grants for a total cost of \$185,334,000.

The next National Heart, Lung, and Blood Advisory Council (NHLBAC) meeting is scheduled for 8:30 a.m. on September 2, 2004. It is open to the public and will be held in NIH Building 31C, Conference Room 10.

The *FYI from the NHLBI* staff thanks Ms. Sue Byrnes, member of the NHLBAC and director of the LAM Foundation, for her efforts in preparing this summary. Full minutes of Council meetings and summaries of the initiatives are available at [www.nhlbi.nih.gov/meetings/nhlbac](http://www.nhlbi.nih.gov/meetings/nhlbac).

## Research Findings from the NHLBI

### Parental Atrial Fibrillation Increases Risk in Offspring

Having a parent with atrial fibrillation (AF) strongly increases an individual's risk of developing the disorder, according to findings from the Institute's Framingham Offspring Study of AF. The study involved 1,165 women and 1,078 men whose parents were members of the original Framingham Heart Study.

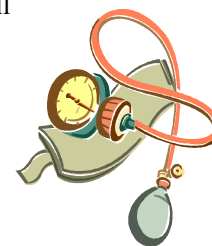
The overall risk of AF nearly doubled for people who had at least one parent with AF compared with those whose parents did not have the condition. Moreover, the risk of AF tripled when one or both parents developed AF before age 75.

The Framingham Offspring Study of AF is the first to find a familial connection for AF in a community sample. The findings open up a new avenue of research on AF and will encourage scientists to search for genetic factors that contribute to the disorder.

### Average Blood Pressure Levels Rising Among Children and Teenagers

Systolic and diastolic blood pressure levels for children and teenagers have risen substantially since 1988, according to a study supported by the NHLBI. The research involved 5,582 children aged 8-17 years, who were part of the 1988-94 and 1999-2000 National Health and Nutrition Examination Surveys (NHANES).

Results showed that average systolic pressure increased by 1.4 mm Hg and diastolic pressure, by 3.3 mm Hg from 1988-94 to 1999-2000. These increases occurred in both boys and girls and in all age and race/ethnic groups. The study also showed a dramatic increase in the percentage of children who were overweight, from 11.7 percent in 1988-94 to 16.3 percent in 1999-2000. The increase in the prevalence of overweight accounted for some, but not all, of the rise in average blood pressure levels, suggesting that other lifestyle factors, such as physical activity and dietary intake, also contributed to the blood pressure trends.



The National High Blood Pressure Education Program has produced a report on the diagnosis, evaluation, and treatment of high blood pressure in children and adolescents to update clinicians on the latest scientific evidence. A copy of the report is available from [www.nhlbi.nih.gov/health/prof/heart/hbp/hbp\\_ped.htm](http://www.nhlbi.nih.gov/health/prof/heart/hbp/hbp_ped.htm).

## Upcoming Events

Activity	Date / Location	More Information
National Sickle Cell Month	September 1-30	<a href="http://www.sicklecelldisease.org/month.htm">www.sicklecelldisease.org/month.htm</a>
National Heart, Lung, and Blood Advisory Council	September 2 and October 21 Bethesda, Maryland	<a href="http://www.nhlbi.nih.gov/meetings/nhlbac/index.htm">www.nhlbi.nih.gov/meetings/nhlbac/index.htm</a>
32 <sup>nd</sup> Annual Sickle Cell Disease Association of America Convention	September 29 – October 2 Atlanta, Georgia	<a href="http://www.sicklecelldisease.org/con_03.htm">www.sicklecelldisease.org/con_03.htm</a>
Healthy Lung Month	October 1 – 31	<a href="http://www.lungusa.org">www.lungusa.org</a>
12 <sup>th</sup> Annual Conference on Sarcoidosis	October 1-3 Seattle, Washington	<a href="http://www.sarcoidosisnetwork.org/events.htm">www.sarcoidosisnetwork.org/events.htm</a>
17 <sup>th</sup> World Conference of Family Doctors	October 13-17 Orlando, Florida	<a href="http://www.aafp.org/x24594.xml">www.aafp.org/x24594.xml</a>
6 <sup>th</sup> International National Lymphedema Network (NLN) Conference	October 20-24 Sparks/Reno, Nevada	<a href="http://www.lymphnet.org/2004Conf/conference.html">www.lymphnet.org/2004Conf/conference.html</a>
American College of Chest Physicians - CHEST 2004	October 23-28 Seattle, Washington	<a href="http://www.chestnet.org/CHEST/program/index.php">www.chestnet.org/CHEST/program/index.php</a>
National Chronic Obstructive Pulmonary Disease (COPD) Awareness Month	November 1-30	<a href="http://www.uscopd.com/activities/awarenessmonth.htm">www.uscopd.com/activities/awarenessmonth.htm</a>
132 <sup>nd</sup> Annual Meeting - American Public Health Association	November 6-10 Washington, DC	<a href="http://www.apha.org/meetings/schedule.htm">www.apha.org/meetings/schedule.htm</a>
American Heart Association Scientific Sessions	November 7-10 New Orleans, Louisiana	<a href="http://scientificsessions.americanheart.org/portal/scientificsessions/ss/">http://scientificsessions.americanheart.org/portal/scientificsessions/ss/</a>
2 <sup>nd</sup> National Restless Legs Syndrome Meeting	November 12-13 Long Beach, California	<a href="http://www.rls.org/meeting2004.html">www.rls.org/meeting2004.html</a>
National Aplastic Anemia Awareness Week	December 1-7	<a href="http://www.aplastic.org/foundation.shtml">www.aplastic.org/foundation.shtml</a>
46 <sup>th</sup> Annual Meeting – The American Society of Hematology (ASH)	December 4-7 San Diego, California	<a href="http://www.hematology.org/meeting/">www.hematology.org/meeting/</a>

## Constituents' Corner

### *From the Pulmonary Fibrosis Foundation* **Pulmonary Fibrosis Foundation Publishes Patient Handbook**

In response to patient requests for information on pulmonary fibrosis, the Pulmonary Fibrosis Foundation has published a 48-page handbook on the disease. The booklet provides answers to questions such as, What is pulmonary fibrosis? What are its prevalence, symptoms, causes, treatments, and prognosis? Detailed information is provided in language that an average patient can understand.

The impact of pulmonary fibrosis on patients' lives is covered in a caring, supportive manner. Most important, the handbook is full of suggestions for coping mechanisms that will help patients adjust to the loss of function that usually accompanies pulmonary fibrosis and enjoy life as fully as possible. The latest developments in research and new treatments are covered extensively. Patients are advised to be active participants in their treatment team. The issue of doctor visits and their inherent frustrations is covered via specific and detailed suggestions.

Thirteen thousand complimentary copies have been mailed to pulmonologists throughout the United States. We are prepared to distribute up to 50,000 copies if the demand materializes. At this point, we would like to thank Charles P. McQuaid and his family for the very generous financial contribution that made this all possible. Mr. McQuaid's father is a pulmonary fibrosis patient. We would also like to thank James Kiley, Ph.D., Director, Division of Lung Diseases, NHLBI, for his very insightful editorial comments during the preparation of the manuscript.

In cooperation with the American College of Chest Physicians and the American Thoracic Society, we are planning to publish a physician's version of this handbook. In addition, we are having both books translated into Spanish for distribution in Latin America and Spain. Physicians desiring copies may call us at 312-377-6895 or write to the Foundation at 1440 West Washington Boulevard, Chicago, Illinois 60607.

*Submitted by Michael Rosenzweig, Ph.D., President & CEO, Pulmonary Fibrosis Foundation*

## *From the Barth Syndrome Foundation* **Barth Syndrome Foundation Holds Conference**

The Barth Syndrome Foundation, Inc., would like to report on the great success of its second biennial International Scientific/Medical and Family Conference that was held in Orlando, Florida, in July. Barth syndrome is an X-linked recessive condition that encompasses cardiomyopathy, neutropenia, skeletal muscle weakness, and growth delay.

Because both “heart” and “blood” components are involved in the syndrome, people associated with the NHLBI had a significance presence at the meeting for scientists and physicians. Dr. John Fakunding, Director of the Heart Research Program in the Division of Heart and Vascular Diseases, kicked off the Scientific/Medical meeting with an overview of the NHLBI perspective. Later, Dr. Susan Old, Associate Director of the Clinical and Molecular Medicine Program, gave a talk entitled “Genetics, Genomics, and Proteomics.” She described the technical resources in these leading-edge areas that are available to researchers through the NHLBI. After having heard Dr. Old speak at the Public Interest Organization meeting in February, we realized that the information she presented was so valuable and timely that we invited her to give essentially the same talk at our conference. She was kind enough to do so. Consequently, she and one of the researchers funded by the Barth Syndrome Foundation now are collaborating to investigate the creation of an antibody that is needed by a number of scientists working on the disorder. Dr. Liana Harvath, Deputy Director of the Division of Blood Diseases and Resources, also attended our conference, and provided the perspective of the NHLBI blood program, which was wonderful.

One of the other factors that made our meeting so successful was the structure of the conference itself. Our first conference two years ago included two simultaneous tracks of sessions – one for scientists and doctors and the other one for families. At the most recent meeting, a third track was added – one for the affected boys themselves. We found that this framework served our needs incredibly well.

Having researchers and physicians meet together is a very positive experience. Interaction among researchers and within the physician communities has obvious benefits, but we also see tremendous advantage in having the bench scientists and the clinicians meet together. The basic scientists are intrigued by the clinical manifestations of the processes that they study on a cellular or even molecular level. In turn, the doctors who treat patients with the syndrome often gain a lot from an increased understanding of what occurs on a microscopic level.

I believe that including the families of those affected by Barth syndrome in simultaneous meetings at the same

location made the real difference in our conference. Because Barth syndrome is rare (though almost definitely much less rare than commonly thought), most physicians have seen only one case, if any. And, of course, most bench scientists never have any exposure to patients with a condition related to the basic science they study. This convergence of people interested in an uncommon condition on so many levels is a unique, and often very compelling, experience for everyone involved. The physicians are intrigued by seeing additional patients with the syndrome and being able to make even cursory comparisons. Furthermore, we received many comments from basic scientists, such as, “I have always been involved in my particular research because I am fascinated by it and I love working on it, but having come to your meeting, I *now* know that what I do also is important.”

The patients and their families benefit as well. In this conference model, families have access to the world’s experts in specialties that are very important to them. Because people with Barth Syndrome, like victims of many other rare genetic disorders, now fortunately are living much longer and, with continuing advances, have a much more promising future, it is really important that the boys and young men with Barth syndrome themselves have an opportunity to meet with these experts as well. During our previous conference, we offered some opportunities for the boys to meet with various world-class physician experts on the disorder. Building on that success, this year, we also held sessions, just for the patients, with basic researchers on subjects such as “I am the Research.” During one such session, the young men affected by Barth syndrome had a chance to talk with and ask hard questions of a bench scientist who studies important aspects of the science related to the condition. The young men thought it was great, and so did the biochemist who led the session.

I think it is safe to say that *all* those who attended the recent Barth Syndrome International Scientific/Medical and Family Conference came away with a renewed sense of strength, community, and collaboration and a reinvigorated sense of determination, urgency, and commitment. This conference model may not be appropriate for every condition, but in the right circumstances, it can work beautifully.

*Submitted by Kate McCurdy, Vice President of Science and Medicine, Barth Syndrome Foundation, 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](mailto: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.