

FYI from the NHLBI



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

Volume 4, Issue 2, September 2003

Leadership Changes at the NHLBI

Effective August 30, 2003, Dr. Claude Lenfant retired from his position as NHLBI Director. Before assuming leadership of the NHLBI in July 1982, he directed the NIH Fogarty International Center (1981-1982) and the NHLBI Division of Lung Diseases (1971-1980).

During his tenure at the NHLBI, Dr. Lenfant oversaw development and completion of clinical trials that have had widespread impact on the ways in which disease is treated and prevented. The studies addressed important clinical issues including therapies to interrupt the course of heart attacks and life-threatening arrhythmias, interventions to reduce blood pressure and serum cholesterol levels, surgical approaches to improve lung function in severe emphysema, and strategies to alleviate the recurrent pain of sickle cell disease.

In the area of basic science, Dr. Lenfant led the NHLBI into the modern era with landmark initiatives such as the Programs of Excellence in Molecular Biology, the Programs of Genomic Applications, and the Proteomics Initiative — all of which brought cutting-edge, multidisciplinary resources to bear on complex problems.

One of Dr. Lenfant's most tangible legacies has been programs of professional, public, and patient education that have had national visibility and impact. Under his stewardship, the NHLBI launched its National Cholesterol Education Program, National Asthma Education and Prevention Program, and National Heart Attack Alert Program, as well as special

initiatives focused on obesity, sleep disorders, and women's heart health. All of these activities reflect his oft-repeated belief that the goal of scientific research — improved health for the public — should always be paramount.

A search committee, co-chaired by National Human Genome Research Institute Director Dr. Francis Collins and National Institute on Alcohol Abuse and Alcoholism Director Dr. T. K. Li, is soliciting recommendations for candidates who are qualified to lead the NHLBI and will be contacting public, patient, and professional groups for suggestions.

Dr. Barbara Alving, who joined the NHLBI in 1999 to lead the Division of Blood Diseases and Resources and was appointed NHLBI Deputy Director in 2001, will be the NHLBI Acting Director until a new director is hired. In addition to her leadership experiences at the NHLBI, Dr. Alving's impressive employment history includes positions such as chief of the Department of Hematology and Vascular Biology at the Walter Reed Army Institute of Research, a job she held from 1992 until leaving the army at the rank of Colonel in 1996, and director of the Hematology/Medical Oncology Section at the Washington Hospital Center in Washington, D.C. An accomplished researcher — she is a co-inventor on two patents, an editor of three books, and co-author of more than 100 papers in the area of thrombosis and hemostasis — and a practicing physician who sees patients at the NIH Clinical Center, Dr. Alving brings to her role a wealth of knowledge about the challenges of designing and conducting research projects and the realities of translating research results into clinical practice.

What's Inside?

News from Capitol Hill	2
September is National Cholesterol Education Month	2
Constituents' Corner	2
Need More Information?	2
NHLBI Research Initiatives	3
Donated Blood Now Tested for West Nile Virus Thanks to NHLBI Resources	4
Study Defines Risks and Benefits of Lung Surgery to Treat Severe Emphysema	4
National Heart, Lung, and Blood Advisory Council's May Meeting	4
Upcoming Events	5
American Thoracic Society Public Advisory Roundtable (ATS-PAR) Members Discuss Barriers Faced by Patients Requiring Supplemental Oxygen During Air Travel.	6

Applicants Sought for the NIH Council of Public Representatives

The NIH Director's Council of Public Representatives (COPR -- pronounced "copper") is seeking applicants for its 2004 panel. The COPR advises the NIH Director on how to enhance public participation in NIH activities and to increase public understanding of the NIH. Members include patients, health care professionals, members of patient or not-for-profit groups, and health and science educators. Next spring, they could include you if you visit copr.nih.gov/application_process.shtm and submit your application by September 15.



News from Capitol Hill

Fiscal Year 2004 Appropriations Bills

On June 10, 2003, the House of Representatives passed its version of the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Act, 2004 (H.R. 2660). It includes \$2,867,995,000 for the NHLBI, as requested in the President's budget. This is a 2.66 percent increase over the \$2,793,733,000 that the NHLBI received in fiscal year 2003. The Senate version (S. 1356), which the Senate appropriations committee approved on June 26, includes \$2,897,595,000 for the NHLBI.

Senators and Representatives Raise Awareness of Chronic Obstructive Pulmonary Disease

On July 16, the House of Representatives passed H. Con. Res. 6 to show their support of the goals and ideals of Chronic Obstructive Pulmonary Disease Awareness Month. The resolution was then forwarded to the Senate, which referred it to the Health, Education, Labor, and Pensions (HELP) Committee. A similar resolution (S. Con. Res. 59), introduced by Senator Mike Crapo (R-ID), also has been assigned to the Senate HELP Committee.

The NIH Teaches Congressmen and Constituents How Research Improves Public Health

At the invitation of Representatives David Obey (D-WI) and James Oberstar (D-MN), NIH leaders participated in community health forums at Rice Lake and Superior, Wisconsin, where they discussed NIH activities and steps people can take to improve their health. Approximately 200 people attended each event, held August 1. After NIH Director Dr. Elias Zerhouni opened the events with a presentation titled "The Benefits of NIH Research: Reaping What We Sow, Applying What We Know," attendees learned about diagnostic tools and treatments that may develop from results of recent genetic studies. Treatments for people who have osteoporosis and osteoarthritis and new methods for diagnosing and preventing these two increasingly prevalent conditions were highlights. Dr. Alving led breakout discussions titled "What You Do About Your Blood Pressure Could Save Your Life," and other NIH participants led sessions about diabetes prevention, the link between obesity and cancer, and research on ways to delay and prevent Alzheimer disease.

September is
National Cholesterol Education Month.

Know your cholesterol numbers --
have your blood cholesterol levels measured.

Know your risk --
visit www.nhlbi.nih.gov to learn how you can
reduce your risk of heart disease.

Constituents' Corner

Please email your suggestions for future *FYI from the NHLBI* articles to NHLBI.Listens@nih.gov or send them to Public Interest News, c/o Office of Science and Technology, Building 31, Room 5A03, 31 Center Drive, MSC-2482 Bethesda, MD 20892-2482.

Coalition for Pulmonary Fibrosis Receives \$60,000 to Advance Education Initiatives

*From Mr. Mark Shreve,
Chief Operating Officer,
Coalition for Pulmonary Fibrosis*

In May, the Coalition for Pulmonary Fibrosis (CPF) received a \$60,000 contribution toward its efforts to educate patients and professionals about idiopathic pulmonary fibrosis (IPF). Now, only four months later, they are conducting a national survey of patients who have IPF to increase understanding of individual differences in detection, diagnosis, and treatment. Survey data will be examined to identify delays between symptom onset, diagnosis, and management and to characterize IPF patient needs. By quantifying patient experiences, the CPF expects to enhance its ability to convey the IPF community's concerns to healthcare professionals and others who can improve patient care. Survey results will be announced in December.

As part of the survey, the CPF also is creating one of the largest registries of IPF patients in the United States. The CPF has enrolled more than 600 patients and expects to enroll another 700-900 before the project is complete. The CPF also plans to partner with other organizations in the IPF community to compile a single, national registry of IPF patients in the hope that access to patients will advance research efforts to find a cure.

IPF is a disease of inflammation that results in scarring of the lungs. It affects more than 80,000 Americans and is difficult to diagnose. For more information on IPF or on CPF programs, visit the CPF Web site at www.coalitionforpf.org.

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.

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.

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.

Biological Basis of Hutchinson-Gilford Syndrome: Relationship to Mutations in the Lamin A/C Gene and to Other Known Laminopathies (PA-03-069)

- Objectives: To understand how mutations in the gene for lamin A/C affect the structure of cell nuclei and lead to dysfunctions that, and in some instances, cause Hutchinson-Gilford syndrome.

Cellular and Molecular Imaging of the Cardiovascular, Pulmonary, and Hematopoietic Systems (RFA-HL-04-003)

- Applications due: January 22, 2004
- Objectives: To develop new methods of monitoring specific cell populations in vivo that can be used for cell-based therapies and to identify cellular pathways that regulate heart, lung, and blood functions.

Chemical Screens for New Inducers of Fetal Hemoglobin (SBIR/STTR) (PA-03-049)

- Applications due: April 1, August 1, and December 1
- Objectives: To develop drugs that increase fetal hemoglobin levels for the treatment of beta-chain hemoglobinopathies such as sickle cell disease and Cooley's anemia (beta-thalassemia).

Clinical Research Consortium to Improve Resuscitation Outcomes (RFA-HL-04-001)

- Applications due: November 13, 2003
- Objectives: To establish a Resuscitation Research Consortium to test research advances that may improve recovery from cardiopulmonary arrest.

Development of Diagnostic Screening Test for Salt Sensitivity (SBIR/STTR) (PA-03-123)

- Applications due: April 1, August 1, and December 1
- Objectives: To develop a noninvasive or minimally invasive, practical diagnostic screening test for salt sensitivity of blood pressure.

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 develop biological substitutes for damaged tissues and organs.

Granulomatous Lung Inflammation in Sarcoidosis (RFA-HL-04-009)

- Applications due: October 20, 2003
- Objectives: To develop models of granulomatous inflammation in the lungs and to encourage investigators in other research areas to study sarcoidosis.

Immune System Development and the Genesis of Asthma (RFA-AI-03-041)

- Applications due: November 21, 2003
- Objectives: To define cellular and molecular mechanisms that lead to the development of asthma and to devise strategies to prevent or reverse the disease.

Inflammation and Thrombosis (RFA-HL-04-005)

- Applications due: January 22, 2004
- Objectives: To identify new targets and develop therapies for thrombotic disorders such as heart attack, stroke, deep vein thrombosis (DVT), and pulmonary embolism in preclinical studies.

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

- Objectives: To stimulate research on the biology of the lymphatic system; the 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 treatment strategies.

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

- Objectives: To study 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.

Sleep Disturbance in Parkinson's Disease and Parkinson-like Conditions (PAS-03-131)

- Objectives: To stimulate research on sleep disorders in Parkinson's disease and related conditions.

Research Advances from the NHLBI



Donated Blood Now Tested for West Nile Virus Thanks to NHLBI Resources

Only 1 in 150-200 people infected with West Nile virus (WNV) develop a severe reaction. Most who are infected do not develop symptoms, which creates a public health problem because the virus can spread if a transfusion recipient is given blood from an infected donor. Last year, when health officials realized that WNV can spread via blood products, the NHLBI and Gen-Probe Corporation launched an intensive effort to develop a method to protect the blood supply. Nine months later, the Food and Drug Administration gave permission for the resulting test to be used to screen blood donated at various centers. By July 4, the test was being used for at least 75 percent of the U.S. blood supply.

Study Defines Risks and Benefits of Lung Surgery to Treat Severe Emphysema

Because of a study supported by the NHLBI and the Centers for Medicare and Medicaid Services, surgeons can better predict which patients who have emphysema are likely to benefit from bilateral lung volume reduction surgery (LVRS). LVRS was first used in the 1950s to treat patients who had emphysema. Although some patients seemed to benefit from the procedure, high mortality and morbidity discouraged its widespread use. In the early 1990s, surgeons began using LVRS again; early reported successes led to rapidly increasing use of the procedure despite uncertainty about its safety and effectiveness. The National Emphysema Treatment Trial (NETT) clarified the short-term and long-term benefits and risks of LVRS. It also demonstrated that patients whose emphysema was predominantly in the upper lobes of the lung and whose exercise capacity was low were most likely to benefit from LVRS, and conversely, that patients who did not have upper lobe distribution of emphysema and who had greater exercise capacity were poor candidates for LVRS.

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

On May 29, 2003, Dr. Lenfant welcomed members to the 210th meeting of the National Heart, Lung, and Blood Advisory Council (NHLBAC). He presented awards to Drs. Sidney Smith and Aram Chobanian, who have worked closely with the NHLBI. Dr. Smith, Director of the Center for Cardiovascular Science and Medicine at the University of North Carolina, received an award for his service to the NHLBI during his tenure as the Vice President for Science of the American Heart Association. Dr. Chobanian, Dean and Provost of the Medical Campus at the Boston University of Medicine, was acknowledged for his role in developing the *7th Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure*.

In a presentation to the Council, Dr. Chobanian described aspects of the report including data from recent clinical trials, new and simplified classifications of blood pressure, and concise guidelines for all clinicians. The Council discussed how to increase patient adherence to treatment regimens and the development public health interventions to reduce the prevalence of hypertension.

Dr. Carl Roth, NHLBI Associate Director for Scientific Program Operation, discussed the NIH requirement that grant applicants obtain approval before submitting applications for more than \$500,000 in direct costs for any budget period. Data presented by Dr. Roth showed that the NHLBI has accepted more than 80 percent of requests each year for the past three years. The number of grant applications in excess of \$500,000 submitted to the Institute has not decreased since the review was initiated.

The fall 2003 National Heart, Lung, and Blood Advisory Council (NHLBAC) meetings are scheduled for 8:00 a.m. on September 4 and October 30. They are open to the public and will be 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.

Dr. Gregory Morosco, Director of the NHLBI Office of Prevention, Education, and Control, presented an overview of the Institute's outreach programs. Council members also heard presentations on:

- Hearts N' Parks, a program to reduce obesity and risk of coronary heart disease.
- *Salud para su Corazón*, an initiative to train health educators in Latino communities.
- Healthy Hearts in Housing, a project to develop a cardiovascular health program in Baltimore's public housing communities.
- The Heart Truth, a campaign to raise the level of awareness among women about the dangers of heart disease and the risk factors leading to its development.

Council members who had attended the recent meeting of the NHLBI Board of Extramural Advisors described some of the topics that were presented at the meeting. They included the need for physician scientists to continue medical research and the issue of patient privacy rights associated with biological samples.

Seventeen initiatives were presented and reviewed by the Council. While Council members supported all of them, they had several specific recommendations. NHLBI leadership will take these recommendations into consideration, along with other issues, when determining which programs will be implemented.

During the closed portion of the meeting, the Council concurred on the award of 426 grants for a total cost of \$198,757,000.

Upcoming Events

Activity	Date	Details	For Additional Information
National Sickle Cell Awareness Month	September	Because September is "back to school" month, the Sickle Cell Disease Association of America wants you to reflect on the children and adults whose education has been affected by sickle cell disease.	www.sicklecelldisease.org/month.htm
National Heart, Lung, and Blood Advisory Council	September 4, October 30	8:00 a.m. - 2:00 p.m., NIH Campus, Building 31C, Conference Room 10, Bethesda, MD. Meetings are open to the public.	www.nhlbi.nih.gov/meetings/nhlbac
Lupus Today Conference	September 5	Washington, DC. Panels of researchers and patients will explain what recent advances mean for current and future management of lupus.	www4.od.nih.gov/orwh
Cardiac Arrhythmias Research and Education (CARE) Foundation Patient Empowerment Program	September 13	Rochester, NY. Patients who have inherited heart rhythm disorders are encouraged to attend with their doctors, school nurses, athletic coaches, and friends so they can become better informed about cardiac arrhythmias such as long QT syndrome.	www.longqt.org/whatsnew.html
Living with Idiopathic Pulmonary Fibrosis (IPF) Seminar	September 20	Durham, NC. The seminar will address IPF diagnosis, current standards of care, emerging research, lung transplantation, life management issues, and support resources available to IPF patients and families.	www.coalitionforpf.org/aboutus/registereducation.asp
National Histiocytic Disorders Symposium	September 21	Philadelphia, PA. Participants will learn about histiocytosis research and treatments and will meet other families that have been affected by histiocytic disorders.	www.histio.org/association
31st Annual Sickle Cell Disease Association of America Convention	September 24-27	Beverly Hills, CA. Patients, health care providers, educators, advocates, and community-based organizations are welcome at this conference on "Empowerment Through Education and Advocacy."	www.sicklecelldisease.org/con_03.htm
11th Annual Conference on Sarcoidosis	September 26-27	Seattle, WA. Patients will meet with doctors, researchers, counselors, and others who are interested in and affected by sarcoidosis.	sarcoidosis_network@prodigy.net
Adult Congenital Heart Association Northern California Regional Conference	October 11	Mountain View, CA. Adults with congenital heart defects and their families will learn about advances and resources to help people who are living with congenital heart disease.	www.achaheart.org
2003 National Conference of the Narcolepsy Network	October 12-14	Atlanta, GA. Titled "Fragmented Sleep - Fragmented Lives," the conference will address how families cope with sleep disorders, medications that may help people who have narcolepsy, and advances in understanding sleep and sleep disturbances.	www.narcolepsy-network.org
11th Annual Hereditary Hemorrhagic Telangiectasia (HHT) Conference	October 17-18	Dallas, TX. Patients and their families will attend lectures on HHT, learn about research advances in the understanding of HHT and in treatments for patients who have HHT, and have questions answered by health care professionals.	www.hht.org/web/conference/default.asp
Sarcoidosis Patient Conference	October 24-25	Orlando, FL. Topics include "Living Well with Sarcoidosis," "The Future of Therapy," and "Update in Genetics of Sarcoidosis."	www.sarcoidosis-research.org
American College of Chest Physicians - CHEST 2003	October 25-30	Orlando, FL. The annual conference for physicians and allied health professionals provides an update of pulmonary medicine, critical care medicine, pediatric chest medicine, thoracic surgery, and cardiovascular medicine.	www.chestnet.org/CHEST
55th Annual National Hemophilia Foundation (NHF) Conference	November 6-8	Salt Lake City, UT. Patients of all ages and their families will learn about information resources for patients and their doctors, the latest in treatment advances, and the NHF advocacy program.	www.hemophilia.org
Indiana Sarcoidosis Conference	November 7-8	Indianapolis, IN. The conference theme is "Reaching New Heights of Sarcoidosis Awareness."	www.indysarcoid.org
American Heart Association Scientific Sessions	November 9-11	Orlando, FL. This annual meeting is the world's largest convention for scientists and healthcare professionals devoted to the science of cardiovascular disease and stroke.	www.scientificsessions.org/portal/scientificsessions/ss
National Chronic Obstructive Pulmonary Disease (COPD) Conference	November 14-15	Arlington, VA. COPD and respiratory specialists, representatives from federal health agencies, public health experts, and others will confront the growing problem of COPD at this conference organized by the U.S. COPD Coalition.	www.uscopd.com/confer.html

American Thoracic Society Public Advisory Roundtable (ATS-PAR) Members Discuss Barriers Faced by Patients Requiring Supplemental Oxygen During Air Travel

At a recent meeting with the American Thoracic Society (ATS) Research Advocacy Committee, ATS-PAR representatives from the Alpha-1 Foundation, American Lung Association, American Sleep Apnea Association, LAM Foundation, Pulmonary Fibrosis Foundation, Pulmonary Hypertension Association, and Sarcoidosis Research Institute provided insights into the barriers and challenges faced by travelers who need supplemental oxygen when they fly. Discussion focused on changes that the airline industry, or individual companies, could make to ease travelers' burdens.

Whereas the major issues for patients who travel by car, train, or bus are having enough oxygen containers available for the trip and arranging for a commercial oxygen provider to deliver oxygen to their destinations, air travel is much more complicated. Airlines prohibit passengers from using their own oxygen equipment on planes and charge a fee for in-flight supplemental oxygen, which is covered by few private insurance companies and not at all by Medicare. They also require that patients make separate arrangements, which entail additional costs, for supplemental oxygen during layovers if patients are not traveling on direct flights. Overall added expenses can range from \$50 to \$1500.

An additional problem encountered by many patients is the risk that a flight may not be equipped to provide supplemental oxygen even though the traveler provided the required documentation and gave the airline sufficient notice. Because flying without supplemental oxygen is not an option, such an oversight can jeopardize a person's entire business trip or vacation.

The ATS-PAR provides the society with a patient perspective on pulmonary and critical care medicine, education and advocacy opportunities, and research needs. It serves as the bridge between the ATS and organizations that represent people affected by lung diseases and breathing disorders. For more information on the ATS-PAR, visit www.thoracic.org/aboutats/par/par.asp.

Tips for air travelers requiring supplemental oxygen

Making Arrangements

- **Travel on non-stop or direct flights.** Because many airlines base their oxygen charges on the number of segments in a trip, using non-stop or direct flights may save money. If you need oxygen service on the ground but have a direct flight, you may be able to stay on the plane during stops in order to receive a continuous supply of oxygen.
- **Find out what equipment is available.** Equipment varies, even among planes in the same airline. Verify that your prescribed flow rate can be provided. On most airplanes, supplemental oxygen can be used only in certain seats.
- **Arrange for oxygen on the ground.** Airlines do not provide supplemental oxygen service in airport terminals.
- **Shop around for the best total price.** Charges for supplemental oxygen vary by airline and by oxygen supply companies that service airports. If an oxygen company representative needs to meet your plane, you may be charged more if you travel outside of normal business hours.
- **Plan ahead.** Most airlines request 2 weeks notice that supplemental oxygen will be needed although some will accommodate requests made only 48 hours in advance.
- **Get answers.** If the ticket agent cannot answer all of your questions, speak to someone in the airline's medical or special services department.

Traveling

- **Bring your nasal cannula.** Some airlines provide only masks.
- **Confirm all arrangements 48 hours** before your flight.
- **Arrive early.** Unfortunately, mistakes happen. If last-minute arrangements have to be made because of miscommunications among the reservations agent, the medical office, and the ground crew, arriving 90 minutes or more before your flight is scheduled to leave can give the airline a chance to obtain and install the oxygen tank so you can travel as planned.
- **Carry extra copies of your doctor's letter.** The airport First Aid Station may have oxygen available if you have an unexpected layover or get stranded, but you will need to provide your doctor's instructions.
- **Get help.** Travel is tiring; just because you *can* walk the length of the terminal, doesn't mean you *should*. Don't hesitate to use the airport's wheelchair services, baggage assistance, and mobile carts. Carry small bills to tip service providers.

Many thanks to Dr. Vlady Rozenbaum, Moderator of COPD-Alert, and Ms. Sue Byrnes, Director of the LAM Foundation, for their help with this article and the associated "Tips for air travelers...."