FYI from the NHLBI

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

Volume 3, Issue 1, May 2002

Message from the Director

It was a pleasure to meet with representatives from many of your organizations at our Public Interest Organization meeting in February. Comments from participants and Council members lead me to believe that each meeting is more useful than the previous one. We currently are planning our fourth annual meeting, and with the help of comments and suggestions you submitted following this year's event, I expect it will be the best ever.

We're also using some of your comments as the basis for this month's "Spotlight on Our Web Site" column (page 4). And remember, back issues of the *FYI from the NHLBI,* with articles such as "Media Tips to Get Your Message Heard" (December 2001) and "Conference Grants are Available from the NHLBI" (May 2001), are accessible online at **www.nhlbi.nih.gov/public/FYIfront.htm**.

Many of you asked for advice and NHLBI contacts for partnering to fund qualified grant applications. If you are one of those people, contact the director of the division most relevant to your organization's focus. We've also established a new Web page, through the "research funding" section of our Web site, so heart, lung, blood, and sleep researchers who are looking for funding can identify public interest organizations that might be willing to support their work.

Many of you said you would like to see better recruitment materials for clinical studies. Examples of our most successful recruitment materials are now available online, through the "scientific resources" section of our Web site. We hope that the examples will give researchers, and organizations such as yours that help them raise awareness about their studies, ideas for designing informational brochures.

Perhaps more important than what we can do for you, however, is what your groups can do for, and with, one another. The meeting gave participants a chance to meet leaders from other organizations and develop the beginnings of a network. I urge you to keep in touch with each other throughout the year. Even though your organizations may be very different, you face many similar challenges. Whereas the NHLBI can introduce you to resources and provide general advice, your colleagues from other organizations can draw on their own experiences to offer concrete suggestions specific to your needs.

Sincerely yours,

Claude Lenfant, M.D.
Director

The NIH Opens Genetic and Rare Diseases Information Center

Thanks to a new project from the National Institutes of Health's Office of Rare Diseases and National Human Genome Research Institute, called the **Genetic and Rare Diseases Information Center**, patients and their families now have free and immediate access to specialists who can give them current, accurate information about genetic and rare diseases. The center, however, does not provide genetic counseling, diagnostic testing, referrals, medical treatment, or advice.

Genetic and Rare Diseases Information Center

Phone: 888-205-2311
TTY: 888-205-3223

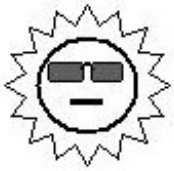
Calls by phone (888-205-2311) and TTY text telephone (888-205-3223) are answered Monday through Friday, from noon to 6 p.m. Eastern time. Inquiries also can be submitted via email (gardinfo@nih.gov), fax (202-966-5689), or U.S. mail (The Genetic and Rare Disease Information Center, P.O. Box 8126, Gaithersburg, MD 20898-8126). Depending on the information requested, a written response will arrive in 5 to 10 business days.

What's Inside?

"Cell-a-brate" the Genome Project by Exploring Your Molecular Self

The Human Genome Project began in 1990 as an effort by researchers from around the world to map and sequence the human genome - the totality of human DNA - as well as the genomes of experimental organisms, such as yeast and mice. To mark the publication of the preliminary genome sequence of humans, the Human Genome Project has produced a free multimedia educational kit, **The Human Genome Project: Exploring our Molecular Selves.** The kit, which is available for download or online viewing at **www.nhgri.nih.gov/educationkit/**, includes

- an interactive timeline presenting more than 90 *Milestones in Genetics*.
- two interactive activities, *Genetic Variation in Populations* and *Using Genes to Trace Human History,* that clarify similarities and differences among individuals and among populations.
- an animated clip titled *How to Sequence a Genome.*
- a segment on *Ethical, Legal, and Social Issues,* complete with questions to encourage dialogue.
- written definitions, phonetic spelling, illustrations, and a "talking" *Glossary of Genetic Terms*.
- a 3D computer-animated video, *Exploring Our Molecular Selves*, that illustrates basic components and principles of molecular biology and shows how the information in DNA is converted into the molecules necessary for life.



Ozone Alert! Days Can Be Bad for Your Heart

"Code Red," "Ozone Action Day," and other terms describing poor air quality in a community usually are associated with an increase in respiratory ailments. Now, researchers have shown that invisible air pollutants so small that they can evade the lungs' normal defense mechanisms and get into the bloodstream may trigger a heart attack as little as 2 hours after being inhaled. Although it is too early to predict what medical interventions might be effective in preventing heart attacks triggered by fine-particle exposure, some recent data suggest that the particles may cause inflammation and increase levels of certain proteins that cause clots to form. Year-round processes such as combustion in automobile engines, power plants, and refineries cause fine-particulate air pollution, but the associated health concerns are largely summer phenomena. The study's co-author, Douglass W. Dockery, Sc.D., professor of environmental epidemiology at Harvard School of Public Health, advises people to "avoid outdoor activity on hot, hazy days," because when people exercise outside, their increased respiratory activity also increases the amount of particles that are absorbed into the blood stream. But don't use that as an excuse for not going to the gym you joined as part of your New Year's Resolution; air conditioning can reduce indoor concentrations of the pollutants by 30-50 percent.

News from Capitol Hill

The House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education are working on their respective appropriations bills for the NIH for Fiscal Year (FY) 2003. Dr. Ruth Kirschstein, Acting Director, NIH, and the Directors of the various NIH Institutes and Centers, participated in overview hearings with the House and Senate subcommittees on March 13 and 21, respectively. Dr. Kirschstein and other Directors also met with the House subcommittee for "theme hearings" on specific topics:

- From Bench to Bedside and Beyond
- Fundamental Research: Biomedical Science in the Future
- Collaborations in Research
- Disease Prevention and Health Promotion

Dr. Lenfant was invited to speak during the Disease Prevention and Health Promotion hearing on April 16. He presented several examples of NHLBI activities that bring research results to local communities and described ongoing collaborations to allow the Institute's messages to reach people of all ages and backgrounds.

This May, Educate Yourself about High Blood Pressure Prevention

May is High Blood Pressure Education month. According to a recent study, 90 percent of middle-aged Americans are at risk of eventually developing hypertension. Fortunately, high blood pressure is easily diagnosed and can be prevented by adopting certain lifestyle measures — follow a low fat eating plan that includes lots of fruits and vegetables and limits sodium, maintain a healthy weight, be physically active, and if you drink alcoholic beverages, do so in moderation. Adopting healthy lifestyle habits is an effective first step in both preventing and controlling high blood pressure. More information, including suggestions for ways that your community can participate in National High Blood Pressure Education Month, is available online at **hin.nhlbi.nih.gov/nhbpep_kit/**.

Fourth Annual World Asthma Day

Join us on May 7th to celebrate World Asthma Day and highlight May as Asthma and Allergy Month. The special U.S. theme, "Communities Working for Life and Breath," is a reminder that persistent and collective efforts at the national, state, and local levels are needed to reduce the burden of asthma. Hundreds of organizations are expected to commemorate World Asthma Day by working with their state and local colleagues to promote public awareness of the global burden of asthma and what can be done about it. To get yours involved, visit **www.nhlbi.nih.gov/health/prof/lung/asthma/wad_2**.

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.

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

- Objectives: To encourage development of organ-specific tolerance protocols using large animal models for heart transplantation and both large and small animal models for lung transplantation.

Cellular and Molecular Mechanisms of Primary Pulmonary Hypertension (PPH) (PA-00-043)

- Objectives: To promote research to elucidate cellular and molecular mechanisms involved in the unique vascular remodeling that characterizes PPH and in the regulation of vascular tone during its development.

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

- Applications Due: 3/13/03, 3/12/04
- Objectives: To stimulate development of biological substitutes for damaged tissues and organs and exploration of novel approaches to tissue remodeling.

Mechanisms of Fetal Hemoglobin Gene Silencing for Treatment of Sickle Cell Disease and Cooley's Anemia (RFA-HL-02-015)

- Applications Due: 7/12/02
- Objectives: To characterize mechanisms involved in fetal hemoglobin (gamma-globin) gene silencing during normal human development and to develop approaches capable of inhibiting gene silencing.

Molecular Mechanisms of Mucous Cell Metaplasia and Excess Mucous Secretion in Human Airway Diseases (RFA-HL-02-011)

- Applications Due: 6/14/02
- Objectives: To encourage characterization of molecular pathways involved in mucin secretion and mucous cell metaplasia to determine contributions of specific pathways in chronic airway inflammation and identify potential therapeutic targets.

Molecular Targets and Interventions in Pulmonary Fibrosis (RFA-HL-02-020)

- Applications Due: 9/20/02
- Objectives: To support the development of new therapeutic approaches for pulmonary fibrosis.

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 therapeutic interventions for patients with primary and secondary lymphedema.

Pathophysiologic Mechanisms of Obesity-Associated Cardiovascular Disease (RFA-HL-02-016)

- Applications Due: 6/19/02
- Objectives: To clarify the biological basis of various obesity-related cardiovascular diseases through basic and clinical mechanistic studies.

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

- Objectives: To provide a better understanding of CFS pathogenesis and pathophysiology with the goal of improving diagnostic and intervention strategies.

Physical Activity and Obesity Across Chronic Diseases (PA-01-017)

- Objectives: To examine relationships between physical activity and obesity, to improve assessment of physical activity and energy balance, and to test interventions that incorporate physical activity for obesity prevention or treatment related to chronic diseases.

Research on Stem Cell Biology and Cell-Based Therapies for Heart, Lung, Blood, and Sleep Disorders (RFA-HL-02-019)

- Applications Due: 9/20/02
- Objectives: To provide the scientific basis needed to accelerate research efforts leading to the use of cellular therapies for regenerative and reparative medicine.

Specialized Centers of Clinically Oriented Research (SCCOR) in Translational Research in Acute Lung Injury (RFA-HL-02-014)

- Applications Due: 6/11/02
- Objectives: To foster multidisciplinary basic and clinical research on clinically relevant questions related to acute lung injury and adult respiratory distress syndrome.

Specialized Centers of Research (SCOR) in Neurobiology of Sleep and Sleep Apnea and Airway Biology and Pathogenesis of Cystic Fibrosis (RFA-HL-02-013)

- Applications Due: 6/11/02
- Objectives: To foster multidisciplinary basic and clinical research on clinically relevant questions related to the neurobiology of sleep and sleep apnea and the airway biology and pathogenesis of cystic fibrosis.

Specialized Centers of Clinically Oriented Research (SCCOR) in Pediatric Heart Development and Disease (RFA-HL-02-027)

- Applications Due: 1/16/03
- Objectives: To stimulate research that will aid in the prevention, diagnosis, and treatment of congenital cardiovascular malformations, pediatric arrhythmias, conduction disturbances, disorders of myocardial function, and acquired pediatric cardiac diseases.

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

Dr. Lenfant began the meeting by announcing that February is National Heart Month. In his report of the Director, Dr. Lenfant reviewed the President's 2003 budget for the Institute, noting that it is $2.8 billion, an increase of 8.4 percent from 2002. He also informed Council members that applications for the Loan Repayment Program would be presented in May.

Presentations were made on cell-based therapies. Dr. Elizabeth Nabel, NHLBI Division of Intramural Research, spoke about the Intramural Research Report on Stem Cell Plasticity; Dr. Charles Murry, University of Washington, discussed the role of stem cells in repair of damaged cardiac muscle; and Dr. Hal Broxmeyer, Indiana University School of Medicine, presented data on hematopoietic stem cell plasticity.

Council members described the Institute's 3rd annual Public Interest Organization (PIO) meeting, held on February 6, 2002, as demonstrating continued improvement over the previous ones. The sessions were interesting and relevant, and provided valuable information to the PIOs. It was suggested that next year, PIOs should have more opportunities to interact and share best practices. Representatives thanked Dr. Lenfant for the opportunity to allow professionals and PIOs to come together in a positive environment.

During the closed portion of the meeting, the Council concurred on the award of 249 grants for a total cost of $104,996,405.

The next National Heart, Lung, and Blood Advisory Council (NHLBAC) meeting is scheduled for 8:00 A.M. on May 9, 2002. It is open to the public and will be in NIH Building 31C, Conference Room 10.

The *FYI from the NHLBI* staff thanks Ms. Paula Polite, member of the NHLBAC and President of the Sarcoidosis Research Institute, for her efforts in preparing this summary. Full minutes of Council meetings are available at **www.nhlbi.nih.gov/meetings/nhlbac**.

Spotlight on Our Web Site

Many participants at our third annual PIO meeting asked for suggestions on where they can get information to use in their organizations' newsletters, names of researchers in their local communities who are studying certain diseases, and materials that will help them explain what clinical trials are and how they work.

If you need ideas for **articles for your organizations' newsletters**, the NHLBI Web site is a wealth of information. Much of it is in a "ready to use" format. From our Home page (**www.nhlbi.nih.gov**), you can access News and Press Releases, browse our Special Web Pages and Interactive Applications, and, with the click of a button, find out what's new on the NHLBI Web site. None of our materials, including articles that you read in the *FYI from the NHLBI*, has copyright restrictions. Feel free to use whatever is of interest to your readers.*

If you're wondering **how to find researchers at your local universities who are studying a subject you're interested in**, use CRISP (Computer Retrieval of Information on Scientific Projects), a searchable database of federally funded biomedical research projects conducted at universities, hospitals, and other research institutions. From **www-commons.cit.nih.gov/crisp/**, click on "Go to CRISP Query Form," enter your "search terms" (e.g., sarcoidosis) and select a state (e.g., Pennsylvania), submit your query, and receive names of researchers, their institutions, and brief descriptions of their research projects.

If you want **general information about clinical trials** that you could provide to your members, remember that **Clinicaltrials.gov** is more than just a listing of NIH-sponsored clinical studies. It links to resources including "What Is A Clinical Trial?" "Taking Part In Research Studies: What Questions Should You Ask" "Clinical Trials of Medical Treatments: Why Volunteer?" and "Understanding Clinical Trials From The Patient's Perspective."

**The fine print:* We do, however, request that you cite the NHLBI (as part of the National Institutes of Health), as the source and provide the full title of the document from which it came in your own publication. Further, if implications or conclusions are drawn that are not in the original NHLBI document, this fact should be clearly stated in your publication. Also please note that the material should not be used to promote or endorse any product or company, either directly or indirectly.

Third Annual Public Interest Organization Meeting Fosters Discussions Among Representatives, Council Members, and NHLBI Staff

Following a guest appearance by Garfield ® the cat, NHLBI Star Sleeper, the third annual Public Interest Organization (PIO) meeting started with a roundtable on "Communicating Your Message." Panelists included public relations specialist and PIO representative Ms. Nancy Loving, and science writer and editor Ms. Barbara Culliton. Ms. Mary Woolley, Research!America, highlighted the (disturbing) statistic that only 5 percent of people in the United States know that the NIH funds most of the medical research paid for by U.S. taxpayers. However, she also provided suggestions for ways organizations can educate their members and communities about the NIH and the work it supports. Following the panel discussion, participants talked with NHLBI investigators and staff about ways they can educate their constituents about clinical research and fund research studies. The afternoon period included a presentation on how genetic research is being translated into practice. Ms. Wendy Chaite, Lymphatic Research Foundation, shared her experience with starting up a PIO and provided pointers on how other small groups can leverage their resources to raise awareness and foster research. The meeting concluded after a question-and-answer period and closing remarks by Dr. Lenfant, but several of the PIO representatives stayed into the early evening, exchanging ideas and networking with one another.

Upcoming Events

Date	Activity	Details	For Additional Information
5/9	National Heart, Lung, and Blood Advisory Council	8:00am - 2:00pm NIH Main Campus Building 31C, Conference Room 10, Bethesda, MD. Open to the public.	www.nhlbi.nih.gov/meetings/nhlbac/
5/17-5/22	American Thoracic Society International Conference	Atlanta, GA. The conference will feature symposia, workshops, year-in-review sessions, and postgraduate courses on a variety of clinical topics.	www.thoracic.org
6/21-6/23	International Pulmonary Hypertension Association Conference	Irvine, CA. Patients and their families will learn about the latest advances in treatment and research.	www.phassociation.org/learn/conference.htm
6/29-7/1	Scleroderma Foundation's 2002 National Conference	Las Vegas, NV. The program, "Living Well with Scleroderma," features talks by researchers, workshops, and exhibits.	www.scleroderma.org
7/5-7/9	31st Annual Scientific Meeting - International Society for Experimental Hematology	Montreal, Canada. The scientific program will address topics including stem cell proliferation, malignant transformation and targeted therapy, signaling in normal and malignant cells, and bone marrow and cord blood stem cell transplantation.	www.iseh.org/meetings/2002.cfm
8/2-8/4	Aplastic Anemia & MDS International Foundation Annual Patient and Family Conference	Aurora, CO. Patients and their families will hear the latest medical research findings for treatment of aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria from some of the world's leading experts.	www.aplastic.org/conferences.shtml
8/29-9/1	The 5th International National Lymphedema Network (NLN) Conference	Chicago, IL. This year's educational program for health care professionals, titled Lymphedema: The Quest for Understanding, features state-of-the-art research presentations and posters on a variety of topics specifically related to the lymphatic system and related disorders.	www.lymphnet.org

Recent Advances from the NHLBI

Gene Linked to Sudden Cardiac Death Identified: Researchers have cloned and identified the role of a gene that, in the presence of heart failure, appears to cause irregular heart beats that can lead to sudden cardiac death. Although the study was conducted in mice, the same gene regulates electrical currents that are vital to sustaining a normal rhythm in the human heart. Study coauthor Dr. Ching-Feng Cheng, University of California, San Diego, explained that the gene functions like an electrical switch; during heart failure, the switch disrupts current flow, leading to malignant heart rhythms and sudden death. He also noted, however, that sudden cardiac death may be caused by a wide spectrum of underlying mechanisms. "The challenge," he said, "is to identify the key molecular switches that lead to the disease, and to design new ways to treat complex human cardiac diseases."

Heart Assist Device Extends and Improves Lives of Patients with End-Stage Heart Failure: Despite several serious side effects, a type of implantable heart pump, called a left ventricular assist device, can extend and improve the lives of terminally ill patients with end-stage heart failure who are not eligible for cardiac transplantation. "This study is an initial step in demonstrating the feasibility of restoring or replacing heart function for extended periods of time," said Dr. John Watson, director of the NHLBI Clinical and Molecular Medicine Program and study coauthor. Heart failure affects an estimated 4.7 million Americans, and 550,000 new cases are diagnosed each year. Dr. Lenfant commented, "This compelling study shows that even with a high rate of complications, a left ventricular assistance device can provide a significantly longer and better quality of life in extremely ill heart failure patients for whom a poor quality of life and death are certain."

Scientists Use Gene Therapy to Correct Sickle Cell Disease in Mice: For the first time scientists have corrected sickle cell disease in mice using gene therapy. "Scientists have been working to accomplish this since the creation of an animal model for sickle cell disease several years ago. Although much more research is needed before human application, this is a significant achievement that brings us closer to human gene therapy for what is a very serious genetic blood disorder," said Dr. Lenfant. The next step is to see how safe and effective the gene transfer process is in larger animals more similar to humans.

Sickle cell disease affects about 1 in 500 African Americans and 1 in 1,000 Hispanic Americans. Currently, the only cure available is bone marrow transplantation, which requires a healthy, matched sibling donor, and only approximately 18 percent of children with sickle cell disease qualify.

Constituents' Corner

This space is reserved for you, our readers, to share ideas and broadcast opinions. We invite you to submit your comments, thoughts, and suggestions via email (NHLBI.Listens@nih.gov) or snail mail (Public Interest News, c/o Office of Science and Technology, Building 31, Room 5A03, 31 Center Drive, MSC-2482 Bethesda, MD 20892-2482).

ATS Public Advisory Roundtable Symposium

The American Thoracic Society (ATS) Public Advisory Roundtable (PAR), which provides the ATS with a patient perspective on pulmonary and critical care medicine, will host a symposium at *ATS 2002-Atlanta*, the 98th International Conference (May 17-22). Scheduled for Monday, May 20 at 8:15 a.m., the symposium, "Genetic Mechanisms in Lung Disease," will be chaired by ATS Immediate Past-President and National Heart, Lung, and Blood Advisory Council Member, William J. Martin, II, M.D. Through this symposium, the PAR hopes to:

- enlist the expertise of exemplary basic scientists in understanding the molecular and cellular pathogenesis of lung disorders,
- focus on broad pathophysiologic concepts, rather than disease-specific topics, which are of general interest to the ATS membership, and
- introduce the ATS membership to the missions and resources of foundations and associations that represent the ATS Public Advisory Roundtable.

Attendees are invited to the PAR Poster Session, a visual display and explanation of the lung-related not-for-profit organizations involved with ATS/PAR, following the symposium.

The PAR, which focuses on issues related to patient care, patient rights, patient education, advocacy and research/research funding, is composed of not-for-profit, lung-related organizations including the Alpha-1 Foundation, the American Sleep Apnea Association, the Asthma and Allergy Foundation of America, the LAM Foundation, the Pulmonary Fibrosis Foundation, the Pulmonary Hypertension Association, the Sarcoidosis Research Institute, and three local American Lung Association chapters. To learn more about the PAR, go to **www.thoracic.org/aboutats/par/par.asp** or contact **par@thoracic.org**.

PIO Influences NIH Research Agenda

On December 11, the NIH issued a new Program Announcement (PA) on chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS). The PA is remarkable because the CFS community helped direct the priorities outlined in the announcement.

The development of the PA began in 1999, when the CFIDS Association of America launched an aggressive campaign to stimulate NIH funding of CFS research. They sought guidance from experts at NIH, and found Dr. Paul Velletri at NHLBI to be an especially welcoming partner. One of the best suggestions Dr. Velletri and others made was for the organization to host a series of meetings to establish current knowledge, identify the top areas for future exploration, and most important, introduce a new group of scientists to CFS research.

Since January 2000, the CFIDS Association of America and the NIH have collaborated on five CFS meetings. Two were funded by the NIH and three by the Association, although the organizations worked closely on all five meetings. Recommendations for future study outlined at the meetings formed the basis of the NIH PA and the CFIDS Association's grant announcements. Several non-CFS researchers who participated in the meetings entered as skeptics, but emerged with a better understanding of CFS, as well as with a desire to apply their expertise to CFS. Although engaging researchers outside of the CFS community seemed risky at the outset, the Association now believes that going outside the CFS community's circle will increase the amount and quality of CFS research funded by the NIH and other organizations, and ultimately result in the conquering CFS.

For more on the CFIDS Association's symposium series, see **www.cfids.org/about-cfids/research-symposia.asp**. Information about the NIH CFS Coordinating Committee is available at **www4.od.nih.gov/cfs**.

Many thanks to Ms. Nancy Pietri, ATS, and Ms. Vicki Walker, the CFIDS Association of America, for contributing the articles.

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 (SL34V@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.