FYI from the NHLBI

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

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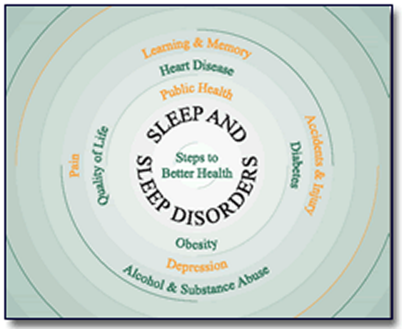
First National Sleep Conference Explored Sleep's Role in Public Health

Evidence linking sleep with behavior, mood, and learning continues to accumulate. Now, scientists are finding that reduced or disrupted sleep appears to increase the risk of obesity, diabetes, and cardiovascular disease. The first national sleep conference, "Frontiers of Knowledge in Sleep & Sleep Disorders – Opportunities for Improving Health and Quality of Life," was held March 29 and 30 on the NIH campus. It addressed the latest evidence regarding sleep and sleep disorders, and explored ways to improve public health and safety.



Sponsored by the National Center on Sleep Disorders Research (NCSDR), which is a component of the NHLBI, the conference was attended by more than 400 health care providers, public health and education experts, policy makers, patient advocates, and sleep medicine specialists. Conference cosponsors were the American Academy of Sleep Medicine, the American Insomnia Association, the American Sleep Apnea Association, the Narcolepsy Network, the National Sleep Foundation, the NIH Office of Rare Diseases, the Restless Legs Syndrome Foundation, and the Sleep Research Society.

The conference provided a forum for experts from a variety of fields to take an interdisciplinary, systematic approach to bridging the gap between knowledge and effective health care. Participants identified populations at risk and opportunities for and barriers to improving public health. Their recommendations will be used to formulate a national action plan for implementing clinical practice changes and to expand the public's knowledge, attitudes, and behaviors related to sleep to improve public health and quality of life.

The archived videocast of the conference is available at http://videocast.nih.gov/PastEvents.asp?c=26. For additional information about the NCSDR visit www.nhlbi.nih.gov/sleep.

5th Annual PIO Meeting Promoted Sharing and Interaction

The NHLBI hosted the fifth annual Public Interest Organization (PIO) Meeting on February 11, 2004, in Bethesda, Maryland. This year's meeting was the largest ever, with more than 130 people in attendance and nearly 70 PIOs represented. Two main themes of the meeting were fostering collaborations and sharing best practices. The meeting agenda was designed to encourage interactions among the PIOs and to provide them time to share ideas.

Meeting highlights included:

- Remarks by Dr. Elias Zerhouni, Director, NIH, on the NIH Roadmap
- Presentations describing the American Thoracic Society Public Advisory Roundtable
- Discussions of collaborations in disseminating public information, helping patients, and promoting relevant research
- Scientific tutorials on nanotechnology; gene therapy; tissue engineering; and genetics, genomics, and proteomics
- A research presentation on sleep and its disorders
- Roundtables for PIOs to share best practices and lessons learned

The NHLBI extends a warm thank you to all PIOs who participated, especially those who facilitated group discussions. We welcome your feedback and look forward to seeing you again next year.

What's Inside?

News from Capitol Hill

On March 24, the House passed **H. Res. 522**, a resolution expressing the sense of the House that increased awareness and education about heart disease and the risk factors of heart disease among women are critical needs. The resolution specifically commends the NHLBI for *The Heart Truth* campaign.

The House passed **H.R. 339**, the **Personal Responsibility in Food Consumption Act**, on March 10. If passed by the Senate and signed into law, the bill would protect manufacturers, distributors, or sellers of food or non-alcoholic beverage products that comply with applicable statutory and regulatory requirements from claims of injury relating to a person's weight gain, obesity, or any health condition associated with weight gain or obesity. The bill has been placed on the Senate calendar.

The **Organ Donation and Recovery Improvement Act** became law on April 5, 2004. **P.L. 108-216**, formerly known as **H.R. 3926**, establishes several new initiatives related to organ donation, including activities to:

- encourage organ donation
- reimburse living donors for expenses related to organ donation
- establish a registry to monitor the long-term health of living donors

On March 25, Representative Alcee Hastings (D-FL) introduced **H.R. 4042**, a bill to amend the Internal Revenue Code of 1986 to allow a deduction for expenses paid in connection with the donation of an organ. H.R. 4042 has been referred to the House Ways and Means Committee.

The discussions about stem cell research continue, as Representative Juanita Millender-McDonald (D-CA) introduced **H.R. 3960**, the **Stem Cell Replenishment Act of 2004**, on March 11. The bill would permit Federal funds to be used for research on human embryonic stem cell lines that were created after the August 9, 2001, deadline established by President Bush. It was referred to the House Energy and Commerce Committee.

Spotlight on Our Web Site

The Garfield Star Sleeper Campaign has teamed up with Time for Kids to help children learn about the importance of getting at least nine hours of sleep each night. Time for Kids is a subsidiary of Time, Inc. that provides materials for use in classrooms.

During National Sleep Awareness Week, March 29-April 4, nearly 30,000 third grade teachers received a teacher's guide and "Be a Star Sleeper" magazines for their approximately 750,000 students. Download a free copy of the materials at www.nhlbi.nih.gov/health/public/sleep/starslp/tfk.htm.

Women's Health Initiative: Estrogen-Alone Study is Stopped, Participants Begin Follow-up Phase

Participants in the estrogen-alone study of the Women's Health Initiative (WHI), a large multi-center trial, have now begun the follow-up phase of the study, after the NIH stopped the active component of the trial.

After considering the data, the NIH concluded that estrogen alone has no effect (either increase or decrease) on heart disease, a key question of the study. However, estrogen alone appears to increase the risk of stroke and decrease the risk of hip fracture. No increased risk of breast cancer was observed during the course of the study. (*JAMA*, 2004; 291:1701-1712.)

Another component of the WHI, a trial of estrogen plus progestin, also was stopped early, in July 2002, because the risks were found to outweigh the benefits. (*JAMA*, 2002; 288:321-333.)

The NIH is advising women to continue to follow the FDA guidance regarding hormone therapy, which is that postmenopausal women who use or are considering using estrogen or estrogen plus progestin should discuss the risks and benefits with their physicians. The products are approved therapies for relief from moderate to severe hot flashes and from symptoms of vulvar and vaginal atrophy.

NHLBI Funds Pediatric Heart Disease Clinical Centers

The NHLBI recently awarded $68 million to fund four clinical centers to accelerate research on heart development and treatment of pediatric heart disease. The research is part of the Specialized Centers of Clinically Oriented Research program, which is designed to stimulate multidisciplinary collaborations so that basic research advances can be rapidly translated to clinical care.

Birth defects are a leading cause of infant mortality, with cardiovascular malformations, which are present in about one percent of live births, being the largest contributors to deaths from birth defects.

The Centers will encourage experts, including pediatric cardiologists, cardiovascular surgeons, immunologists, geneticists, pediatric clinicians, molecular biologists, cell biologists, and statisticians, to combine their talents to conduct state-of-the-art research addressing a central pediatric cardiovascular theme. The Centers will be located in Boston, Philadelphia, Pittsburgh, and Cincinnati.

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.

Asthma Exacerbations: Biology and Disease Progression (RFA-HL-04-029)
- Applications due: June 18, 2004
- Objective: To explore the underlying pathobiology and mechanisms of resolution of exacerbations, and their impact on lung function, physiology, and disease state.

Biological Basis of Hutchinson-Gilford Syndrome: Relationship to Mutations in the Lamin A/C Gene and to Other Known Laminopathies (PA-03-069)
- Objective: To understand how mutations in the gene for lamin A/C affect nuclear structure, thus leading to both dysfunction of the nuclear envelope, and depending on the mutation, Hutchinson-Gilford syndrome.

Chemical Screens for New Inducers of Fetal Hemoglobin (SBIR/STTR) (PA-03-049)
- Applications due: April 1, August 1, and December 1
- Objective: 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).

Chronic Illness Self-Management in Children (PA-03-159)
- Objective: To support research related to sociocultural, environmental, and behavioral mechanisms as well as biological/technological factors that improve self-management and quality of life in children and adolescents with chronic diseases.

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 diseases in the areas of heart, lung, and blood disease and sleep disorders.

Idiopathic Pulmonary Fibrosis Clinical Research Network (RFA-HL-04-021)
- Applications due: June 21, 2004
- Objective: To establish a clinical research network and data coordinating center to conduct multiple treatment trials on patients with newly diagnosed idiopathic pulmonary fibrosis.

NHLBI Programs of Excellence in Nanotechnology (RFA-HL-04-020)
- Applications due: July 21, 2004
- Objective: To develop and apply nanotechnology and nanoscience solutions to the diagnosis and treatment of cardiovascular, pulmonary, hematopoietic, and sleep disorders through the establishment of multidisciplinary teams.

Pathogenesis and Treatment of Lymphedema and Lymphatic Diseases (PA-04-071)
- Objectives: to stimulate research on the biology of the lymphatic system, to characterize the pathophysiologic mechanisms that cause the disease, to develop new methods for quantitating and imaging lymph flow, to discover new therapeutic interventions, and to determine the safety and efficacy of complementary and alternative therapies.

Pulmonary Complications of Sickle Cell Disease (RFA-HL-04-015)
- Applications due: May 24, 2004
- Objective: To stimulate translational research on the pulmonary complications of sickle cell disease.

Sleep Disturbance in Parkinson's Disease and Parkinson-like Conditions (PAS-03-131)
- Objective: To stimulate research on sleep disorders in Parkinson's disease and Parkinson's related neurological conditions, and on associated sleep disorders such as Restless Legs Syndrome and sleep-disordered breathing.

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 that enables basic science findings to be more rapidly applied to 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 February Meeting

February 12, 2004

Dr. Barbara Alving, Acting Director of the NHLBI, welcomed members to the 213th meeting of the National Heart, Lung, and Blood Advisory Council (NHLBAC). Dr. Alving reminded everyone that February is American Heart Month and she introduced four new Council members.

Ms. Sandra Gault, Financial Management Branch, gave an update of the President's FY 2005 budget request for the NHLBI. Ms. Terry Long, Office of Prevention, Education, and Control, discussed *The Heart Truth* campaign.

Dr. William Baumgartner, Cardiac Surgeon-in-Charge, The Johns Hopkins Hospital, gave a presentation on cardiothoracic surgery. Dr. Alice Mascette, Division of Heart and Vascular Diseases (DHVD), described some of the activities in cardiothoracic surgery supported by the Institute and discussed future initiatives.

Dr. Milton Packer, Chief of Circulatory Physiology in the Department of Medicine, Columbia-Presbyterian Medical Center and chair of the NHLBI Working Group that addressed future directions for congestive heart failure research, provided an overview of the group's recommendations. Dr. John Fakunding, DHVD, summarized current NHLBI research support in heart failure and outlined plans to address the recommendations of the working group.

Ms. Sue Byrnes, Executive Director of The LAM Foundation and member of the NHLBAC, reported on the PIO meeting, describing the tremendous synergy that it generated. She thanked the NHLBI for sponsoring it and for allotting more time in the agenda for PIO representatives to interact.

Dr. James Kiley, Division of Lung Diseases, presented three new initiatives for Specialized Centers of Clinically Oriented Research. Council members enthusiastically supported all three initiatives. Dr. Robert Musson, Division of Extramural Affairs, described the Institute's recent efforts to streamline its interaction with the Council.

During the closed portion of the meeting, the Council concurred on the award of 294 grants for a total cost of $143,954,939.

The next National Heart, Lung, and Blood Advisory Council (NHLBAC) meeting is scheduled for 8:00 a.m. on May 13, 2004. It is 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.

Research Advances from the NHLBI

Device Reduces Heart Failure Deaths

An implantable cardiac defibrillator (ICD), a device placed under the skin of the chest to send electrical signals to correct potentially fatal arrhythmias, can significantly reduce deaths in heart failure patients according to preliminary results from the Sudden Cardiac Death in Heart Failure (SCD-HeFT) study.

SCD-HeFT tested whether an ICD that provides a shock without pacing or an antiarrhythmic drug called amiodarone could help prevent sudden death.

Over 2,500 patients, 19 to 90 years of age, with moderate to severe heart failure - New York Heart Association classes II and III - were assigned to ICD, placebo, or treatment with amiodarone. By the end of the study, those who got the ICD had substantially fewer deaths than those who got amiodarone and those who got placebo.

Heart failure affects about 5 million Americans and about 50 percent of deaths are probably due to rapid heartbeats in one of the lower chambers, or ventricles, of the heart. SCD-HeFT results indicate that ICDs could help reduce the number of heart failure patients who die from arrhythmias.

Fitness in Young Adults Protects the Heart in Middle Age

Cardiorespiratory fitness in early adulthood significantly decreases the chance of developing high blood pressure and diabetes, two major risk factors for heart disease and stroke, in middle age, according to a new study supported by the NHLBI. Fitness also reduces the risk for the metabolic syndrome, a group of factors that includes excess abdominal fat, elevated blood pressure and triglycerides, and low levels of high density lipoprotein, the "good" cholesterol.

The study enrolled over 4,400 black and white men and women, who were ages 18 to 30 years at their enrollment, and followed them for 15 years. Results were the same for blacks and whites and for males and females. They indicated that those who were rated as low or moderately fit at the time of enrollment had twice the risk of high blood pressure, diabetes, and metabolic syndrome as those who were considered highly fit when they entered the study. The risk increased directly as fitness level dropped. Also, weight gain was inversely related to fitness over the course of the study.

The study underscores the importance of both fitness and maintaining a healthy weight in the fight against heart disease and stroke and their risk factors, and indicates that improving fitness in young adults could reduce the risk for diabetes and metabolic syndrome by as much as 50 percent.

Upcoming Events

Activity	Date	Details	More Information
National Stroke Awareness Month	May 1-31	During May, the National Stroke Association urges people to take charge of their health by asking their doctor about stroke prevention and adopting healthy lifestyle habits.	http://199.239.30.192/NationalStroke/AboutUs/NationalStrokeAwarenessMonth/default.htm
National Heart, Lung, and Blood Advisory Council	May 13 and September 2	8:00 a.m. - 1:30 p.m. Building 31C, Conference Room 10, NIH Campus, Bethesda, MD. Meetings are open to the public.	www.nhlbi.nih.gov/meetings/nhlbac/index.htm
100th International Conference of the American Thoracic Society	May 21-26	Orlando, FL. The conference, which is focused on respiratory diseases, will offer the latest information relating to clinical practice, clinical and basic research, advocacy, and education.	www.thoracic.org/ic/ic2004/program_glance.asp
2004 Scleroderma Foundation National Conference	June 26-28	Los Angeles, CA. Patients will hear experts in the field present the latest in research and management of scleroderma. Special sessions will be offered for newly diagnosed patients.	www.scleroderma.org
Sixth International Pulmonary Hypertension Conference	June 24-27	Miami FL. The Conference provides an opportunity for PH patients, caregivers, and medical professionals to learn about advances in treatment and research.	www.phassociation.org/Conference
Aplastic Anemia MDS International Foundation Patient and Family Conference	July 8-10	Linthicum, MD. Patients and their families will hear the latest medical research findings for treatment of aplastic anemia, myelodysplastic syndromes, and related disorders.	www.aplastic.org/conferences.shtml

May is National High Blood Pressure Education Month

Help increase public awareness of the risks of high blood pressure and promote improved prevention and control by taking action at the local level. Activity ideas, fact sheets, media tools, and other easy-to-use materials are available in the National High Blood Pressure Education Program's Community Kit (http://hin.nhlbi.nih.gov/nhbpep_kit/com_kit.htm).

For more ideas, check out the activity registry (http://hin.nhlbi.nih.gov/nhbpep_kit/events.htm) to see what events will be held throughout the United States and the world, and be sure to register your event.

Constituents' Corner

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).

Rare Lung Diseases Consortium Meets

The first annual meeting of the Rare Lung Diseases Consortium (RLDC) was held in Cincinnati, Ohio, March 26-28, 2004. The National Center for Research Resources/NIH Rare Lung Diseases Consortium is a Cincinnati-based international network of clinical centers that are focused on clinical research in rare pulmonary diseases, including lymphangioleiomyomatosis (LAM), alpha one antitrypsin deficiency (AATD), pulmonary alveolar proteinosis (PAP), and pediatric interstitial lung disease (pILD).

The meeting was modeled after prior LAM conferences, and included nearly 400 clinicians, scientists, patients, and NIH staff. Like "LAMposium," a unique and powerful aspect of the RLDC conference was the inspiration and synergy that resulted from the interactions among the scientific participants and the patients. Deliberate efforts were made to attract investigators from diverse disciplines, to introduce novel thinking, and to set new research directions. Dr. Betsy Nabel's address to the patients on "The Value of Patient Advocacy in NHLBI-sponsored Translational Research" was a highlight of the meeting.

The pathogenesis of autoimmune lung disease was one theme that emerged as a focus for next year's Cincinnati RLDC meeting scheduled for April 8-10, 2005. The NHLBI and the Office of Rare Diseases supported this conference through the R13 mechanism with awards to Drs. Frank McCormack for LAM, Bruce Trapnell for PAP, and Robin Deterding for pILD.

Submitted by Drs. Frank McCormack and Bruce Trapnell, University of Cincinnati

Educational Series to Inform Patients about the Fourth Most Common Cause of Death in the United States

Educating the patient community about a major national health problem that accounts for 8 million office visits, costs over $32 billion dollars in medical expenditures, and is the fourth leading cause of death in the United States and advising this same community on the most efficacious treatments and prevention strategies is the objective of a new series of all-day seminars organized by the Alpha-1 Foundation: The 2004 COPD and Alpha-1 Education Days Series. Other co-sponsors of the series include the Alpha-1 Association, the National Emphysema/COPD Association, and the NHLBI COPD Clinical Research Network (CRN).

Chronic obstructive pulmonary disease (COPD) is a major public health problem that affects more than 16 million Americans. COPD is an umbrella term used to describe airflow obstruction associated with emphysema and chronic bronchitis. Alpha-1 antitrypsin deficiency (Alpha-1) is one of the most common hereditary disorders in the world and can result in life-threatening lung disease in adults and liver disease in children and adults. An estimated 100,000 Americans have the deficiency, yet less than 10 percent have been diagnosed. As many as 25 million people in the United States could carry a single deficient gene that causes Alpha-1 and may pass the gene on to their children.

So what's the connection between COPD and Alpha-1? "Alpha-1 is a strong risk factor for COPD," states David Mannino, M.D., Medical Epidemiologist at the National Center for Environmental Health, Centers for Disease Control and Prevention. "I firmly believe a high percentage of COPD is related to genetics, unfortunately we only know the specific genetic cause of a small percentage." Approximately three percent of people with COPD may have Alpha-1.

"When I learned the Alpha-1 Education Days series was going to be expanded to include COPD, I was pleased with the aims and thought it was important that the NHLBI COPD CRN was offered the opportunity to participate," stated James Kiley, Ph.D., Director, Division of Lung Diseases, NHLBI. The 2004 COPD and Alpha-1 Education Days Series incorporates the successful Alpha-1 Education Days and includes outreach to the COPD community offering educational programming to individuals affected by Alpha-1 and COPD throughout the country. This community-based effort increases general awareness by including a broader segment of the affected population. "There is a tremendous need for greater public awareness about COPD. In recognition of this need, the NHLBI is developing a COPD education program to reach patients and clinicians," Dr. Kiley added.

In 1998, a task force led by representatives from the American Thoracic Society (ATS) and the European Respiratory Society (ERS) began a systematic review of the diagnosis and management of individuals with Alpha-1. The result of their 5-year study established new guidelines for physicians. Among its most significant recommendations is diagnostic genetic testing for Alpha-1 for all adults with emphysema, COPD, irreversible asthma, or unexplained liver disease.

"The guidelines establish a new standard for the detection and treatment of Alpha-1 because this genetic disorder is often going undiagnosed or misdiagnosed," said John W. Walsh, President and CEO, Alpha-1 Foundation. The expanded education series has come about, in large part, by the announcement of the ATS/ERS consensus document.
Submitted by Ms. Silvana Piñeiro, Alpha-1 Foundation

The NHLBI is currently planning a workshop to formulate strategies for a COPD education program. It will be held in the fall 2004 and representatives from COPD-related PIOs will be invited.

Need More Information?

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