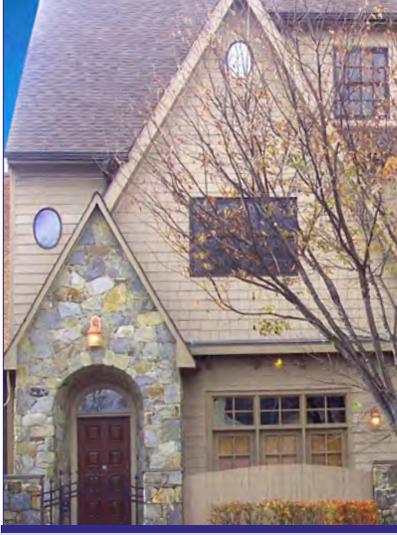


# nih record



ABOVE • Woodmont House is a new annex to the Children's Inn. See story below.

## features

<b>Collins Presides Over First ACD Meeting</b>	1
<b>Nobelist Greider To Give Trent Lecture</b>	3
<b>Three at NIH Are Named 2009 AAAS Fellows</b>	5
<b>Busy NIH'ers Discuss Work-Life Balance</b>	16

## departments

Briefs	2
Milestones	10
Digest	15

### A Busy To-Do List

## Collins Convenes First ACD Meeting as Director

By Carla Garnett

Host the President. Account for unprecedented stimulus windfall. Meet reps from dozens of constituency groups. Announce new stem cell lines. Plan to avoid fall from future fiscal cliff. These were just a few items on the to-do list of NIH director Dr. Francis Collins in the first 4 months of his new job. At the Dec. 4 meeting of the advisory committee to the director, he described life in the top chair at NIH.

“This has been a pretty wild ride, this first 115 days. Trying to figure out the right metaphor is sort of like this,” Collins joked, showing a slide of a boy attempting to sip from a rush of water. “I don’t think it quite does justice, though, because it really feels like drinking from a fire hose while riding a rollercoaster. There are so many things coming at you every day, but the staff here is phenomenal and the science is truly exciting.”



Dr. Francis Collins holds his first ACD meeting as NIH director.

SEE ACD MEETING, PAGE 6



Dr. William Gahl of Undiagnosed Diseases Program

### Where Science, Hope and Sadness Intersect

## New Undiagnosed Diseases Program Awash in Potential Patients

By Carla Garnett

If the Clinical Center is the “House of Hope,” then one of NIH’s most recently established components, the Undiagnosed Diseases Program, must seem like a harried gatekeeper at the house’s new entryway. Similar to a bouncer at the most exclusive club in town, the UDP evaluates those waiting anxiously in a long queue to get in.

“This is a program that lets us see the juxtapo-

SEE UNDIAGNOSED DISEASES, PAGE 8

### Children’s Inn Annex

## Woodmont House To Open in Spring

By Belle Waring

For the family with a seriously ill child, the world can change overnight. Hit with a youngster’s hospitalization, many parents struggle as routines collapse and everyday life is swamped.

But the Clinical Center is not an everyday hospital.

“The concept of family-centered care is a hallmark of the Clinical Center philosophy,” says Kathy Russell, CEO of the Children’s Inn at NIH, which, since 1990, has provided lodging for families whose children are receiving treatment at NIH. “We partner with biomedical research, and psychosocial support and housing are part of that.”

Now the inn has purchased “a beautiful house,” says Russell, “which expands our mission in a personal, tangible way that people can understand.”

The new place is Woodmont House, a 7-year-old former single-family dwelling just south of

SEE INN ANNEX, PAGE 4



The NIH Record is published biweekly at Bethesda, MD by the Editorial Operations Branch, Office of Communications and Public Liaison, for the information of employees of the National Institutes of Health, Department of Health and Human Services. The content is reprintable without permission. Pictures may be available upon request. Use of funds for printing this periodical has been approved by the director of the Office of Management and Budget through September 30, 2010.

To receive alerts to our latest issue, send an email to [listserv@list.nih.gov](mailto:listserv@list.nih.gov) with the words "Subscribe NIHRECORD" in the message body.

NIH Record Office Bldg. 31, Rm. 5B41  
Phone (301) 496-2125 Fax (301) 402-1485

Web address <http://nihrecord.od.nih.gov>

#### Editor

Richard McManus  
[Rich.McManus@nih.gov](mailto:Rich.McManus@nih.gov)

#### Assistant Editor

Carla Garnett  
[Carla.Garnett@nih.gov](mailto:Carla.Garnett@nih.gov)

#### Staff Writers

Jan Ehrman  
[Jan.Ehrman@nih.gov](mailto:Jan.Ehrman@nih.gov)

Valerie Lambros  
[Valerie.Lambros@nih.gov](mailto:Valerie.Lambros@nih.gov)

Belle Waring  
[Belle.Waring@nih.gov](mailto:Belle.Waring@nih.gov)

The NIH Record reserves the right to make corrections, changes or deletions in submitted copy in conformity with the policies of the paper and HHS.

## briefs

### STEP Forum on Nanotechnology and Food

The staff training in extramural programs (STEP) committee will present a Science in the Public Health forum on the topic "Out of the Lab and into Our Lunch: Nanotechnology and Food" on Thursday, Jan. 14, from 8:30 a.m. to 12:30 p.m. in Lister Hill Auditorium, Bldg. 38A.

Do you know that nanotechnology is being used to modify some foods you eat? This is not science fiction—hundreds of nanofoods are on the market already. Nanotechnology has the potential to improve our food supply, making it tastier, healthier and more nutritious. Yet little is known about how nanoparticles behave in the body or the toxic effects they could have. What is the science behind nanofoods? What are their potential benefits and risks? You may be surprised at some of the answers.

### NEI 40th Anniversary Event

A series of symposia are being organized to commemorate NEI's 40th anniversary and to showcase the interface between vision and diverse aspects of biology and medicine. The goal of these symposia is to foster collaborative interactions with colleagues within and outside the NIH research community and to promote new initiatives for understanding the biology of vision and blindness.

"Symposium on Stem Cell Therapies: From Degeneration to Regeneration" will be held Tuesday, Jan. 12 from 8:30 a.m. to 2 p.m. in Lister Hill Auditorium, Bldg. 38A.

Upcoming symposia include:

Focus on Glaucoma—Feb. 18-19

Sayer Vision Research Lecture—Mar. 10

Translational Research and Vision—June 24-25

For a complete program listing, visit [www.nei.nih.gov/anniversary/symposia/](http://www.nei.nih.gov/anniversary/symposia/).

### Oncology Fellowship Opportunities

The interagency oncology task force, a joint initiative between NCI and FDA, has announced fellowship training opportunities for Ph.D.s, M.D.s, and M.D./Ph.D.s or their equivalents in cancer-related scientific research and research-related regulatory review. The objective of the IOTF Joint Fellowship Program is to train a core of scientists in cancer research and regulatory review to develop skills that bridge the two processes. Fellows will learn to build awareness of regulatory requirements into the early stages

of medical product development and will devise strategies to improve planning throughout the research and regulatory review phases. Fellows will also learn how to bring state-of-the-art knowledge and technology to bear on the design, conduct and review of clinical trials. More information about the program fellowships can be found at <http://iotfftraining.nci.nih.gov>.

### Summer Camp Guide 2010

NIH is offering Summer Camp Guide 2010 at four locations on four different days, sponsored by the Office of Research Services' Division of Amenities and Transportation Services.

Wednesday, Jan. 13, Bldg. 10, B1 cafeteria

Thursday, Jan. 14, Rockledge I (6705), 4th floor cafeteria

Tuesday, Jan. 19, Bldg. 31 cafeteria

Wednesday, Jan. 20, Executive Plaza North (6130) lobby

Attend one of these events to pick up the 2010 Summer Camp Guide and samples of camp brochures. The guide contains summer activities in Virginia, Maryland and D.C. It separates the camps by cost, type and activities. It also includes additional resources to survey your child's interests. Camp vendors will not be on site. However, a child care referral specialist and NIH staff will be available to help you get started. With summer only a few months away, now is the time to begin researching quality summer programs for your children. All services are free of charge to all NIH staff.

Those who need reasonable accommodation to participate should contact Tonya Lee at (301) 402-8180, 5 days prior to the event.

### NCRR Hosts CTSA Industry Forum, Feb. 17-18

On Feb. 17 and 18, the National Center for Research Resources will present a Clinical and Translational Science Award industry forum: Promoting Efficient and Effective Collaborations among Academia, Government and Industry. Designed to explore ways to streamline development of new drugs, devices and diagnostics, the forum will focus on current practices and successful management models to improve this process. NIH director Dr. Francis Collins will deliver the opening address, "Why Industry and Academia Should Work Together: An NIH Perspective."

The forum will take place in the Natcher Conference Center. Both days will begin at 8 a.m.; a poster session and networking reception will be held from 5:30 to 7 p.m. on the first day. The event is free and open to the public. Posters are due by Monday, Feb. 1 and registration is requested by Feb. 5. To register or submit a poster, visit [www.palladianpartners.com/CTSAIndustryForum](http://www.palladianpartners.com/CTSAIndustryForum). The forum will be video-cast at <http://videocast.nih.gov>.

# nih record



Nobel laureate Dr. Carol Greider

### Nobel Laureate Greider To Give Trent Lecture

Newly minted Nobel laureate Dr. Carol Greider will give the seventh annual Jeffrey M. Trent Lectureship in Cancer Research on Tuesday, Jan. 19 from 1 to 2 p.m. in Masur Auditorium, Bldg. 10.

Greider received her B.A. from the University of California at Santa Barbara in 1983 and her Ph.D. in 1987 from the University of California at Berkeley. In 1984, working together with Dr. Elizabeth Blackburn, she discovered telomerase, an enzyme that maintains telomeres, or chromosome ends.

Greider first isolated and characterized telomerase from the ciliate *Tetrahymena*. In 1988, as an independent Cold Spring Harbor fellow, she cloned and characterized the RNA component of telomerase. In 1990, she was appointed assistant investigator at Cold Spring Harbor Laboratory and became an investigator in 1994. She expanded the focus of her telomere research to include the role of telomere length in cell senescence, cell death and cancer.

Together with Dr. Calvin Harley, she showed that human telomeres shorten progressively in primary human cells. This work, along with work of other researchers, led to the idea that telomere maintenance and telomerase may play important roles in cellular senescence and cancer.

In 1997, Greider moved her laboratory to Johns Hopkins. In 1999, she was appointed professor and, in 2004, she was appointed the Daniel Nathans professor and director of the department of molecular biology and genetics.

Once at Hopkins, Greider's group continued to study the biochemistry of telomerase and determined the secondary structure of the human

telomerase RNA. She also expanded her work on a mouse model of dyskeratosis congenita and stem cell failure in response to short telomeres. Greider currently studies both the biochemistry of telomeres and telomerase, as well as the cellular organismal consequences of short telomeres.

Greider has won numerous awards for her work on telomerase, including the Gairdner Foundation Award in 1998, the Albert Lasker Award for Basic Medical Research in 2006, and the Dickson Prize in Medicine in 2007. In 2009, she accepted the Paul Ehrlich and Ludwig Darmstaedter Prize and the Pearl Meister Greengard Prize.

Last Oct. 5, she was awarded the Nobel prize for the discovery of how chromosomes are protected by telomeres and the enzyme telomerase.

### Guttmacher Named NICHD Acting Director

Dr. Alan Guttmacher's vision of biomedical research is 20/20: it leads to better health for people in this country and around the world.

"Fostering exceptional research is our most important job, but the research is not an end in itself," he said. "What also matters is how we apply the results of that research to improving human health."

On Dec. 1, Guttmacher became acting director of the National Institute of Child Health and Human Development. In announcing the appointment, NIH director Dr. Francis Collins noted that Guttmacher possessed "a unique combination of expertise and experience."

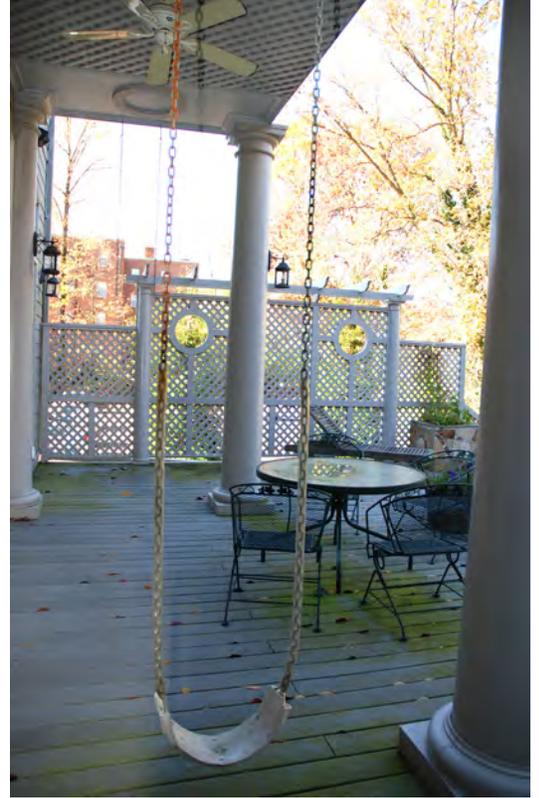
Trained in pediatrics and medical genetics, Guttmacher was acting director of the National Human Genome Research Institute immediately before coming to NICHD. He began his NIH career in 1999, as senior clinical advisor to the NHGRI director. He became that institute's deputy director in 2002, a position he held until he became the acting director in 2008. From his experience at NHGRI, he said, he learned how NIH support can catalyze the research process. But his thinking on the appropriate goal for that research was shaped by his early experiences as a pediatrician.

"My primary objective at NHGRI was to apply the lessons of genomics to improving health and health care," he said. Similarly, Guttmacher intends to apply what he referred to as "the clinical researcher's mindset"—looking out for and improving the health of his patients—to advancing the health of NICHD's constituencies.

Guttmacher stressed, however, that basic research and applied research are both important in the quest to help patients. "While one cannot always predict which basic research will lead to improved health, over and over again basic science advances have made critical contributions to our ability to improve health," he said. "In fact, the basic science tools of today offer an unparalleled opportunity to base more and more applied research on a truly scientific model, rather than relying only on empiricism."

He said one of his immediate priorities would be NICHD's National Children's Study, which seeks to follow children from early life through adulthood, to determine the influence of genetics and the environment on human health. 📍





## INN ANNEX

CONTINUED FROM PAGE 1

### **Above:**

*At left, the Woodmont House interior has more than 7,000 square feet. The grounds, which extend to the NIH fence, include an alleyway behind the house.*

PHOTO COURTESY CHILDREN'S INN

*At right, a view of the house's back porch*

PHOTO: BELLE WARING

the NIH fence, near the intersection of Woodmont Ave. and Battery Ln. Following a renovation phase, thanks in part to a grant from Merck & Co., Inc., the house will feature 7 bedrooms, plus kitchen, dining room, living room, exercise room, library/recreation room and 2 laundry rooms. There's also ground-level garage parking.

As an annex to the Children's Inn, Woodmont House will provide free, safe and convenient lodging for 3 to 5 families, each eligible to stay for 6 to 12 months. And while the same healing spirit will inhabit the place, the level of illness will be less intense.

"We have seen that as care has changed—more outpatient care, and inpatient care more intensive—some families have to stay in the community for extended periods," Russell explains. "They may be seen in clinic once or twice a week. They don't need the acuity of services the inn provides, but they're not well enough to go home either."

Such patients may include children with cancer or those with aplastic anemia, many of whom have received transplants.

"Bethesda housing is expensive," she continues. "Transportation is expensive. Right now, families may end up renting basements in Hagerstown, where it takes 45-60 minutes on a bus, one way, to get to NIH. And these are kids with compromised immune systems." It's much harder for them to fight infection.

For clinicians, "this niche of patients who aren't well enough to go home" is a concern, says Russell. "There's a risk to follow-up if you don't help them, a risk of losing research momentum."

Some 4 years ago, she and her colleagues started brainstorming: "How can we help them transition, these families who are suddenly without resources? Kids need to be in school. Parents need income; they too have educational needs. A lot of these people are multi-cultural. In some cases they have sold everything to get to the NIH for care; they have nothing here."

When the Woodmont property became available, Randy Schools, NIH R&W president and a Children's Inn board member, was approached by the house's owner, a local builder and developer. The Children's Inn, a non-profit corporation, purchased the Woodmont property, which is not on federal land, yet is an inn asset in sole support of the NIH mission.

Both Schools and Dennis Coleman, director of NIH's Office of Public Liaison, are friends and supporters of the project, Russell says.

"The Woodmont property was zoned residential and [Coleman] was able to make introductions with the neighbors," she recalls. "We got zoning approval in record time...The Children's Inn helps put a face on NIH, because [some folks] don't understand labs and test tubes, but they understand sick kids."

To be eligible for Woodmont House, families may have surpassed the maximum stay at the inn, but the same patient age requirements—from newborn to age 26—will apply. NIH shuttle service, tutoring and other support will be available, but since the building is not on NIH property, a private firm will provide security.

"It's not everything to everybody," Russell says. "Woodmont House is empowerment via integration with the Bethesda community... getting you ready to go home, whether it's in

Kenya or in Idaho. But meanwhile we'll work with social services to get kids back in school, help you get a job."

Woodmont House will help kids like Oscar, a 15-year-old Kenyan with aplastic anemia, which is fatal if untreated. Along with his mother and sibling, who is Oscar's bone marrow donor, Oscar had exceeded the maximum stay at the Children's Inn. The Bethesda Community Church offered to shelter them in a house it owns and uses for charitable purposes. Oscar and his sibling are now in local schools, while Mom volunteers, stocking food in the Children's Inn pantry.

"She gets support here for Oscar's health," says Russell, "and she also gives back."

Such volunteer work will be encouraged at Woodmont House. And, as part of the plan, families will have responsibility for cooking their own meals and caring for their home.

"A shared kitchen is good," Russell says. "Common space lets families come together and talk about their concerns."

Woodmont House is the fruit of teamwork by parents' groups, donors, clinicians, legal advisers, administrators and the NCI nurse who served as a catalyst.

"Kelly Richards is a Public Health Service R.N. with a lot of Latin American contacts," Russell says, "and he knew what families were dealing with, in terms of living conditions. He wrote a research project while we wrote our feasibility study, in parallel. We were thinking about the same things, so we joined forces."

Woodmont House will open in the spring, when its trees should be in bud.

"This is one of the best examples of a successful public/private partnership," Russell says. "And it can help people understand what NIH does... We're blessed to be able to address this need. All the stars aligned." 🍀



NIH's newly elected AAAS fellows are (from l) Dr. Michael Lenardo, Dr. Harold Gainer and Dr. Sharon Hrynkow.

### Three NIH'ers Named 2009 AAAS Fellows

The American Association for the Advancement of Science recently awarded the distinction of AAAS fellow to three NIH scientists. Election as a fellow is an honor bestowed on AAAS members by their peers. The NIH honorees are:

From the section on medical sciences, Dr. Michael Lenardo, chief, molecular development section, Laboratory of Immunology, NIAID: "For discovery of important immunoregulatory pathways and human genetic diseases of immunoregulation and for founding several innovative international collaborative programs to advance biomedical research and training."

From the section on neuroscience, Dr. Harold Gainer, chief, Laboratory of Neurochemistry, NINDS: "For distinguished contributions to the field of peptidergic neuron cell biology and neuroendocrinology, particularly for studies on the regulation of oxytocin and vasopressin gene expression."

From the section on societal impacts of science and engineering, Dr. Sharon Hrynkow, special advisor to the deputy director, Office of the Director, NIH: "For distinguished contributions in global health policy, programs and diplomacy and as deputy director and acting director of the Fogarty International Center."

In 2009, 531 members were awarded this honor by AAAS because of their scientifically or socially distinguished efforts to advance science or its applications. New fellows will be presented with an official certificate and a rosette pin on Feb. 20 at the AAAS Fellows Forum during the 2010 AAAS annual meeting in San Diego.

AAAS is the world's largest general scientific society and publisher of the journal *Science* as well as *Science Translational Medicine* and *Science Signaling*. It was founded in 1848, and includes 262 affiliated societies and academies of science, serving 10 million individuals.



**ACD MEETING**  
CONTINUED FROM PAGE 1

**Above:**  
NIH deputy director Dr. Raynard Kington (l) and Collins chat shortly before the ACD meeting gets under way.

**Below:**  
ACD member Dr. Mary-Claire King (c), American Cancer Society professor at the University of Washington, makes a point. Flanking her are Dr. Michael Gottesman (l), NIH deputy director for intramural research, and Dr. Ralph Horwitz of Stanford.

PHOTOS: MICHAEL SPENCER

**Searches Under Way**

In opening remarks, Collins noted that he had recently announced his first IC director appointment: Dr. Eric Green now leads NHGRI, the institute Collins himself vacated in August 2008 after 15 years. He also mentioned that searches were under way for several other top NIH leadership posts: permanent directors for NHLBI and NICHD (two pediatricians, Dr. Susan Shurin and Dr. Alan Guttmacher, respectively, were named temporary directors of those ICs); and the NIH deputy director for extramural research.

The director added a new position to his immediate staff, a chief of staff. Dr. Kathy Hudson, a former associate director at NHGRI under Collins, recently left Johns Hopkins' Genetics and Public Policy Center to take on the new post.

"The issues that surround NIH are sufficiently complex with many issues relating to our outside relationships that we need that kind of senior expertise by someone who knows both science and policy," Collins explained.

Also within the Office of the Director, other senior leadership positions need filling. Directors are needed for the Office of Behavioral and Social

Sciences Research; the Office of Legislative Policy and Analysis; and the Division of Program Coordination, Planning and Strategic Initiatives.

Collins noted roster changes for the ACD as well: The 3-year terms of five members expired at the end of the Dec. 4 meeting: Drs. Catherine DeAngelis, Karen Holbrook, Mary-Claire King, John Nelson and Barbara Wolfe.

At the start of the meeting, Collins also bid a public farewell to a longtime leader in Bldg. 1, Dr. Ruth Kirschstein, "a dear colleague and one of the true giants of NIH," who died Oct. 6 after serving NIH in various capacities for more than 50 years. He led a moment of silence in her honor.

**Director's Vision**

Collins offered an abbreviated slide show version of his vision for NIH, "Exceptional Opportunities for Biomedical Research." Priorities include high-throughput technologies that open unexplored scientific pathways, translation of basic research into new and better treatments, "putting science to work for the benefit of health care reform," emphasizing the nation's "soft power" with a greater focus on global health and reinvigorating the medical research community.

He praised the ACD for its history of providing valuable perspective, advice and feedback to the NIH director. He said he looked forward to continuing the tradition, particularly given the unique challenges and opportunities facing the agency at this time in history.

One big challenge will be finances, Collins acknowledged. He asked NIH Associate Director for Budget John Bartrum, who was serving in his last day in that post before starting a new job with Congress, to give an update on fiscal year 2010 and prospects for 2011.

At the time of the ACD meeting, NIH was operating under a Continuing Resolution due to expire on Dec. 18. In consideration on Capitol



Hill was the 2010 budget request of \$30.9 billion. The House version tacks on an additional \$500,000; the Senate version matches NIH's request exactly. Bartrum estimated that the final version will be some amount between the two figures. The 2011 budget request is due to roll out on the first Monday in February.

### Up for Discussion

Rosalind Gray, acting NIH associate director for legislative policy and analysis, summarized the year's congressional activity involving NIH: There had been 18 hearings, 21 courtesy visits (half of those in the last 5 months of 2009), 27 briefings, 3 member visits (one visit included 16 members of Congress and 19 congressional staffers—the largest contingent in the last 25 years or so) and 154 bills introduced. She also briefly discussed several health care reform provisions related to NIH, including autism, comparative effectiveness research (CER), emergency medicine, health care quality, pain, postpartum depression and prevention and wellness.

Of particular interest is the CER component. Gray said the two versions—one in the House, one in the Senate—under discussion have significant differences that may not be able to be resolved and passed in the current session of Congress. ACD member Wolfe noted CER discussions that ignore cost-effectiveness issues go only halfway toward solving the health care problems the nation faces.

Recalling the first meeting he convened as NIH director, a brainstorming session with more than a dozen health economists, Collins agreed, saying, "I do think there is an opportunity here for NIH to consider funding some interesting research about even such things as how to model incentives for [health care] providers to result in good outcomes, but also cost-effectiveness... We're going to be involved in this in whatever way we think scientifically makes the most sense."

The 99th session of the ACD also covered several other issues: an update on the \$10.4 billion NIH received from the American Recovery and Reinvestment Act stimulus funds; the agency's upcoming role in oversight of extramural financial conflicts of interest and the status of stem cell policy. NIH had announced just days before the ACD meeting release of the first human stem cell lines available to scientists since President Obama issued the Executive Order to remove barriers to such research.

The full day's session is archived under past events at <http://videocast.nih.gov/>. 



### Sieving Receives Special Recognition Award

NEI director Dr. Paul Sieving (c) accepted the American Academy of Ophthalmology (AAO) 2009 Special Recognition Award at the AAO's joint meeting with the Pan-American Association of Ophthalmology in San Francisco recently. The award is in "recognition of the commitment of the National Eye Institute's valuable contributions to medicine and ophthalmology through pioneering research that meets the vision-related health care needs of people of all ages." Flanking Sieving are Dr. David W. Parke II (l), CEO of the American Academy of Ophthalmology, and Dr. Michael Brennan, AAO president.



### R&W Plays Santa at Goodwill Dinner

On Dec. 16, NIH's R&W, in association with Bethesda's Hyatt Regency Hotel, hosted the annual Goodwill Dinner. "We chair the event along with various members of the community who come together," said Randy Schools, R&W president. "We served 409 individuals in need in our community, made sure every homeless person had a backpack filled with longjohns, hats, gloves and hand warmers. Everyone gets gifts, including items from Santa for children in shelters." The 21st annual Goodwill Dinner welcomed families from A Wider Circle, National Center for Families & Children, the Scotland Community and Bethesda Cares, plus adults from Magruder's Discovery, Waverly House, Bethesda Place and Bethesda Cares.



## UNDIAGNOSED DISEASES

CONTINUED FROM PAGE 1

**Above:** ORDR director Dr. Stephen Groft (l) and CC director Dr. John Gallin discuss NIH's Undiagnosed Diseases Program.

PHOTOS: BILL BRANSON

sition of science and sadness in the world," said Dr. William Gahl, head of the intramural program at NIH's Office of Rare Diseases Research, which began the UDP nearly 2 years ago. "It lets us as investigators see the human condition in the person of all the patients who apply."

Gahl, who also serves as NHGRI clinical director, is one third of what could be called NIH's "3G network" for people suffering from unknown ailments. ORDR director Dr. Stephen Groft and CC director Dr. John Gallin form the remaining two-thirds. All three recently presented "Mystery Diagnosis—the Undiagnosed Diseases Program," an hour-long update on the UDP's progress since it began in May 2008 and accepted its first patients in July that year.

### CC Tailor-Made for the UDP

Gallin said two major things are new about the UDP. "First," he noted, "there is a call for all undiagnosed diseases with no phenotype restrictions." Before now, only patients with a definite diagnosis and who met a clear set of study criteria were treated at the CC.

The Clinical Research Center is uniquely equipped to serve the UDP, he said. "Our nurses say, 'There's no other place like it.'" Since opening in 1953, the center has hosted more than 350,000 patients; about half of them have had rare diseases.

"We're inviting anybody with an unexplained problem to make an inquiry," Gallin pointed out. "Second, a multidisciplinary approach is given to every patient."

From its vast cadre of credentialed physicians and highly educated nurses to its unique collection of specialized equipment for imaging and specimen testing and producing candidate drugs—all available free of charge to patients—the CRC offers medical care few hospitals can match.

"Our hope is that the facility will transform from being not only a national hospital for patients but also an institution that serves investigators both here and across the nation," Gallin said.

### 'Developing a Global Approach'

In some ways, NIH is long overdue in setting up the UDP.

According to Groft, when NIH first established the Rare Diseases Clinical Network in 2000, resources were funneled not toward diagnosis, but toward natural history studies of the disorders, training of the next generation of physicians that will treat such diseases and clinical trials.

The strategy now, he said, is to develop better characterization and diagnostic criteria for rare diseases, expand newborn screening programs (currently, states screen for up to 29 disorders), and increase focus on genetic diagnostic testing and counseling.

"We're developing a global approach," he said, "as more and more nations are coming on board with a focus on rare diseases. Most of the patients are being seen by a small number of investigators, but we'd like to see this program extended into more protocols and clinics here at the Clinical Center. At some point—if additional resources become available—we'd like to expand this into NIH's Extramural Research Program, using the Clinical Center as a hub of activities. We have the Clinical Translational Science Awards program, the Rare Diseases Clinical Research Network and other existing research networks that are very fertile ground for introducing a program like this."

### Recreating the 'Fascinoma Clinic'

The UDP is not a totally new concept, Gahl noted. In the 1960s and 1970s, NIH investigators routinely convened what they called a "fascinoma clinic." Interesting, but baffling cases would come up for discussion and dissection by some of the hospital's top physicians-turned-medical detectives.

The power of intellectual stimulation cannot be discounted, he said. "Our goals are, of course, to assist patients and come up with a diagnosis, but also to discover new diseases that will reveal something to us about biochemistry, about pathways, about cell biology."

One common factor that complicates diagnosis (and frustrates patients)—particularly for most of the rare disease cases—is that symptoms show up not all at once, but sporadically over time—often over a number of years, Groft acknowledged. Some people write of having vis-



Groft, Gallin and Gahl form NIH's 3G network for people with unknown ailments.

ited specialist after specialist, to no avail. NIH's UDP often represents their last best chance to discover what's wrong.

### More Than One Year In, Going Strong

To get into the Clinical Center via the UDP, patients' medical records and summary letters from physicians are submitted and triaged to NIH specialists in related medical fields. Those specialists recommend whether to accept the patient.

Since May 2008, the UDP has received more than 2,300 inquiries and 900-plus medical records; 190 patients have been accepted, including 80 children.

Gahl said the top three criteria for inviting the patient to the CC for in-person evaluation are whether the case offers a "good clue to pursue, unique presentation and whether the patient's family is involved.

"The good news is that virtually every patient is pleased with the attention and the hope that we provide for them, and occasionally we solve a case," he concluded, acknowledging that several new disease investigations have been initiated, and that the UDP seems to have brought scientists together in ways that are positive both for individual careers and for research in general.

The bad news includes dealing with the disappointment of the often desperate patients who are turned away. Still a relatively small unit, the UDP has been inundated with applicants as well as attention by the media and even Congress.

### Disease Detective Wannabes, Beware

Finally, Gahl said that as fascinating as the work is (and as full as the work load), he does not recommend that researchers early in their careers concentrate exclusively on UDP cases.

"This is a program that doesn't really fit into the current paradigm of professional advancement, because it's so high-risk," he said. "Someone could pursue a case for a couple of years and not find the cause. But more important, our advancement system values experts in a particular pathway; that takes years. The UDP has many different disorders to pursue and being a jack-of-all-trades does not get tenure." ①

## Symposium Highlights Research in Women's Health

NIH recently hosted the sixth annual Interdisciplinary Women's Health Research Symposium, where junior investigators funded under the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program and senior investigators funded from the Specialized Centers of Research (SCOR) on Sex and Gender Factors Affecting Women's Health presented results of their work.

Dr. Vivian Pinn, director of the Office of Research on Women's Health, kicked off the symposium by explaining the aims of the two programs. "The key concepts of the BIRCWH program, which targets junior faculty, are mentoring, interdisciplinary research and career development" to bridge the transition to research independence. While the SCOR Program involves a collaboration of established investigators, "the requirement that the SCOR necessarily include both basic science and clinical projects should advance scientific discoveries out of the lab and into a clinical environment."

Dr. Duane Alexander of the Fogarty International Center noted how pelvic floor disorders are a major component of women's health. "We have started a program of clinical trials, epidemiology and basic science. And, as a result, changes in practice have occurred," he said.

Keynote speaker Dr. Thomas Insel, director of NIMH, highlighted the sexual dimorphism of brain developmental trajectories during childhood and adolescence and the differential risk for boys versus girls for a variety of mental illnesses. He then gave a talk on the neural basis of attachment. "Social attachment can now be studied at the gene, cell, system, individual and social levels," he said.

Dr. Jeffrey P. Henderson of Washington University School of Medicine spoke on how compounds secreted by bacteria, yersiniabactin in particular, may contribute to reinfection in urinary tract infections.

Dr. Djuana Harvell of the University of Colorado, Denver, shared study findings that showed that women diagnosed with pregnancy-associated breast cancer (PABC) have a lower 10-year survival rate (44 percent) than non-PABC women (69 percent). She concluded that PABC is more aggressive due to elevated hormones during pregnancy.

Dr. Jon Levine of the Northwestern University SCOR said his research team has isolated an estrogen receptor alpha (ER $\alpha$ ) signaling process that could mean that selective ER $\alpha$  agonists might be developed that would "confer reduced risk for development of obesity and type 2 diabetes in menopausal women."

The symposium was sponsored by ORWH and the Office of Dietary Supplements, multiple institutes and centers, the Agency for Healthcare Research and Quality and the Food and Drug Administration.



Dr. Vivian Pinn of ORWH opens the symposium.

### Morales Named Director of NIMH Outreach Partnership Program

Diana Morales recently joined NIMH's Office of Constituency Relations and Public Liaison as the director of the Outreach Partnership Program. A nationwide initiative with support from the National Institute on Drug Abuse and in cooperation with the Substance Abuse and Mental Health Services Administration, OPP enlists national and state organizations in partnerships to help bridge the gap between research and clinical practice by disseminating the latest scientific findings; informing the public about mental disorders, alcoholism and drug addiction; and reducing the stigma and discrimination associated with these illnesses. OPP includes 55 state outreach and 81 national partners.

Prior to coming to NIMH, Morales served as vice president of public education at Mental Health America (formerly the National Mental Health Association), a century-old national advocacy and education organization. In this role, she led the Campaign for America's Mental Health, a 19-year education program carried out by up to 60 MHA affiliates nationwide.

Morales earned her bachelor's degree in journalism from the University of Maryland and a master's in public health from Johns Hopkins Bloomberg School of Public Health. She began her career in social marketing during which she worked on NIMH's award-winning National Panic Disorder Education Program. She also brings extensive experience in health and science communications representing both the public and private sectors.

### Bhattacharyya To Head CSR Branch

The Center for Scientific Review has named Dr. Dipak Bhattacharyya as the new chief of its Information Management Branch.

"We have to be one of the luckiest ICs," said CSR director Dr. Toni Scarpa. "CSR depends heavily on information management, and Bhattacharyya has a rare combination of education, experience and skills to meet challenges in providing IT services in a demanding center."

Over the last 11 years, Bhattacharyya has held senior-level IT positions at CSR and in private industry. Most recently, he served as software

and web development team leader in CSR's Information Management Branch; he also served as an IT specialist and project manager in previous CSR positions. Prior to joining NIH, Bhattacharyya worked as a senior software developer, senior systems architect and senior web developer.



In his earlier career as a scientist, he was a visiting fellow in the department of biochemistry at Michigan State University, a research scientist in the department of biological sciences at Northern Illinois University and an IRTA fellow at an NCI lab.

He earned a master's degree in biochemistry from Calcutta University, a master's of business administration in project management from the University of Northern Virginia and a doctorate in biochemistry from Jadavpur University in India.

### NIEHS Appoints Balbus as Senior Advisor

NIEHS recently announced the appointment of Dr. John Balbus as the institute's senior advisor for public health. Assigned to the NIEHS Bethesda office, he will act as a liaison to those with an interest or



PHOTO: STEVE MCCAWE

involvement in the many aspects of the NIEHS mission—external constituencies, stakeholders and advocacy groups.

"I am pleased to welcome John to our NIEHS team," said NIEHS director Dr. Linda Birnbaum. "His wealth of experience in public health from environmental health research to service on federal advisory boards makes him a great advocate for NIEHS who will understand the concerns of those outside our institute."

Balbus is board-certified in internal medicine and occupational medicine. As an associate professor at George Washington University School of Public Health, he founded the Center for Risk Science and Public Health, practiced clinical occupational and environmental medicine and was involved with public health education.



*Diana Morales recently joined NIMH's Office of Constituency Relations and Public Liaison as the director of the Outreach Partnership Program.*

Balbus became chief health scientist at the Environmental Defense Fund in 2002, maintaining academic appointments at Johns Hopkins Bloomberg School of Public Health and George Washington University.

He has served as a member of several federal advisory committees including EPA's science advisory board and children's health protection advisory committee and the National Academy of Sciences board on environmental studies and toxicology. He continues to serve on the Institute of Medicine Roundtable on Environmental Health Sciences, Research, and Medicine and as chair of the monitoring and surveillance work group for the National Conversation on Public Health and Chemical Exposures.

### Boerboom To Head CSR Review Group

The Center for Scientific Review recently named Dr. Lawrence Boerboom as chief of its cardiovascular and respiratory sciences integrated review group.



"Dr. Boerboom brings extensive experience and leadership skills to this key position," said Dr. Toni Scarpa, CSR director. "He has excelled as a project leader in academia, industry and at CSR."

Since 2004, Boerboom has been the scientific review officer for the CSR study section that reviews cardiac- and vascular-related small business grant applications. In addition, he has served as the center's point person for the review of small business grant applications.

Boerboom came to CSR from LifeCell Corp. in Branchburg, N.J., where he was director of research, leading a team focused on developing tissue-engineered medical devices. Prior to this, he had a 20-year career on the faculty of the Medical College of Wisconsin, holding a primary appointment in cardiothoracic surgery, a secondary appointment in physiology and also serving as director of cardiovascular surgical research. His research focused on factors influencing myocardial blood flow, cardiac function and vascular bypass graft atherosclerosis. He earned his Ph.D. in physiology from the University of North Dakota.



### NCI's Gorelic Retires

Dr. Lester S. Gorelic of NCI's Center for Cancer Training (CCT) retired recently. He spent 20 years at NCI starting as a cancer prevention fellow and finishing his career as a program director and acting deputy chief of the Cancer Training Branch in CCT.

Gorelic received a Ph.D. in chemistry from the University of Chicago and completed postdoctoral training in molecular biology and microbiology at Washington University School of Medicine. He became assistant professor of chemistry/biochemistry at Wayne State University and then associate research scientist at Southwest Foundation for Biomedical Research. He moved to NCI where he spent 3 years in the Cancer Prevention Fellowship program. In 1992, Gorelic became an NCI scientific review administrator, managing grant reviews in cancer prevention and control. Two years later, he joined NCI's Comprehensive Minority Biomedical Program where he managed a portfolio of research training and career development awards focused on underrepresented minorities and other ethnic groups in cancer research. In 1996, he joined the Cancer Training Branch.

Gorelic represented NCI on numerous committees including NIH's training advisory committee. He chaired an advisory group that developed the first NCI flexible workplace policy. At his retirement reception, he was praised for his dedication, enthusiasm and leadership and his commitment to training the cancer research workforce.

In retirement, Gorelic will continue his passion for teaching and educating as a museum docent at the National Archives in Washington, D.C.

### Moen To Direct Extramural NIAMS

Dr. Laura K. Moen has been appointed director of the Division of Extramural Research Activities at the National Institute of Arthritis and Musculoskeletal and Skin Diseases. She will oversee the NIAMS Scientific Review Branch, Grants Management Branch, clinical research coordinators and key scientific management functions.

She comes to NIAMS from the National Center for Complementary and Alternative Medicine, where she served as a program official in the Division of Extramural Research since 2008. Her portfolio at NCCAM included cardiovascular, gastroenterology, urology, renal, diabetes, endocrinology, metabolism and stroke research. Her other positions at NIH included working as a scientific review administrator at the National Institute of General Medical Sciences from 1999 to 2005, and as a program official at the National Institute of Diabetes and Digestive and Kidney Diseases from 2005 to 2008. During her tenure there, Moen oversaw projects in basic, translational and clinical research in urology and nephrology as well as career development and institutional training awards.

Before joining NIH, Moen was a tenured associate professor in the department of chemistry and biochemistry at Old Dominion University. She received her B.S. in biological sciences from the University of Southern California and her Ph.D. in biochemistry from the University of Virginia and held postdoctoral positions at Oregon State University and the University of California Medical School in San Francisco.

Moen has received numerous awards and honors including NIH Director's Awards and the NIDDK Director's Award.





NIAMS's first director Dr. Lawrence E. Shulman

## Shulman, First NIAMS Director, Dies at 90

Dr. Lawrence E. Shulman, the first director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, died Oct. 10, 2009, at age 90 at his home in Washington, D.C.

Shulman, who served as NIAMS director from 1986 to 1994, was a leader in the field of rheumatology research and a mentor and teacher of many of today's leading rheumatology investigators, both in the United States and abroad. Upon his retirement in 1994, then-NIH director Dr. Harold Varmus conferred the title of director emeritus on him in recognition of Shulman's distinguished service to NIH. In addition, Shulman served as an ombudsman for clinical research.

Shulman received his undergraduate degree from Harvard University and was later awarded both a Ph.D. in public health and an M.D. from Yale University. He began his medical career at Johns Hopkins University in the early 1950s. "That was quite a wonderful education," he recalled in the October issue of the American College of Rheumatology publication *The Rheumatologist*, shortly before his death. "It was at that time cortisone and ACTH [adrenocorticotropic hormone] were discovered to have the most remarkable effects on rheumatoid arthritis. At the same time, the NIH, in its wisdom, was developing graduate training programs in various medical specialties."

Shulman served as director of Johns Hopkins' connective tissue division prior to coming to NIH in 1976. One of his early responsibilities at NIH was to develop and implement programs recommended in the Arthritis Plan presented to Congress that year by the National Commission on Arthritis and Related Musculoskeletal Diseases. Ten years later, he became acting director of the newly established NIAMS.

During his tenure as NIAMS director, he successfully guided the development of the institute through its formative years. He played a pivotal role in facilitating the growth of both the intramural and extramural programs, encouraging innovation and pursuit of new scientific opportunities. He was a strong supporter of research on both women's health and minority health issues and made studies of diseases such as osteoporosis, lupus, rheumatoid arthritis and scleroderma a high priority for the institute. He also initiated new studies of rare diseases of the bones, joints, muscles, skin and connective tissues.

Shulman made many contributions to rheumatology research, including the discovery in 1974

of eosinophilic fasciitis, a connective tissue disorder that is known today as Shulman's syndrome. He served as president of the American Rheumatism Association (now the American College of Rheumatology) from 1974-1975, and president of the Pan-American League Against Rheumatism from 1982-1986.

"We at the NIAMS will always be indebted to Dr. Shulman for his tremendous vision and dedication to the institute and its public health mission," said NIAMS director Dr. Stephen Katz. "He will be greatly missed by his many friends and colleagues."

Shulman is survived by two daughters and three grandchildren.

## Cohen, Geriatric Psychiatrist, Dies

By Anne Decker

Dr. Gene D. Cohen, 65, who led the first aging programs at NIMH and served as deputy director and acting director at NIA from 1988 to 1993, died at his home in Kensington on Nov. 7, 2009, after a long battle with cancer.



"We will remember Gene Cohen as a talented and dedicated scientist as well as a kind and compassionate friend and mentor to many at NIH and in the aging community," said Dr. Richard Hodes, NIA director.

Cohen was a pioneer in the field of geriatric psychiatry who in later years turned his focus from the problems of aging to enhancing the creative potential of the elderly. His career in the Public Health Service began as a commissioned officer at NIMH where he was chief of the first Center on Aging and director of the Program on Aging.

"I spent 11 extraordinary years with Gene Cohen at the NIMH Center on Aging," said Dr. Nancy Miller, now senior scientist policy analyst in the NIH Office of the Director. "He was an enormously warm, capable and enthusiastic man with a bounce in his step, an impish sense of humor and a penchant for word games and jokes and a boundless enthusiasm about what could be accomplished. This was a man who was committed to improving the lives of the elderly and who served as an inspiration to many, within NIH, and across the nation and the world."

Over the years, Cohen was involved in many ground-breaking studies on Alzheimer's disease.

These activities included the first task force on Alzheimer's disease under the auspices of the Department of Health and Human Services, resulting in publication of a report from the Secretary's task force in September 1984, which helped increase federal support for research. He became interested in other mental disorders of later life and focused on individuals with early onset diagnosis of schizophrenia who were followed in old age as well as those who received the diagnosis in later life.

Cohen maintained his commitment to biological, psychological and social issues in geriatric medicine when he moved to NIA. "He has been a close friend," said former NIA director Dr. T. Franklin Williams. "I have admired him for his leadership in aging and geriatric understanding and especially for his imaginative emphasis on creativity in later years."

After leaving NIH in 1994, Cohen became the first director of the Center on Aging, Health and Humanities at George Washington University, where he was also professor of health care sciences and professor of psychiatry and behavioral sciences. In recent years, Cohen's interest in the medical and psychosocial aspects of aging focused on creativity in old age and how creativity grows and changes over time. This later work brought a new view to aging, which Cohen interpreted with the development of interactive and intergenerational games. His most recent game—Making Memories Together—helps families and caregivers recognize the untapped imaginative potential of Alzheimer's patients.

Born in Brockton, Mass., Cohen graduated from Harvard College in 1966 with a degree in art history. In 1970, he received a medical degree from Georgetown University's School of Medicine and a doctorate from Union Institute and University in 1981.

A former president of the Gerontological Society of America, he was the founding editor of the *American Journal of Geriatric Psychiatry* and *International Psychogeriatrics*. In addition to the many scientific papers he authored, he wrote two books for the general public, *The Creative Age: Awakening Human Potential in the Second Half of Life*, and more recently, *The Mature Mind: The Positive Power of the Aging Brain*.

"Gene Cohen was a Renaissance man, merging mental health and aging research outcomes with the nourishment of creativity in the aged," said Dr. Marie Bernard, NIA deputy director. "He was a perpetual presence at meetings of the Gerontological Society of America, distinguished by his bow tie, curly hair and welcom-

ing smile. He will be missed in the aging research community."

He is survived by his wife Wendy Miller, daughter Eliana Miller-Cohen, son and daughter-in-law Alex and Kate Cohen, a brother and four grandchildren.



### NIAID Mourns Pediatrician Wedgwood

NIAID pediatrician and immunologist Dr. Josiah F. Wedgwood died Nov. 27 while traveling overseas with his son to meet his wife in Paris. He was 59.

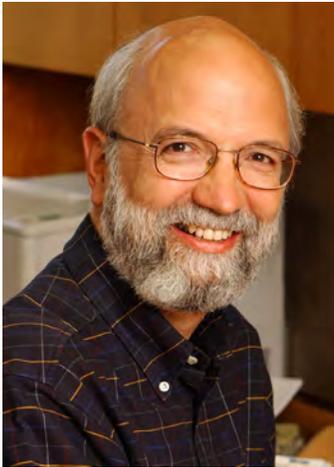
Wedgwood joined NIAID in 2002 as chief of the immunodeficiency and immunopathology section in the Clinical Immunology Branch of the Division of Allergy, Immunology and Transplantation (DAIT). While there, he oversaw research into the mechanisms and treatment of primary immune deficiency diseases. Wedgwood was instrumental in developing research programs in autoimmune diseases to help understand their causes and to develop potential treatments.

"He was not only a highly skilled clinical trials specialist with extensive expertise in pediatric infectious diseases and immunology," notes NIAID DAIT director Dr. Daniel Rotrosen, "but he also was a wonderful colleague and a devoted husband and father. Josiah was unfailingly generous with his time, deeply committed to improving the lives of people living with various diseases of the immune system and a tireless advocate for research into those diseases. His many achievements will be remembered by his colleagues and friends at NIAID and within the scientific and patient communities he served."

Just prior to joining NIAID, he had held concurrent appointments as director of newborn services at the Hospital of Saint Raphael, New Haven, Conn., assistant clinical professor of pediatrics at Yale Medical School and attending neonatologist at Yale/New Haven Hospital.

Wedgwood received his Ph.D. in biochemistry and molecular biology from Harvard University and his M.D. from George Washington University School of Medicine. He received the Basil O'Connor Scholar Award from the March of Dimes to support his research to fight immune diseases affecting children. He also provided medical care to patients with pediatric rheumatologic and orthopedic diseases while at the Hospital for Special Surgery in New York City. During his tenure on the faculty of Mt. Sinai Medical School, his primary clinical duties included service on the neonatal intensive care unit and research in pediatric immunology.

Wedgwood is survived by his wife, Ruth, and his 11-year-old son, Josiah.



*NIEHS's Dr. Allen Wilcox is the recipient of the 2009 Greg Alexander Award for Advancing Knowledge.*

PHOTO: STEVE MCCAWE

### NIEHS's Wilcox Honored with Award

NIEHS senior investigator Dr. Allen Wilcox is the recipient of the 2009 Greg Alexander Award for Advancing Knowledge—one of the highest honors bestowed each year by the Coalition for Excellence in Maternal and Child Health (MCH) Epidemiology. He received the award for his contributions to public health knowledge through epidemiology and applied research at the coalition's 15th annual MCH Epidemiology Conference, held recently in Tampa, Fla.

In choosing recipients for the Alexander award, the selection committee gives preference to those whose focus is applied, recognizing originality of scientific work, contribution to the field and impact on the health of mothers and children. "One of the hallmarks of this coalition," Wilcox said, "is that it draws from a broad spectrum of public health people—from the very applied folks in the county health departments to university researchers."

A reproductive epidemiologist who recently celebrated his 30th year as an investigator at NIEHS, Wilcox is also editor-in-chief of the journal *Epidemiology*. He is a past president of both the American Epidemiologic Society and the Society for Epidemiologic Research.

Wilcox is an adjunct professor of epidemiology at the University of North Carolina, Chapel Hill. He is author of the forthcoming textbook, *Fertility and Pregnancy: An Epidemiologic Perspective*, described by publisher Oxford University Press as "the first truly comprehensive textbook on the topic."



### Vanpool Ponies Up for Inn Gift

NIH Columbia VPSI vanpool #23601, which has been in operation since Mar. 1, 2006, recently made a gift to the Children's Inn at NIH. Using money collected from part-time riders who pay for their lifts, the pool donated \$300 to the inn. Pictured are (from l) OD's Christine McCray, vanpool co-coordinator; Fern Stone, director of development and public relations at the inn; and vanpool co-coordinator Dr. Rosemary Wong of NCI. The money was to be used to purchase holiday gifts for inn residents. "The selection of the Children's Inn to be the recipient was a logical choice since the vanpool riders have benefited tremendously through the past years by participating in the NIH Transhare program and believe in the great work that the NIH does especially in treating and care for children with different diseases," said Wong.



### NIH Toastmasters Club Marks 40 Years

Founding charter member of the NIH Toastmasters Club Dr. Padman Sarma (r) receives a plaque from club president Dr. Jonah Odum, senior scientific and medical officer in NIAID's Transplantation Biology Branch, in appreciation of Padman's 40 years of "outstanding support and mentorship of the club." Club members met at a local restaurant recently to celebrate the group's 40th anniversary. The Toastmasters welcome new members. The club meets on Fridays at noon in Bldg. 38, 2nd fl., Conf. Rm. B. For information, call Odum at (301) 541-3138.

## digest

**Survival of Children with HIV in the U.S. Has Improved Dramatically**

The death rates of children with HIV have decreased ninefold since doctors started prescribing cocktails of antiretroviral drugs in the mid-1990s, concludes a large-scale study of the long-term outcomes of children and adolescents with HIV in the U.S. In spite of this improvement, however, young people with HIV continue to die at 30 times the rate of youth of similar age who do not have HIV, found researchers from NIH and other institutions. Earlier studies have shown that adults with HIV are living longer because of improved multi-drug antiretroviral regimens known as highly active antiretroviral therapy (HAART). However, limited information has existed about the effectiveness of HAART in improving the survival of children with HIV. The current analysis, published online in the *Journal of Acquired Immune Deficiency Syndromes*, delineates the effects of HAART on the rates and causes of death for HIV-infected children and adolescents. The study was cofunded by the National Institute of Child Health and Human Development and the National Institute of Allergy and Infectious Diseases.

**Multiple Myeloma Drug Extends Disease-Free Survival**

Initial results from a large, randomized clinical trial for patients with multiple myeloma, a cancer of the blood and bone marrow, showed that patients who received the oral drug lenalidomide (Revlimid, also known as CC-5013) following a blood stem cell transplant had their cancer kept in check longer than patients who received a placebo. The clinical trial, for patients ages 18 to 70, was sponsored by NCI and conducted by a network of researchers led by the Cancer and Leukemia Group B in collaboration with the Eastern Cooperative Oncology Group and the Blood and Marrow Transplant Clinical Trials Network (BMT CTN). BMT CTN is cosponsored by NCI and the National Heart, Lung, and Blood Institute. The independent data and safety monitoring committee overseeing the trial found that the study demonstrated a longer time before the cancer progressed following autologous blood stem cell transplantation for those patients on the study drug than those on placebo and so the trial was stopped early.

**Gene Linked to Hearing Loss in Males Identified**

A gene associated with a rare form of progressive deafness in males has been identified by an international team of researchers funded by the National Institute on Deafness and Other Communication Disorders. The gene, PRPS1, appears to be crucial in inner ear development and maintenance. The findings were published in the Dec. 17 early online issue of the *American Journal of Human Genetics*. "Not only does [this discovery] give scientists a way to develop a targeted treatment for hearing loss in boys with this disorder,

it may also open doors to the treatment of other types of deafness, including some forms of acquired hearing loss," said NIDCD director Dr. James Battey. The gene is associated with DFN2, a progressive form of deafness that primarily affects males. Boys with DFN2 begin to lose their hearing in both ears roughly between the ages of 5 and 15 and over the course of several decades will experience hearing loss that can range from severe to profound.

**Amyloid Deposits in Cognitively Normal People May Predict Risk for Alzheimer's**

For people free of dementia, abnormal deposits of a protein associated with Alzheimer's disease are linked to increased risk of developing the symptoms of the progressive brain disorder, according to two studies from researchers at Washington University in St. Louis. The studies, primarily funded by the National Institute on Aging, linked higher amounts of the protein deposits in dementia-free people with greater risk for developing the disease and with loss of brain volume and subtle declines in cognitive abilities. The two studies were reported in the Dec. 14 online issue of *Archives of Neurology*. The scientists used brain scans and other tests to explore the relationship between levels of beta-amyloid, a sticky protein that forms the hallmark plaques of Alzheimer's disease, and dementia risk in cognitively normal people.

—compiled by Carla Garnett



*A gene associated with a rare form of progressive deafness in males has been identified by researchers funded by the National Institute on Deafness and Other Communication Disorders.*



Wellness Lecture Series panelists include (from l) Dr. Eric Green, new director of NHGRI; Chris Major, director of the Office of Human Resources; Randy Schools, president and CEO of the R&W; and Maureen Gormley, chief operating officer of the Clinical Center.

PHOTOS: ERNIE BRANSON

## Four Busy NIH'ers Discuss Work-Life Balance

By Valerie Lambros

Being busy doesn't mean having to feel overwhelmed. It's all a matter of balance and keeping things in perspective.

That was the message of the recent Wellness Lecture Series event titled "In Search of Work/Life Balance" held at Lipsett Amphitheater. Four NIH officials—Randy Schools, president and CEO of the R&W; Christine Major, director of the Office of Human Resources; Dr. Eric Green, recently named director of the National Human Genome Research Institute; and Maureen Gormley, chief operating officer of the Clinical Center—shared what balance means in their lives and urged everyone to find what works for them.

"Work-life balance is not a recipe," said Gormley. "What works for me is not necessarily the same thing that's going to work for other people."

Green, who juggles work responsibilities with those of his home life—including being photographer for his daughter's soccer team, coach of his son's baseball team, timer for his children's swim team and primary food shopper for his household—shared a similar sentiment.

"Don't think for a minute that anything I'm going to tell you will apply to you or will apply to your family," he said. "I think these things have to be defined in your own context."

Balance, the panelists said, looks a little different for everyone. Some people need to exercise every day or meditate. Others may need to weigh in the responsibilities of caring for young children or aging parents, while still others must factor in time for academics, as Gormley does. In addition to her work at NIH and her home life as a wife and mother to two

young children, she's also working toward a Ph.D. in human and organizational development and enjoys running.

It would seem more than enough to make anyone's head spin, but Gormley takes it in stride.

"For me, balance is really an active presence, thinking about who and what is most important to me and how can I honor that on a daily basis," she said.

One way Schools and his wife—who also keeps a busy schedule working at Georgetown University Hospital—manage to carve out time for each other is by building it into their schedules.

"Sometimes...we get out our appointment books," he said. "We make time for each other as a couple because we know it's important."

Major, whose three sons are now in their 20s, said she has always made it a point to work in places that support family life.

"While at my job I will always give 100-plus percent, my family's important too," she said. "And if you find yourself not in that kind of environment, maybe that needs to be an internal thought for you."

Major also stressed how important it is to be in a job you enjoy, a sentiment that drew the assent of other panelists.

"We spend a lot of time at work, and if you don't enjoy what you do, that's not good for you," she said.

Green said there are plenty of tools available now, courtesy of technology, to make working smarter and more efficient—even while away from the office. He is a big proponent of teleworking, flexible schedules and using cell phones and laptops to keep tabs on work while on the go.

However, a big part of maintaining balance, said Green, is outlook.

"Having learned only a few days ago about my new position, you are looking at somebody who at this moment in time has the most imbalanced work-life situation, yet I'm smiling and you'll see I'm in a great mood," he said. "But it illustrates what my view is on all of this. You can be in a situation where you're completely off balance, but if your family is supportive and if you have the right attitude about it, you will adjust and it's fine."

The Wellness Lecture Series will hold its next event on Wednesday, Jan. 20. "Be Happier & Healthier in 2010—Throw Away Your New Year's Resolutions: Tips on How to Make Positive Lifelong Changes" will be held at Rockledge II, Conf. Rms. 9100 and 9104. The speaker is Terry Bowers, personal trainer and group exercise instructor at the R&W Fitness Center. 📍