JUNE 13, 2008
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The Second Best Thing About Payday

nih record

ABOVE • *NIAMS cuts ribbon on new home for four laboratories. See story on p. 15.*

features

departments

The NIH Record is recyclable as office white paper.

Era of Personalized Prevention Comes with Challenges

By Rich McManus

Although the era of personalized cancer prevention is already under way, the decisions people will have to make regarding their own risk of disease are likely to get no easier.

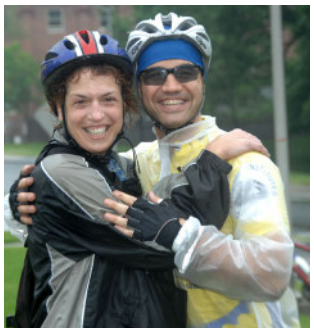
Epidemiologists are getting better at predicting who will come down with which ailment when—which is an undoubted benefit. But their studies, while offering a clearer picture of what is likely to occur, will require patients to exhibit the wisdom of Solomon in making health care choices.

Dr. Alice Whittemore

That was the take-home message of Stanford epidemiologist Dr. Alice Whittemore's recent Wednesday Afternoon Lecture. Her talk, "Personalized Cancer Prevention," was the 14th Robert S. Gordon, Jr. Lecture, held annually to commemorate the late Dr. Gordon, an esteemed NIH scientist.

In a series of vignettes involving three hypothetical patients, Whittemore illustrated just how savvy patients will have to be when confronted with their own matrix of risks.

SEE **PREVENTION**, PAGE 4



Margarita Valencia (NIMH), commuted for the first time from Mt. Pleasant with the help of friend and colleague Jerry Overman (CC).

NIH Bike to Work Day Succeeds, Despite Rain

By Jenny Haliski

The NIH Bicycle Commuter Club drew 465 registered riders—the strongest showing yet—to its pit stop for the Washington Area Bicyclists Association's 2008 Bike to Work Day. NIH had 324 registered participants in the 2007 event and won the Metropolitan Washington Council of Governments award for the area employer with the highest registered BTWD participation in 2006 and 2007. Confirmation of NIH's third win in a row will come in mid-June.

Regionally, 7,000 people registered for the 2008 event, making it one of the largest

SEE **BIKE TO WORK**, PAGE 8

NIH Marks First Annual Yoga Week

Yogiraj Alan Finger, founder of ISHTA Yoga, presents "The Sciences of Hatha Yoga, Tantra and Ayurveda."

In May, NIH celebrated its first annual Yoga Week. Highlighting the science and practice of yoga, the 5-day series of events provided employees and the public with an opportunity to learn about the benefits of yoga and experience them through stretching and practice.

The event was presented in partnership with R&W, the Office of Research Services, the National Heart, Lung, and Blood Institute, the National Cancer Institute and the National Center for Complementary and Alternative Medicine.

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briefs

Imaging of Organ Development Is Topic of Seminar, June 18

Dr. Scott E. Fraser will deliver the third lecture in NIDCR's seminar series on Wednesday, June 18 at 2 p.m. in Lipsett Amphitheater, Bldg. 10. He will speak on "Advances in High-Resolution Imaging of Complex Biological Systems." Fraser will describe his recent work using novel imaging approaches to study mammalian development and organ function in real time. These approaches have allowed him to create high-resolution temporal and spatial images of the embryonic heart and to model and analyze heart function *in vivo*. Such "live imaging" techniques could be used to analyze a broad range of organs and tissues.

Fraser is the Anna L. Rosen professor of biology, professor of bioengineering and director of the Biological Imaging Center at the California Institute of Technology Beckman Institute. He earned his bachelor's degree in physics at Harvey Mudd College and his doctorate in biophysics from Johns Hopkins University.

The lecture is part of the NIDCR Seminar Series "From Basic Research to Therapy—The Latest Frontier," which focuses on research topics of broad interest to the NIH community. If you wish to meet the speaker during his visit, contact Dr. Nadya Lumelsky at (301) 594-7703 or nadyal@nidcr.nih.gov.

The lecture is open to all employees. Sign language interpretation will be provided. Those who need reasonable accommodation to participate in this event should contact Mary Daum, Mary.Daum@nih.gov, (301) 594-7559 and/or the Federal Relay (1-800-877-8339).

Training on New NED Offered in June

NIH has begun offering a series of town-hall style training programs to the NIH Enterprise Directory (NED)-user community in preparation for the switchover to the new NED system this July. ORS and CIT teamed up to develop the training programs and are offering the 3-hour sessions at locations across campus and at off-site facilities. The presentations will familiarize NED users with Homeland Security Presidential Directive (HSPD)-12 and the impact it will have on administrative staff. The sessions will include background information, common misconceptions and an introduction of the changes to NED that will support employee efforts with regard to the new HSPD-12 badging process. The training schedule is posted on the CIT training web site at http://training.cit.nih.gov?702-08G. Those interested in attending one of the 18 classes can sign up online.

Anniversary IntraMall Showcase Set, June 18-19

The 10th anniversary NIH IntraMall Summer Showcase will be held Wednesday and Thursday, June 18-19 from 9:30 a.m. to 3 p.m. in the Clinical Research Center on the 3rd- and 5th-fl. pedestrian bridges. The event will display the award-winning IntraMall electronic purchasing system designed exclusively for NIH to simplify purchasing and now featuring "Smart Match" tools to speed monthly credit card reconciliation in the NIH Business System.

Since opening in June 1998, the IntraMall has become a leading NIH web site for using government purchase cards to locate, buy and track purchases from 240 of its most frequently used vendors, offering more than 10 million laboratory, office and computer items. New online inventory and convenient IntraMalls EXPRESS delivery options will also be demonstrated at the showcase. Learn how purchasing through the IntraMall can save your IC money and ease your workload. Register for the event and the free lunch online at www.intramalls.com/showcase. View a list of IntraMall vendors today at www.intramalls.com/livevendors.html. For reasonable accommodation, call 1-888-644-6255 between 8:30 a.m. and 5 p.m. at least 7 days prior to the event.

NIH Tennis Team Recruits

The NIH/HHS interagency tennis team is looking for advanced (NTRP of 4.0 or higher) players for the 2008 season, which runs through July. The doubles-only matches are played on Har-Tru (green clay) courts. You need not sign up with a partner and do not need a season-long commitment—play only as often as your schedule allows. The cost for each match is about $10/player, which covers court rental and balls. Matches are on Thursdays at the Fitzgerald Tennis Center in Rock Creek Park, Washington, D.C., starting at 6 p.m. For more information, contact Jenny Strasburger, (301) 594-8901, strasbuj@mail.nih.gov or Jerry McLaughlin, (301) 402-6626, gmclaughlin@mail.nih.gov.

China Earthquake Emergency Relief

One of the worst earthquakes in decades struck central China on May 12, killing many thousands of people and causing heavy damage. The Chinese Students and Scholars Association of NIH is calling upon the community for donations for disaster relief. A web page (www.dccssa.org/earthquakerelief.html) has been established so that donations can be accepted from the Greater D.C. Chinese Students and Scholars Associations. All donations and proceeds will be sent directly to the Red Cross Society of China.

Weissman To Give Florence Mahoney Lecture, June 18

What do you get when you combine a renowned medical researcher, an entrepreneur and an avid fisherman? The answer is Dr. Irving Weissman, NIA's 2008 Florence Mahoney Lecturer on Aging. Weissman, director of the Stanford Institute for Stem Cell Biology and Regenerative Medicine, the Stanford Cancer Center and the Stanford Ludwig Center for Stem Cell Research, will present "Normal and Neoplastic Stem Cells" on June 18 at 3 p.m. in Masur Auditorium, Bldg. 10. The lecture is part of the NIH Director's Wednesday Afternoon Lecture Series.

A professor of pathology and developmental biology and, by courtesy, of biological sciences and neurosurgery at Stanford University, Weissman's research encompasses the biology and evolution of stem cells and progenitor cells, mainly blood-forming and brain-forming. He is also engaged in isolating and characterizing the rare cancer and leukemia stem cells as the only dangerous cells in these malignancies, especially with human cancers. And, he has a long-term research interest in the phylogeny and developmental biology of cells that make up the blood-forming and immune systems. Weissman's laboratory was first to identify and isolate the blood-forming stem cell from mice and has purified each progenitor in the stages of development between the stem cells and mature progeny (granulocytes, macrophages, etc.).

As a pioneer in the field of adult stem cell biology, Weissman co-founded three stem cell companies—SyStemix in 1988, StemCells in 1996, and Celtrans (now Cellerant), the successor to SyStemix in 2001. He also served as a member of the founding scientific advisory boards for three other companies: Amgen (1981-89), DNAX (1982-1992) and T-Cell Sciences (1988-1992).

At SyStemix, he co-discovered the human hematopoietic stem cell and at StemCells, he co-discovered a human central nervous system stem cell. In addition, the Weissman laboratory has pioneered the study of the genes and proteins involved in cell adhesion events required for lymphocyte homing to lymphoid organs *in vivo*, either as a normal function or as events involved in malignant leukemic metastases.

As for his love of fishing, Weissman comes by it naturally having been born and raised in Montana. Awarded a B.S. degree in pre-med studies from Montana State College, now Montana State University, in 1960, Weissman received his M.D. from Stanford in 1965.

Weissman is a member of the National Academy of Sciences where he chaired the panel on the scientific and medical aspects of human cloning. He is also a member of the Institute of Medicine, the American Association of Arts and Sciences and the American Academy of Microbiology. He received an Outstanding Investigator Award from NIH in 1986 and was president of the American Association of Immunologists in 1994.

Among his many honors are the California Scientist of the Year Award, the Association of American Cancer Institutes Distinguished Scientist Award and honorary doctorates from Columbia University and Mt. Sinai School of Medicine.

With its 21st annual lecture, NIA honors Florence Stephenson Mahoney (1899-2002), a woman who tirelessly campaigned for increased federal spending for medical research and steadfastly championed the creation of NIA. The lecture series recognizes her contribution to the health of people worldwide. A reception will follow the talk.

Microbiome, Building a Molecular Toolbox Are Topics of June 24 Symposium

On Tuesday, June 24, NIDCR will mark its 60th anniversary with a scientific symposium in Natcher auditorium. At 8:30 a.m., NIDCR director Dr. Lawrence Tabak will introduce the morning session, "Building the Molecular Toolbox: Four Perspectives." The afternoon session, "The Human Microbiome: Biology's Next Revolution," will feature an introduction by NIH deputy director Dr. Raynard Kington at 1:15 p.m.

Morning session speakers include: Dr. David T.W. Wong, University of California at Los Angeles, "Salivary Diagnostics: Scientific and Clinical Features"; Dr. William Maixner, University of North Carolina at Chapel Hill, "Biopsychosocial Risk Factors for TMJD and Related Disorders"; Dr. Paul H. Krebsbach, University of Michigan, "Gene Therapy Strategies for Craniofacial Regeneration"; Dr. Linda Griffith, Massachusetts Institute of Technology, "Design Principles for Tissue Engineering and Regenerative Medicine."

Afternoon session speakers are: Dr. Francis Collins, director, NHGRI, "High Throughput Genomics and the Microbiome"; Dr. David A. Relman, Stanford University, "Open Wide: Microbial Ecology and Metagenomics in the Human Oral Cavity"; Dr. Floyd E. Dewhirst, The Forsyth Institute, Boston, "The Human Oral Microbiome."

The symposium is open to all and no registration is required. Sign language interpretation will be provided. For reasonable accommodation to participate in this event, contact Mary Daum at (301) 594-7559 or Mary.Daum@nih.gov and/or the Federal Relay at 1-800-877-8339.

Whittemore accepts the Gordon Lecture memento from Dr. Barry Kramer, NIH associate director for disease prevention. Behind them is the poster commemorating the event.

PREVENTION

CONTINUED FROM PAGE 1

Consider just one, a 71-year-old political scientist, female, with a risk of stroke, breast cancer and bone fracture who must choose between therapies that will either boost or lower her risk of each of the three ailments. She must decide, along with her physician, whether it's worth it to take a drug that will lower the breast cancer risk a bit, but also raise her risk of stroke. Or she could opt to lower the stroke risk (she had already made it clear that her brain is her source of livelihood) at a cost of up-tweaking her risk of breast cancer.

Ultimately, in Whittemore's story, the professor elects simply to address the risk of fracture with a medication that will have no [known] effect on her risk of cancer or stroke. That seems the safest, most rational course.

But one man gathers what another man spills, acknowledges Whittemore, and what may seem a rational choice to Patient A might be unacceptable to Patient B.

Mammography guidelines offer an example of Whittemore's point: Up until 5 years ago, a "one size fits all" mentality prevailed with respect to the usefulness of the procedure—most medical authorities recommended mammograms at least to age 70, if not for the entire lifecourse.

"Now, the recommendations are based on life expectancy and personal preferences," Whittemore said. "We're not all the same on these."

She cited a paper from 2001 showing the senselessness of state-mandated mammograms in populations that routinely include patients who would never live to see the benefit of mammography, due to other ailments. There is, after all, such a thing as a "clinically unimportant cancer."

Addressing the current popularity of personal genome sequencing, Whittemore noted that the practice "is here and will be increasingly prevalent. But what will happen when everyone gets their genome sequenced for $1,000 and then want their physicians' advice on what to do? This is a huge problem. We don't know what to tell these people and we need more information to guide them."

Whittemore believes that, armed with this information, personalized cancer prevention can be effective. Already there are a number of ways to combat a heightened risk of cancer due to family history or genetic susceptibility, including prophylactic surgery in the case of breast and ovarian cancer, MRI to detect breast cancer early and PSA screening for men at risk of prostate cancer. Patients have to decide "what is the outcome with or without intervention," she said. "Personal preferences are very important...Science needs to provide the data, but it's up to patients to balance choices."

Having one's genome sequenced is not entirely without merit, Whittemore noted. "It can offer more accurate and precise risk estimates, and allows the adoption of prevention strategies, especially in those at highest risk. But," she concludes, "the promise of personalized prevention currently outstrips the data and risk models. Patients must often pit one adverse outcome against another and weigh multiple imprecise probabilities."

She said patients "need decision tools" and conceded that everyone, including epidemiologists "has difficulty balancing probabilities." In calculating benefit vs. harm, there will always be a "moveable fulcrum" owing to varying personal values.

During a brief Q&A following Whittemore's talk, she was able to underscore some important points: there will be a need for quality control ("possibly an NIH imprimatur") as more risk tools are developed; the profit motive will indeed affect the depiction of individual risk; and "patients will have to be much more active in decisions about their own care."

Piatigorsky Receives Helen Keller Award For Vision Research

By Arthur Stone

Dr. Joram Piatigorsky, chief of NEI's Laboratory of Molecular and Developmental Biology (LMDB), received the Helen Keller Award for Vision Research recently. The award, given each year since 1994, is presented by the Helen Keller Foundation for Research and Education for "significant contributions to vision science during the course of a career or for a single contribution of exceptional importance to vision science."

"I am very honored to receive this award," said Piatigorsky. "I am particularly pleased that this award, which is usually given to individuals who have a strong clinical direction to their work, is being given this year to a strictly basic scientist with broad interests who specializes on lens and cornea. I believe it is important to recognize and continue to support basic research, especially today when the focus is increasingly on goal-oriented translational research."

Piatigorsky has been chief of NEI's LMDB since 1981 and has published more than 275 papers in peer-reviewed journals. He has received acclaim and many awards for his scientific achievements. Widely sought after as a speaker, he has delivered many national and international invited lectures.

"I am delighted to see Joram receive this well-deserved award for his years of innovative research," said NEI director Dr. Paul Sieving. "As the first researcher from NEI to receive this prestigious award, Joram admirably exemplifies the creativity and originality that characterize NEI's intramural research program. We are very proud of his achievements."

Dr. Christopher A. Paterson, co-chair of the prize selection committee, said the decision to honor Piatigorsky was based on "his outstanding scientific contributions over the past 40 years," that have "opened the door to a new era of molecular and genetic vision research." Dr. Thom J. Zimmerman, the other selection committee co-chair, added, "Usually, when the committee meets there's lots of discussion about candidates. This time the whole committee recognized immediately that the choice of Dr. Piatigorsky was an excellent one needing no debate or discussion."

In his acceptance speech, Piatigorsky described his research as being "curiosity-driven." He explained how he was led from his early studies using proteins called crystallins as markers for how the cells in the eye's lens become more specialized to comparative studies on the differences between crystallins in vertebrates and invertebrates, and then to the nature of crystallins and the molecular basis for crystallin gene expression. Piatigorsky and his colleagues coined the term "gene sharing" to link multiple functions of a protein to the different expressions of its gene. In further research, he generated the "refraction hypothesis," extending gene sharing to the cornea and conceptually linking lens and cornea by way of the multiple functions of corneal crystallins.

Citing his 2007 book, *Gene Sharing and Evolution*, Piatigorsky proposed that "gene sharing is a general strategy of evolution and a fundamental rule of biology that has numerous implications for medicine."

Piatigorsky received his award at a ceremony held in conjunction with the annual meeting of the Association for Research in Vision and Ophthalmology in Fort Lauderdale, Fla. He received $30,000 as the monetary component of the award.

Association Launches Children's Inn Endowment

The AFCEA, Bethesda Chapter (Armed Forces, Communications and Electronics Association) has announced a gift that will support the inn's mission for decades to come.

On May 19, leaders of the chapter met at the inn to officially dedicate the AFCEA Bethesda Endowment for The Inn, which includes an initial $450,000 contribution.

"AFCEA, Bethesda Chapter is creating a living legacy of giving not only to the inn," said Kathy L. Russell, chief executive officer of the inn, "but to biomedical research and the treatment of pediatric diseases."

In thanking the group, Dr. Lauren Wood, chair of the Children's Inn board of directors, applauded their efforts in caring for the inn's long-term needs. "It takes a level of leadership and courage to commit to the inn's future," she said. "This is an inheritance for our children."

Present at the gift announcement are (seated, from l) Kenneth Touloumes, president of AFCEA, Bethesda Chapter, and Dr. Lauren Wood, chair of the Children's Inn board of directors. At rear are (from l) Robert Guerra, chairman of the Children's Inn gala "A Night for the Children" event hosted by AFCEA, Bethesda Chapter, Madelen Hernandez-Garcia, 4, an inn resident, and Kathy Russell, CEO of the inn.

The endowment was created to honor the 10th anniversary of AFCEA Bethesda Chapter's annual gala that has raised more than $2 million for the inn since 1998. In years to come, proceeds from the annual fundraiser will be directed to the endowment, said Kenneth Touloumes, president of the group.

"We want to make sure that the inn's vital services and programs to seriously ill children and families continue well into the future," said Touloumes, president of the Touloumes Group, based in Potomac.

YOGA WEEK

CONTINUED FROM PAGE 1

***Above**: A free yoga practice on the grass outside Natcher.*

***Below, l**: On stage demonstrating yoga stretches that can be done at a desk are (from l) Jocelyn Gordon, yoga instructor; Dr. Josephine Briggs, NCCAM director; Dr. Jeffrey White, director of NCI's Office of Cancer Complementary and Alternative Medicine; Randy Schools, R&W president; and NHLBI's Dr. Rachel Permuth-Levine.*

***Below, r**: Natcher auditorium became a yoga classroom during the seminar, "Yoga Stretches for the Desk and Office."*

PHOTOS: BILL BRANSON, MICHAEL SPENCER

Participants learned how yoga can be accessible to people at all levels with all body types. NHLBI's Dr. Rachel Permuth-Levine led several yoga sessions during the week and also conducted research on barriers to yoga practice. She said many people mistakenly believe that they're not flexible enough to try yoga, that "just stretching" wouldn't do them any good, or that their body isn't the right type for yoga, especially if they are male or overweight. "We hope to dispel those misperceptions this week," she noted.

Dr. Timothy McCall, medical editor of *Yoga Journal* magazine and author of the book *Yoga as Medicine*, also stressed yoga's inclusiveness, cultivation of awareness and outreach to people in various wellness and disease states. He found in his practice as an internal medicine physician and as a yoga student that reconciliation is possible between Eastern and Western ways of knowing. Yoga and conventional medicine can complement, rather than threaten, each other.

The week also included karma yoga events—participants brought donations of non-perishable foods for Manna Food Center in Rockville and the Safra Family Lodge at NIH. Lectures and practice sessions at Rockledge I and II and 6001 Executive Blvd. allowed off-campus staff to experience yoga.

Instructors encouraged staff to move yoga practice from the mat to daily life by mentally bookmarking parts of the day and dedicating them to remembering to focus on the breath.—**Jenny Haliski**

Former Diplomat Calls for Greater Response to AIDS Crisis

By Ira Allen

Stephen Lewis, a former diplomat and co-founder of AIDS-Free World, delivered a passionate lecture on global efforts to end the pandemic May 6 at Masur Auditorium as part of Fogarty International Center's 40th anniversary celebration. Lewis described the plight of sub-Saharan countries struggling for survival, mired in a cycle of disease and despair both caused by and resulting from the AIDS pandemic.

He cited violence against women, educational discrimination against girls, Western apathy, political barriers to the delivery of existing AIDS services along with limited and in some instances, ideological rather than accurate prevention information as contributing to the death of 2.1 million Africans and the infection of 2.5 million in 2007 alone.

The result is millions of orphans being raised by grandmothers or no one at all. "I don't have the words sufficient to convey the sense of carnage and the toll that has been taken in sub-Saharan Africa," he told the audience of several hundred, including NIH director Dr. Elias Zerhouni, NIH deputy director Dr. Raynard Kington and FIC director Dr. Roger Glass.

"It is beyond the capacity of the mind to absorb...It's a panorama of such heartbreaking and vexing inexplicability that the world stood by and watched the extraordinary deterioration of a continent, with millions of people dying unnecessarily," said Lewis, who has been Canada's ambassador to the United Nations, deputy executive director of UNICEF and the U.N. secretary-general's special envoy for HIV/AIDS in Africa.

Despite the gloom, Lewis said, "The beauty...of speaking here at NIH and under the auspices of Fogarty is that necessarily, it's the research... which underpins the legitimacy of the advocacy." He suggested, for example, that learning how to communicate effectively about sexually transmitted diseases to young Africans is "a subject worthy of exploration."

The U.S. contribution to the AIDS emergency in Africa, through the President's Emergency Plan for AIDS Relief (PEPFAR), which includes the U.S. contribution to the Global Fund Against AIDS, Tuberculosis and Malaria, is expected to increase to $50 billion over 5 years and is the largest amount from any single country. Yet Lewis said that the world's wealthiest country still isn't carrying its fair share and, in a just world, American governmental funding would be even higher.

Stephen Lewis, a former diplomat and co-founder of AIDS-Free World, delivered a passionate lecture on global efforts to end the pandemic May 6 at Masur Auditorium as part of Fogarty International Center's 40th anniversary celebration.

Lewis warned that AIDS, beyond threatening the survival of sub-Saharan countries, could undermine the health and social fabric of other nations as well unless industrialized nations provide more assistance. Uganda, the touchstone of progress when AIDS prevalence fell from 20 percent to 5 percent, is seeing the rate inching up again, he said. He added that 50 percent of African children born with HIV die before age 2 and 80 percent die by age 5. In the U.S. and other rich countries, access to drugs that can be administered during childbirth have all but eliminated transmission of the virus to newborns.

Not one to mince words, Lewis said that preventing mother-to-child transmission, which should in theory be 99 percent effective, is not happening on a large scale, which he says raises the question, "Why is the life of an African child worth so much less than the life of a Western child?

"I am an apologist for the United Nations but I'm also deeply, deeply disappointed in the inability of the international community to come to grips with what has happened," he said.

Lewis concluded on a positive note: "Those of you who care about these issues, particularly in an environment like NIH, with research scientists, with people who understand and bring voices to it...can make a tremendous difference."

Since leaving the world of diplomacy, Lewis helped establish and co-directs AIDS-Free World, a new international AIDS advocacy organization based in the United States. He also is a professor in global health at McMaster University and a senior advisor to the Mailman School of Public Health at Columbia University.

For more information, visit www.aids-free-world.org.

Cyclists (from l) Jean-Charles Grivel (NICHD), Brandy Fureman (NINDS), Al Yergey (NICHD) and Beda Brichacek (NICHD) formed part of the commuter convoy that started in Olney. Fureman's first bike commute was on BTWD.

BIKE TO WORK

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BTWD celebrations in the country, according to WABA. Douglas Franklin, marketing specialist for COG, said overall registration at all pit stops increased only slightly. NIH experienced an increase of about 35 percent.

NIHBCC organizers attribute the high participation levels to higher gas prices, as well as to a seminar in April sponsored by the club and the Division of Amenities and Transportation Services, ORS. ORS staff and NIHBCC members answered questions about how NIH'ers can get started with bike commuting, including packing clothes for the workday, showers and bike parking on campus, mentors who can share routes, bike to Metro rail/bus commuting and safe cycling resources. The event packed a Bldg. 31 conference room with about 100 people.

Nona Colburn (NIAMS) commuted to NIH by bike all but one working day in 2007 and lost 20 pounds in the process.

PHOTOS: BILL BRANSON

NIH had three Bike to Work Day pit stops: Bldg. 1, Rockledge and Executive Blvd. Many employees attended other WABA pit stops and identified NIH as their employer during registration. NIHBCC's awards are on display in the R&W NIH Fitness Center.

Despite drizzle throughout the morning, 246 registered riders showed up on campus with their bikes. Among those were several newcomers who completed their first commute to NIH. The total round-trip miles logged by bike that day to NIH locations was 2,966—an average of 12 miles per rider.

New bike commuter Brandy Fureman of NINDS joined NIHBCC member Al Yergey's (NICHD) commuter convoy, which started in Olney, when they reached Glenmont. Although her office is on Executive Blvd., she happened to have a meeting on campus that coincided with BTWD.

"It made a big difference to meet up with a group of other cyclists," she said. "Bike commuting just made sense to me to cut down on pollution, save gas and get more exercise. I'm going to find my route to Executive next and try to commute two or three times a week from now on."

Tam Sneddon of NLM also joined an NIHBCC convoy. Pamela Shaw of NIAID led a group of four cyclists—including Sneddon and a second newcomer—from Cleveland Park to campus and on to Rockledge. Sneddon, who usually takes Metro to campus, chose BTWD for his first ride to work so he could benefit from the framework of an organized event.

Margarita Valencia of NIMH commuted for the first time from her Mt. Pleasant neighborhood with the help of friend and colleague Jerry Overman of the Clinical Center. Like Fureman and Sneddon, Valencia said she will continue bike commuting and agreed that it helped a great deal to have someone show her how to get started.

For Nona Colburn of NIAMS, attending the 2008 BTWD was the culmination of several goals. Her New Year's resolution for 2007 was to make her 4-mile round-trip commute every day of that year by bike. She missed only one day of bike commuting due to a severe ice storm.

Keith Killian (NCI) and daughter Anais ride to NIH together every day from Bethesda.

She cycled through 14-degree temperatures, snow, rain and sleet to meet her goal and lost 20 pounds in the process. This year, Colburn received a Presidential Active Lifestyle Award from the President's Council on Physical Fitness and Sports for her bike commuting. The award recognizes individuals who record 6 weeks of physical activity on at least 5 days each week.

Colburn's enthusiasm for fitness is infectious: Two of her coworkers have tried bike commuting after hearing her story. "I can't say enough about it to encourage others to try it," she said. "I feel so much better having lost weight. I don't have to spend money on gas and a gym membership. It takes me less time to get to work on a bike than in a car, plus I'm more awake and alert when I arrive."

Nearly tied for the title of longest bike commute were James Nagle of NINDS with 46 miles from Reston, Va., and Steven Rubin of FDA with 45 miles from Buckeystown, Md. The third longest route to campus probably belongs to Phil Snoy of FDA, who biked 22 miles each way from Poolesville. He calculated that with gas approaching $4 per gallon, each day he bikes to work saves him $6.

"It only takes me 30 minutes longer to get to NIH by bike than it would in a car. Plus I'm getting into better shape and saving money," Snoy said.

Perhaps the shortest ride belonged to Mary Gant of NIEHS, who rides from Cedar Lane across from NIH, less than a mile away.

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Moderators Dr. Robert N. Weinreb of the University of California, San Diego (l) and Dr. Paul L. Kaufman of the University of Wisconsin (r) flank NEI director Dr. Paul Sieving at the Glaucoma Clinical Drug Trial Design and Endpoints Symposium; at right, Drs. Malvina B. Eydelman and Wiley Chambers II of the FDA.

NEI, FDA Host Glaucoma Symposium at NIH

Clinical trials of drugs and devices for treating glaucoma, a group of diseases that damage the optic nerve and can lead to blindness, may move forward more quickly as a result of the recent Glaucoma Clinical Drug Trial Design and Endpoints Symposium. Held recently at NIH, the symposium was jointly hosted by the National Eye Institute and the Food and Drug Administration.

The symposium brought together glaucoma investigators, officials from FDA and NEI and representatives from the pharmaceutical industry to discuss ways to improve clinical trial design and to speed up approval of new therapies for glaucoma. NEI director Dr. Paul Sieving welcomed the more than 170 attendees and lauded the increasing collaboration between NIH and FDA. "We at NEI are proud to be part of this wider research community that is making progress in helping move therapeutic compounds toward clinical trials," he said.

A major topic of discussion was how to determine appropriate endpoints and outcome variables for glaucoma clinical trials. An endpoint is a measurable change in the structure or function of ocular tissue as an outcome of the trial. However, structural changes in the optic nerve often do not coincide with changes in vision, making it difficult to predict when or if an observed change will result in a clinically significant loss of vision.

Advances in visual imaging technologies allow researchers to better detect structural changes in the nerve fiber layer of the retina and the optic nerve head, whereas measurements of a patient's functional vision may vary from visit to visit. "Structural measurements are more likely than visual function outcomes to be used in the future as primary endpoints," explained Dr. Wiley Chambers II, acting director of the Division of Anti-Infective and Ophthalmic Products of FDA's Center for Drug Evaluation and Research. "But they must be highly correlated with the ability to predict functional changes in vision to assure the clinical utility of a new therapy."

"The open dialogue between clinical researchers and FDA staff provided a unique opportunity for researchers to get a common understanding of the necessary components of research projects from the FDA's perspective," said Dr. Frederick Ferris III, NEI clinical director. "It also provided a collaborative forum for the development of acceptable new outcome variables, including validated quality of life measures, for use in future glaucoma research protocols."

The symposium, moderated by NEI grantees Dr. Robert N. Weinreb of the University of California, San Diego and Dr. Paul L. Kaufman of the University of Wisconsin, builds on the success of the Ophthalmic Clinical Trial Design and Endpoints Symposium, the first collaborative meeting between NEI and FDA held in November 2006. That symposium focused on therapies for age-related macular degeneration and diabetic retinopathy.

NIBIB staff and POCT Research Network members recently gathered on campus. They include (front row, from l) Dr. Gonzalo Domingo of PATH; Dr. Tala de los Santos of PATH; NIBIB deputy director Dr. Belinda Seto; Dr. Charlotte Gaydos of Johns Hopkins University; NIBIB director Dr. Roderic Pettigrew; Dr. Gerald Kost of University of California, Davis; Dr. Joseph Clark of University of Cincinnati. At rear are (from l) Dr. Bernhard Weigl of PATH; Dr. Ben Hindson of Lawrence Livermore National Laboratory; Dr. Fred Beyette of University of Cincinnati; Dr. Mary Sullivan of Johns Hopkins University; Dr. Joany Jackman of Johns Hopkins University.

NIBIB Network Shares First-Year Progress, Plans

In 2007, the National Institute of Biomedical Imaging and Bioengineering launched a Point-of-Care Technologies Research Network to facilitate the development and application of these technologies to health care. The technologies would be developed through collaborative efforts among clinicians, biomedical researchers and engineers by merging scientific and technological capabilities with clinical needs. NIBIB funded four centers within the network, each with a different POC diagnostic focus. Recently, researchers from the four centers came together in Bethesda to share their early efforts and future plans.

NIBIB director Dr. Roderic Pettigrew noted that POC has the potential to change health care delivery, to expedite diagnosis and clinical testing of disease/conditions and ultimately may reduce health care costs.

"The idea of establishing a POC network," he said, "emerged from a workshop sponsored by NIBIB in April 2006, which focused on improving health care accessibility through POC testing and new technologies."

POC testing refers to the timely provision of clinical diagnostic information in decentralized (i.e., non-hospital) settings such as the primary care physician's office, the patient's home or in low-resource environments including natural disaster sites and economically disadvantaged areas.

"POC testing fits nicely," he said, "into the emerging theme of decentralized health care delivery, with its emphases on a patient-centered approach, decreased dependence on hospitals, increased emphasis on primary care and home health care and cost-reduction."

Dr. Gerald Kost, principal investigator at the University of California, Davis-Lawrence Livermore National Laboratory POC Technologies Center, focuses on rapid multipathogen detection and national disaster readiness. His team's initial work involves the development of POC devices that accelerate diagnosis and treatment of life-threatening bloodstream infections. To illustrate the need for such technologies, Kost pointed to the Hurricane Katrina disaster and the absence of POC diagnostic devices in the field; their availability could have greatly enhanced triage and mobilization efforts.

Dr. Charlotte Gaydos of the Center for POC Technologies for Sexually Transmitted Diseases at Johns Hopkins University emphasized that the new testing must be acceptable to the target population. She and her colleagues are collecting data from patients seen in Johns Hopkins Hospital and Cincinnati Children's Hospital Medical Center emergency rooms pertaining to their willingness to use new POC STD testing. The researchers face a challenge: the development of new technologies that are affordable, sensitive, specific, user-friendly, rapid, robust and transportable, while at the same time deliverable to and maintainable by those who are meant to use them.

Somewhat unique among the four centers is the POC Center for Emerging Neurotechnologies, led by Dr. Fred Beyette of the University of Cincinnati. This group focuses on bringing POC testing to the ER doctor with rapid and reliable information related to a neurologic emergency. Dr. Joseph Clark, co-PI of the center, explained that 1 million brain cells die every minute during a stroke; an initial correct diagnosis results in a 91 percent likelihood of a good outcome, i.e., the ability to carry out all normal duties and activities. Conversely, an incorrect diagnosis results in only a 53 percent likelihood of a good outcome. Thus, correct diagnostic information needs to be made available to ER clinicians quickly. As Clark stated, "Time is brain."

A challenge noted by all centers was lack of a shared language between, for example, clinicians and engineers. This obstacle may be initially difficult, but as the multidisciplinary research teams at each of the centers work to bring prototype technologies into the testing phase, the realization of potential field products supports a common understanding through common goals.

Cherie Nichols will be spending 2 years at Johns Hopkins' Montgomery County campus through the government's IPA program.

NCI's Nichols Assists Hopkins B-School

Science and business may seem worlds apart. But Cherie Nichols, director of science planning for the National Cancer Institute, plans to bring them together through Johns Hopkins University's Carey Business School "Business of Health" programs.

Nichols will be spending 2 years at Hopkins' Montgomery County campus through the government's IPA (interagency personnel agreement) program. Her assignment? To grow the Carey Business School's Business of Health programs, with a particular focus on its joint master of business administration (M.B.A.)/master of science in biotechnology and M.B.A. in the life sciences degree programs and its graduate certificate in leadership and management in the life sciences.

During her assignment, Nichols will develop program curricula, secure projects and market the program within Montgomery County. Her first goal is to attract 25-30 students for the fall 2008 M.B.A. in the life sciences cohort.

Nichols said she took advantage of the opportunity to work with these programs because they are needed, and she speaks from experience.

"I've seen so many Ph.D.s and clinicians put into management positions without training, and these programs can address that issue," she said. "There also are a lot of scientists who won't make a lifelong career out of science. These programs will open other doors."

Rocky Mountain Laboratories Add Facility

NIAID's Rocky Mountain Laboratories in Hamilton, MT, held a recent reception and facility tour for about 150 employees in its new Integrated Research Facility. Employees recently began using offices, conference rooms and biosafety level-2 laboratories in the 105,000-square-foot building. The building's maximum-containment laboratories are undergoing standard extensive reviews.

NIDDK Publishes Resources about Bladder Problems

Millions of women in the United States experience urinary incontinence, or leakage of urine. Yet despite the negative impact the condition can have on quality of life, embarrassment keeps many women from seeking help.

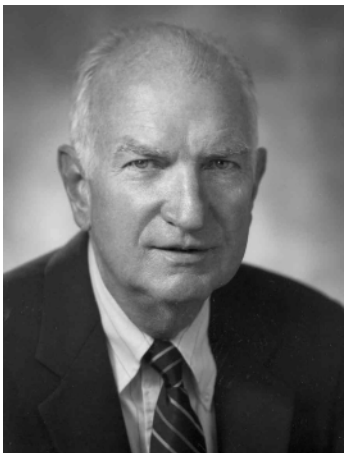
A new, easy-to-read booklet from the National Kidney and Urologic Diseases Information Clearinghouse prepares women to talk about bladder problems with a health care provider. *What I Need To Know about Bladder Control for Women* encourages women to find a doctor who is skilled in treating female urinary problems, such as a urogynecologist or urologist.

Contrary to some beliefs, urinary incontinence is not limited to older women. As many as three quarters of women in the United States report at least some urinary leakage at some point in their lives, and studies consistently find that 20 to 50 percent of women report more frequent leakage, according to the 2007 NIDDK report *Urologic Diseases in America*. The new booklet incorporates useful information and tools from the NIDDK Let's Talk about Bladder Control for Women Series into one comprehensive resource.

The clearinghouse also has a new fact sheet about the opposite problem—urinary retention, the inability to empty the bladder completely. Unlike incontinence, urinary retention is more common in men than women because of prostate enlargement. However, women can experience urinary retention if the bladder or lower part of the colon sags or moves out of its normal position.

Both publications are available at www.urologic.niddk.nih.gov.

milestones



Dr. William Jordan (1983)

Former NIAID Division Director Jordan Mourned

By Veda Charrow

Dr. William S. Jordan, a world-renowned leader in vaccine research and former division director at NIAID, died Mar. 11 in Bethesda at age 90.

As director of the Microbiology and Infectious Diseases program at NIAID from 1976 to 1987, he advanced national and global strategies for disease prevention and promoted new and improved vaccine research. Twenty-seven years ago, Jordan established the Jordan Report, which is considered one of the most complete references on vaccine research and development.

"Bill Jordan was an extraordinary person and a great asset to NIAID," said NIAID director Dr. Anthony Fauci. "From the time he joined the institute as director of the Microbiology and Infectious Diseases program until well past his retirement as he continued to work on a voluntary basis, his leadership and enthusiasm affected all who knew him. He led the effort to make vaccine research and development an important part of the institute's research agenda. Bill had the unique ability to sense what was possible and create opportunities to move the field forward. He will be sorely missed."

In 2004, when Jordan won the Albert B. Sabin Gold Medal, the late John R. LaMontagne, then-NIAID deputy director, praised Jordan as "the creator and chief advocate for a new effort, which he dubbed the Accelerated Development of Vaccines. [Jordan] sensed that scientific progress was accelerating and that the very pace of discovery was going to yield many new ideas for vaccines of all kinds."

Dr. Carole Heilman, who now holds the same position at NIAID that Jordan did, noted that "what Dr. Jordan was most concerned about was that the investment of federal dollars was put to good use. And he saw no better use than vaccine research." Under Jordan's oversight, vaccines were developed or improved for hepatitis B and influenza and the value of antiviral drugs for herpes and flu were confirmed.

According to Heilman, Jordan "was an encyclopedia of knowledge when it came to infectious diseases." He advocated forcefully for neglected diseases such as malaria, schistosomiasis and other parasitic ailments, which led to the creation of the International Collaborations in Infectious Disease Research.

Jordan was born in Fayetteville, N.C., and graduated from the University of North Carolina and, in 1942, from Harvard Medical School.

During World War II, he served with the National Naval Medical Center and was stationed in Reykjavik, Iceland, and then with the Tropical Disease Service, where he treated Marines who came down with filariasis and malaria in the South Pacific. He also served as a medical officer at sea.

Jordan began his career in medical research in 1947 in the preventive medicine department at Western Reserve University in Cleveland. He and his colleagues began a long-term study of illness patterns in middle-class families, a study that is considered an epidemiological classic. His laboratory also contributed findings on pandemic influenza and the transmission of adenovirus.

In 1958, he moved to the University of Virginia's medical school to chair its preventive medicine department. He also was director of the Armed Forces Epidemiological Board's commission on acute respiratory diseases. He later became dean of the University of Kentucky's medical school and spent a year at the London School of Hygiene and Tropical Medicine. From this experience, he wrote *Community Medicine in the United Kingdom* (1978).

Jordan joined NIAID in 1976. At NIAID, he led delegations from the United States to the Soviet Union for joint meetings on interferon and influenza research. After his retirement from NIH, he was an adviser to the National Vaccine Program Office at HHS.

He was past president of the NIH Alumni Association, the American Epidemiology Society and the Society of Medical Consultants to the Armed Forces.

His wife of 51 years, Marion Anderson Jordan, died in 1998.

Survivors include two children, Marion A. Jordan of Potomac and William S. Jordan III of Akron, Ohio; a brother; and three grandchildren.

Davis Retires from Long NCI Career

Norma Davis retired after 44 years of dedicated government service on Apr. 25. Her entire career was in the National Cancer Institute, starting in the Pathological Anatomy Branch, General Laboratories and Clinics. In her final

position she served as program specialist in the Office of Science Planning and Assessment.

Davis attributes her longevity with NCI to knowing she was making a valuable contribution to public health, constantly learning and always keeping in mind the many thousands of individuals who were experiencing medical challenges each day. She often advised that one should not take the gift of life for granted.

In retirement, Davis plans to celebrate "life's every moment" with her family, which recently expanded to include a first grandchild. She also looks forward to having more time to spend on church ministries and her musical talents.

Davis received a Presidential commendation letter for her over 40 years of government service.

NIA Scientific Review Officer Hsu Dies

Dr. Louise Hsu, 68, a scientific review officer in the NIA Office of Extramural Activities, died of a stroke on May 1. "Dr. Hsu was well respected by the neuroscience community for her contributions to science in general and to Alzheimer's research in particular," said Dr. Ramesh Vemuri, chief of NIA's Scientific Review Branch.

A native of Taiwan, Hsu graduated in 1962 from National Taiwan University with a major in chemistry. A Ph.D. from the University of Kansas followed in 1967. She continued her education as a postdoctoral research trainee in bio-organic chemistry at Case Western Reserve University, and, with a growing interest in neurology, she pursued a postdoctoral research fellowship in neuroscience at the University of California, Los Angeles School of Medicine from 1971 to 1972.

In 1990, following a series of university appointments including positions at the University of Texas at Houston and UCLA, Hsu accepted a post at NIA, where she focused on neuroscience and Alzheimer's disease. For more than 10 years, she served as the scientific review officer responsible for managing the NIA neurology committee, which reviews career awards, conference awards and supplements to program projects.

"She was a friend, a guide, a mentor and an inspiration to many in her local community, at NIA, and to the broader neuroscience and aging community," Vemuri said.

Vemuri noted that Hsu enjoyed an active social life. Her hobbies included Chinese and Western literature, opera, classical music, art and painting, world travel and ping pong. She was an enthusiastic participant in church activities and had a gift for cultivating friendships and helping people. Hsu was devoted to her extended family and is survived by her mother, 10 siblings and 22 nephews and nieces.

NHGRI's Myung Receives Young Investigator Award

Dr. Kyungjae Myung, an investigator in the Genetics and Molecular Biology Branch, NHGRI, received the Bea Singer Young Investigator Award recently at the DNA Damage, Mutation and Cancer meeting of the Gordon Research Conference series, held in Ventura, Calif.

The award was established by the late researcher Beatrice A. Singer to encourage young investigators to study DNA repair, mutagenesis and cancer. It is presented every 2 years to a tenure-track investigator in the field.

"It was a total surprise," Myung said. "I am honored that senior investigators in the DNA repair field appreciate our research. I am especially grateful for my mentors and colleagues for their help, laboratory members for performing all the experiments, and my family for their support and trust."

Myung studies genome instability, which is a characteristic of many genetic disorders, including cancer. His conference presentation was titled, "Suppression of DNA-damage-induced Chromosomal Rearrangements by Damage Avoidance and Other Pathways."

digest

Researchers say people in your social network—family, friends and other close associates—can influence whether you quit smoking and other behavior associated with health and disease.

Family, Friends Influence Smokers to Quit

Smokers who kick the habit are probably influenced to quit by family and friends. A new study examined changes in smoking behavior within a large social network over 30 years. Researchers found people stopped smoking in groups, not as individuals. Those who continued to smoke also formed clusters that gradually moved away socially from the larger group. The May 22 *New England Journal of Medicine* report, funded mainly by NIA, could help develop ways to reduce and prevent smoking. The analysis was based on a network of 12,067 people in the Framingham Heart Study, a community-based trial sponsored for 60 years by NHLBI. Framingham collects information on heart health and risk factors among participants who are connected as family, friends and coworkers. Researchers analyzed the network's smoking behaviors between 1971 and 2003. The group ranged in age from 21 to 70. Persons who smoked one or more cigarettes a day were deemed smokers.

New Study Tallies Cost of Mental Disorders

The burden of mental illness is a lot higher when you add up indirect costs. That's according to a new study in the May issue of the *American Journal of Psychiatry*. Major mental disorders cost the nation at least $193 billion annually in lost income alone. "Lost earning potential, costs associated with treating coexisting conditions, Social Security payments, homelessness and incarceration are just some of the indirect costs associated with mental illnesses that have been difficult to quantify," said Dr. Thomas Insel, director of NIMH, which funded the study. Factors such as medication, clinic visits and hospitalization are relatively easy to measure, but reveal only part of the economic impact mental disorders have on society. Indirect costs probably account for huge expenses, but are hard to estimate. In the new study, researchers examined data from a representative study of Americans ages 18 to 64. Data from 4,982 respondents was used to calculate the amount of earnings lost in the year before the survey.

NIAID Advances B-Cell Approach to HIV Vaccines

NIAID recently launched a program to study B cells, immune cells that can produce antibodies with the capacity to neutralize HIV. In order to promote less-traveled approaches to preventive HIV vaccine design, NIAID created a $15.6 million, 5-year program incorporating a network of 10 research teams across the U.S. that will share resources. B cells recognize key parts of microbes, called antigens. Then, in cooperation with T cells—which kill cells infected by pathogens—a reaction is triggered that leads B cells to produce antibodies that can lock onto antigens and sweep them out of the body. But HIV is smart enough to trick B cells, and change itself so antibodies can rarely rid the body of the virus. In recent years, grants funded by NIAID have focused more on T-cell approaches to preventive HIV vaccines than on B-cell avenues. Many experts believe a successful vaccine will need to activate both types.

More Info from WHI on Hormone Therapy

New analysis of data in the Women's Health Initiative hormone therapy clinical trials suggests healthy postmenopausal women whose blood cholesterol levels are normal or lower are not at increased short-term risk for heart attack when taking hormone therapy. In particular, postmenopausal women who had no history of heart disease but whose ratio of low-density lipoprotein (LDL or "bad") cholesterol to high-density lipoprotein (HDL, or "good") cholesterol was less than 2.5 were at no increased risk of heart attack or death due to heart attack from taking estrogen plus progestin or estrogen alone, compared to their peers who did not take hormone therapy, after 4 years of follow up. The study was published in the June 1 issue of the *American Journal of Cardiology*.

Scientists Show Why Some Cocaine Cravings Come Back

Researchers have identified a brain mechanism that helps explain why craving for cocaine—and the risk of relapse—seems to increase in the weeks and months after drug use stops. The NIDA-supported study was published in the May 25 *Nature*. Exposure to environmental cues (e.g., people, places, things) previously associated with drug use can trigger drug craving, often leading to relapse. Previous research in rats showed that sensitivity to these cues follows a defined time course progressively increasing (or incubating) during a 60-day withdrawal period. In the current study, also in rats, researchers demonstrate that after prolonged withdrawal from cocaine use, there is an increase in the number of proteins called AMPA glutamate receptors in a brain region known as the nucleus accumbens (an area involved in motivation and reward). These new AMPA receptors are atypical and appear to be responsible for the "incubation" of cocaine craving. The finding suggests new avenues for development of medications to decrease risk of relapse in abstinent cocaine abusers.—**compiled by Carla Garnett**

Dr. Vivian W. Pinn (front, third from right), director, Office of Research on Women's Health, joins members of the NIH advisory committee on research on women's health at a recent meeting. The group includes (front, from l) Dr. Ronald Gibbs, Dr. Bobbie Yee, Dr. PonJola Coney, executive secretary Joyce Rudick, Dr. Eugene Orringer, Dr. Luther Clark; (back row, from l) Dr. Debra Toney, Dr. Andrea Dunaif, Dr. Linda Giudice, Nancy Norton, Dr. Sally Rosen, Dr. Mary Beth O'Connell, Connie Howes, Dr. Linda Kaste and Dr. Scott Hultgren.

ORWH Advisory Committee Gains Three New Members

The NIH advisory committee on research on women's health recently welcomed three new members: Dr. Linda C. Giudice, Dr. Nancy H. Nielsen and Dr. Debra Toney.

Giudice, the Robert B. Jaffe, M.D., endowed professor and chair of the department of obstetrics, gynecology and reproductive sciences at the University of California, San Francisco, is a biochemist, gynecologist and reproductive endocrinologist whose research focuses on endometrial biology and placental-uterine interactions, as well as environmental impacts on reproductive health.

Nielsen is senior associate dean, State University of New York at Buffalo School of Medicine and Biomedical Sciences, and also president-elect of the American Medical Association. The second woman to hold AMA's highest elected office, she helped formulate policy positions for the AMA house of delegates on such issues as depression, alcoholism among women and Alzheimer's disease.

Toney, 10th president of the National Black Nurses Association, serves as administrator for Rainbow Medical Centers in Las Vegas. Currently responsible for oversight of six primary/urgent care centers and an outpatient diagnostic center, she is president/owner of TLC Healthcare Services, a licensed home health care agency specializing in private duty nursing and supportive care services.

Present at the ribbon-cutting ceremony were (from l) Gilbane senior project engineer Earl Gilliam; NIAMS scientific director Dr. John O'Shea; ORF research space coordinator Cyrena Simons; and NIAMS director Dr. Stephen Katz.

NIAMS Labs Open with Ribbon-Cutting Ceremony

The NIAMS Intramural Research Program recently held a ribbon-cutting ceremony and open house to introduce the new home of four laboratories within the Molecular Immunology and Inflammation Branch and Autoimmunity Branch. The new state-of-the-art facilities, located on the 13th floor of Bldg. 10, will allow researchers within the groups of Dr. John O'Shea, Dr. Juan Rivera, Dr. Richard Siegel and Dr. Raphael Casellas to conduct cutting-edge research in an environment that promotes interaction and collaboration.

Katz (l) and NIAMS acting deputy director Dr. Paul Plotz tour the new laboratories. The open format lab design is conducive to collaboration and allows easy access to shared resources and instrumentation.

Undiagnosed Diseases Program Offers Patients Hope

Patients with symptoms that the medical profession has been unable to understand and treat have a new place at NIH where they can turn for help and hope in finding a diagnosis.

That's because on May 19, the NIH Office of the Director, Office of Rare Diseases, the Clinical Center and the National Human Genome Research Institute launched the Undiagnosed Diseases Program. A trans-NIH initiative, it will focus on the most puzzling medical cases referred to the CC by physicians across the nation.

According to the Genetic and Rare Diseases Information Center, which is funded by NHGRI and ORD, 6.6 percent of inquiries during the past 3 years were related to undiagnosed diseases. A 1989 report of the National Commission on Orphan Diseases found that that although about 50 percent of patients in the U.S. received a diagnosis in less than a year, 31 percent waited between 1 and 5 years to obtain a diagnosis and about 15 percent waited more than 5 years for a diagnosis.

"A small number of patients suffer from symptoms that do not correspond to known conditions, making their care and treatment extraordinarily difficult," said NIH director Dr. Elias Zerhouni. "However, the history of biomedical research has taught us that careful study of baffling cases can provide new insights into the mechanisms of disease—both rare and common. The goal of NIH's Undiagnosed Diseases Program is two-pronged: to improve disease management for individual patients and to advance medical knowledge in general."

The new program is the culmination of efforts by Dr. William Gahl, clinical director at NHGRI; CC director Dr. John Gallin; and Dr. Stephen Groft, director of ORD. It is ready to accept patients in July.

To kick off the program, NIH held telebriefings with representatives of almost 100 patient advocacy groups, which often serve as a source of information and support for people struggling with mysterious ailments, and more than 25 reporters. They were joined by a speaker from the patient community, Amanda Young, a patient of Gallin's. "This is the most exciting news that anyone with an undiagnosed disease could hear: Someone is going to try to help you," Young said.

Young, 26, of Conyers, Ga., lived her early life as a mystery. Seeking an explanation for having contracted spinal meningitis, gas gangrene, salmonella poisoning of the sinuses, an abdominal abscess and more, she finally found an answer at the Clinical Center.

On hand at the program's announcement were (from l) Dr. William Gahl, clinical director at NHGRI; CC director Dr. John Gallin; Amanda Young, a patient seen at the CC for 13 years before her disease was diagnosed; and Dr. Stephen Groft, director of ORD.

PHOTO: MAGGIE BARTLETT

Years of intensive testing led to a diagnosis of an IRAK-4 deficiency. An extremely rare genetic mutation affects her body's ability to create a protein needed to fight bacteria, leaving her vulnerable to life-threatening infections. The oldest of only about 20 patients known to have the deficiency, Young seems to have put the worst behind her.

"The Clinical Center exists for people like Young and her parents," said Gallin. "Our patients are partners in medical discovery. They call this the House of Hope. Our commitment to them is to marshal medical and scientific expertise, resources and care in the search for answers. In a research setting, one patient's answers often generate new avenues for medical advancements that ultimately help others."

"We hope to build upon our strong working relationships with many patient advocacy groups," added Groft. "These organizations provide a crucial link in our nation's efforts to improve human health through biomedical research. We hope that this new partnership of NIH researchers, advocacy groups and patients will give hope for many Americans who now face troubling medical symptoms with no clear diagnosis."

To evaluate each patient enrolled in the new program, more than 25 NIH senior attending physicians will dedicate their expertise, which includes specialties such as rheumatology, immunology, oncology, mental health, nephrology, hematology, ophthalmology, neurology, laboratory medicine, pain and palliative care, bone disorders, endocrinology, dermatology, primary immunodeficiency, dentistry, genetics, pathology, pulmonology, cardiology, internal medicine, pediatrics and hepatology.

Gahl, an expert on rare genetic diseases, will direct the new program. "We have developed a stringent referral process to ensure this program deals with those cases that have truly confounded medical experts," he said. "We will be very selective when it comes to patient eligibility. Our focus is strictly on conditions that have not been diagnosed."

To be considered, a patient must be referred by a physician and provide all medical records and diagnostic test results requested by NIH. Patients who meet the program's criteria—as many as 100 each year—will then be asked to undergo additional evaluation during a visit to the CC that may take up to a week.

Two nurse practitioners will manage patient recruitment and logistics for the new program, which will leverage existing intramural facilities and staff already at the CC, NHGRI and ORD. Funding for the program includes $280,000 per year from ORD.

For more information about the Undiagnosed Diseases Program, visit http://rarediseases.info.nih.gov/Undiagnosed. Physicians and patients with specific inquiries may call the CC's Patient Recruitment Call Center at 1-866-444-8806. Staff there received nearly 300 calls from potential participants and referring physicians during the program's first 2 weeks.—**Jenny Haliski**