



ABOVE • An iPad display attracts a youngster at USASEF 2014. See story below.

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nih record

Disparity Definition Needs Tightening, Braveman Says

By Rich McManus

If the rich people in city A have higher rates of an illness than the rich people in city B, this qualifies, under current NIH criteria, as a health disparity.

Similarly, skiers have higher rates of bone breaks and fractures than non-skiers.



Dr. Paula Braveman gives lecture for National Minority Health Month.

“Does that fill you with moral outrage?” asked Dr. Paula Braveman, professor of family and community medicine and director of the Center on Social Disparities in Health at the University of California, San Francisco.

At her recent keynote talk marking National Minority Health Month, Braveman discussed the range of values informing the field of health disparities, a term coined in the 1990s. A student for more than 25 years of the social determinants of health, she called for a fresh consideration of what constitutes a health disparity, based on international human rights principles that have been endorsed (but not necessarily fulfilled) by nearly all nations.

Disparities, she argued, are health differences that are unfair in a particular way. As the ski example

SEE **BRAVEMAN**, PAGE 8

NIH Pavilion Draws Crowd at Science & Engineering Festival

NIH recently participated in the 3rd USA Science & Engineering Festival (USASEF) in Washington, D.C., the nation’s largest biennial celebration of science, technology, engineering and math. As a testament to President Obama’s initiative to graduate 1 million



A father shares a polyoma-virus model with his son at NIH’s 3-D Print Exchange booth during USASEF.

STEM students over the next decade, the U.S. Senate passed a resolution this year supporting the festival and designated the last week of April as National Science Week.

“A nation gets what it celebrates! As a culture, we celebrate movie stars, rock stars and athletes and we generate a lot of them...but we

SEE **FESTIVAL**, PAGE 6

Link Between Genomics, Theater Shown

By Raymond MacDougall

A group of theater professionals, including a number of award-winning playwrights, met recently with scientists and staff from the National Human Genome Research Institute to explore the intersection of genomics and theater.



Karen Rothenberg introduces plays with a science theme at the Smithsonian Institution in Washington, D.C.

“The Drama of DNA: Theater and Genomics Workshop” was part of an initiative led by Karen Rothenberg to explore theater as a way to examine the ethical, legal and social implications of genomics.

Participants heard about real-life case studies involving ethical dilemmas and family drama. Dr. Sara Hull, director of the

SEE **THEATER**, PAGE 4



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NIH...Turning Discovery Into Health

briefs

Common Fund Hosts Anniversary Symposium, June 19 in Masur Auditorium

On Thursday, June 19, the NIH Office of the Director will host a symposium to commemorate a combined 10 years of achievement by the NIH Roadmap/NIH Common Fund. Join us as we look back over a decade of discovery and showcase the extraordinary achievements of this unique set of programs. NIH leadership, both past and present, will discuss the history of the Common Fund and share a glimpse of what the future may hold. Grantees from several Common Fund programs will present scientific findings and share how Common Fund support played a critical role in these discoveries. The symposium will also feature winning videos from a competition that was open to all Roadmap/Common Fund grantees, as well as a special song performance by NIH director Dr. Francis Collins.

The symposium will be held from 8:30 a.m. to 5 p.m. in Masur Auditorium, Bldg. 10. The event will be videocast at <https://videocast.nih.gov>. For more information, visit <http://commonfund.nih.gov/commemoration> or contact Rachel Britt, rachel.britt@nih.gov.

IntraMall Holds Summer Showcase, June 11-12

The 16th annual NIH IntraMall Summer Showcase will be held in the South Lobby of Bldg. 10 on Wednesday, June 11 and Thursday, June 12 from 9:30 a.m. to 2 p.m. The event is hosted by the IntraMalls electronic purchasing site designed exclusively for NIH to simplify purchasing.

Since opening in June 1998, the IntraMall has become a leading NIH web site for government purchase cardholders to locate, buy and track purchases from hundreds of the most frequently used suppliers, offering more than 14 million laboratory, office and computer items.

Those with a valid fda.gov or nih.gov email address may register for a free lunch at www.intramalls.com/showcase. A daily list of vendors will be displayed to assist you in visiting more than 60 suppliers to learn about new product and service offerings.

If you require reasonable accommodation to participate, call 1-888-644-6255 during business hours.



NCI Shady Grove Trains for Emergency Response

About 2,000 National Cancer Institute employees and contractors recently participated in a tornado response drill at the NCI Shady Grove facility. It was part of the Federal Emergency Management Agency's PrepareAthon! Campaign, which conducts bi-annual National Days of Action. NCI Emergency Preparedness Program volunteers helped carry out the exercise. The drill allowed NCI staff to practice escape to nearby safe areas and ensured that occupancy levels in each shelter area did not exceed capacity. Prior to the drill, 19 members of the NCI emergency response team received FEMA certificates for completing the national Community Emergency Response Team curriculum.

Sieving Elected to German Academy of Sciences

Dr. Paul Sieving, director of the National Eye Institute, has been elected to the German Academy of Sciences. Known as *Deutsche Akademie der Wissenschaften*, or simply the *Leopoldina*, it is the German counterpart of the U.S. National Academy of Sciences and the British Royal Society. *Leopoldina* is the oldest learned society in the world and provides analysis on issues that affect the world from a scientific and medical perspective. About three-quarters of its 1,500 members are from Germany, Austria or Switzerland. The remaining membership represents 30 other nations. Notable members include Charles Darwin, Albert Einstein, Johann Wolfgang von Goethe and Max Planck, as well as 57 Nobel laureates.



nih record

Clinical Trials Participant Helps in Search for Parkinson's Cure

By Shannon E. Garnett

Twelve years ago, Jean Burns' life was quite full. A military wife, she had lived in Germany and the U.S. and was working as a software trainer, web developer and ESL (English as a second language) instructor. But in 2003, her life changed: She was diagnosed with Parkinson's disease, which led her to shift gears and make room for yet another role—clinical trials participant.

"I found my first trial on the web," Burns said. "I signed up 6 months after my diagnosis because I wanted the chance to have a promising treatment as early as possible."



Jean Burns offers a comment at the Parkinson's Disease 2014 conference held earlier this year at NIH.

Using her web skills, she searched the Internet for information about PD and taught herself about clinical trials. She quickly understood their importance and the vital role of participation. "Before me there were hundreds and thousands of other people with PD who participated in clinical trials. Their participation gave me the

ability to have the medications I take today," she said. "If no one participates, there will be no new treatments and no cure." So, Burns not only participates, she advocates and promotes clinical research as well.

Clinical trials are research studies that involve people. Some test new therapies, new ways of using known treatments or methods of disease detection or prevention. Others help researchers learn important fundamental information about disorders. Most treatments used today are the results of past clinical trials.

Burns' first trial—called PRECEPT or Parkinson Research Examination of CEP-1347 Trial—tested a potential neuroprotective drug called CEP-1347 that researchers thought would slow or even stop the progression of PD. Although the drug did not perform as hoped and the trial was later stopped, Burns kept the faith. Her first trial led to a second, long-term follow-up trial called PostCEP.

Since then she has participated in many stud-

ies. In fact, she is currently involved in an NINDS trial at the Clinical Center.

"I'm especially proud of being in PRECEPT and PostCEP because they have given researchers a lot of data about PD," she said. "We were the first large group to be considered a control group for PD."

Of course, participation is one of the key requirements for a clinical trial. However, it is also one of the most difficult elements for most trials to fulfill.

People take part in trials for many reasons. Healthy volunteers may participate to help others or to help advance science. Participants with an illness may participate to receive access to what might become the newest treatment or to gain access to additional care and attention from clinical staff.

The flip side is that there also are many reasons that keep people from participating. Reasons vary and range from potential health risks that may be associated with a study medication to scheduling conflicts and travel costs. For research conducted at the Clinical Center, participants typically incur little cost, but that is not the case for all trials.

According to Burns, there are also disease-related issues that hamper participation. "Another barrier that is little understood by 'healthy' people is the fatigue we have with PD," she explained. "Traveling by plane is a form of torture. On paper, asking me to travel on Tuesday for an appointment on Wednesday morning and then return travel on Wednesday afternoon seems reasonable. But it is totally exhausting for a person with PD who lives in a western state like Arizona with a 5-hour plane ride each way. I have done it but it takes me several days to recover once I get home."

To overcome these barriers as well as others, Burns suggests that researchers include patients in the planning stages of trials. "Have more patients as members of institutional review boards to ensure that patient volunteers are treated respectfully and with care. And, include patients when you have conferences or meetings or need input before making decisions that affect our lives," she said.

Burns also suggests that people considering trial participation do their homework. "Take your time," she said. "Research. Learn everything you can about the trial. Don't join a clinical trial unless you feel very sure. Call the study nurse and ask questions. List the pros and cons."

Her trial experiences are well documented in her private blog—Pdblogger.com—and web site she co-founded—PDPlan4life.com. Through these sites, she and her fellow advocate, Sheryl Jedlinski, share personal experiences about living well with PD. NIH also provides a web page, Clinical Trials and You at www.nih.gov/health/clinicaltrials as well as Clinicaltrials.gov (www.clinicaltrials.gov), a searchable database of federally and privately supported clinical studies conducted in the U.S. and around the world. The Michael J. Fox Foundation offers a trial finder web site for PD trials, <https://foxtrialfinder.michaeljfox.org/>.

"You don't have to sit back and take the disease as it comes—you can fight back," said Burns. "Participating in clinical trials is my way of fighting back." 🍌



Burns said the difficulty of patient travel should be a consideration in clinical trial planning.



THEATER

CONTINUED FROM PAGE 1

Above:

The Drama of DNA workshop featured a panel of nationally acclaimed playwrights: (from l) Dorothy Fortenberry, Lisa Loomer, Cassandra Medley and Anna Ziegler.

PHOTOS: JOHN DANIELS, MAGGIE BARTLETT

NHGRI Bioethics Core, described a research project in which a father, who carried the gene mutation associated with a high risk for breast and ovarian cancer, chose not to tell his daughters of their potential risk for the disease. NIH researchers requested an ethics consult because they felt torn between a parent's rights and those of his children and wondered whether they were morally obligated to persuade him to share the information.

"Families are full of drama," Hull said. "At their best, they're nurturing and caring—great places to grow up and come home to. But it's not all good. They lie to each other and keep secrets from each other. They pass along their bad habits and their bad genes to their children—and they blame each other for that."

"Families are full of drama. At their best, they're nurturing and caring—great places to grow up and come home to. But it's not all good. They lie to each other and keep secrets from each other. They pass along their bad habits and their bad genes to their children—and they blame each other for that."

Among the 15 playwrights were local theater professionals associated with Arena Stage and Theater J in Washington, D.C.; and the theater department at Montgomery College in Rockville. One attendee was Joshua Ford, a playwright affiliated with Theater J's Locally Grown Initiative.

"I tend to write about history and am always interested in science as a theme," said Ford. He is currently exploring the dramatic possibilities associated with the life of Fritz Haber, recipient of the 1918 Nobel Prize in chemistry. A controversial figure, Haber was credited with a process for synthesizing ammonia from its elements used both for fertilizer (food production) and explosives.

"I love contradictions in people," Ford said. "Those are stories that I'm interested in telling, the stuff that grabs me. I'm really interested in hearing the case studies and narratives because

you never really know what you might hear that you can use."

Dr. William Gahl, director of the NIH Undiagnosed Diseases Program, told about a patient whose complex and undiagnosed disorder had been studied at NIH. She developed an unrelated condition, which became serious after local doctors didn't treat it quickly enough. The story illustrated how undiagnosed patients face prejudice—even from their doctors—because of their undiagnosed conditions. "They lose some credibility because they can't put a name on their disease," he said.

Dr. James Evans, Bryson distinguished professor of genetics and medicine at the University of North Carolina School of Medicine at Chapel Hill, described a genetic counseling session with a patient whose family members carried a gene mutation that meant they had a high risk for early onset Alzheimer's disease.

"She was really grappling with this," Evans said, describing her dilemma to seek genetic testing herself. "The pros and the cons for her were much different than they would be for someone else."

"Common to all the narratives is the fact that genetics and genomics are all about family and relationships," Rothenberg observed. "There's so much richness. If there were more plays that explored these dilemmas, it might encourage these conversations in families. With the increase in genetic testing and genomic sequencing, wouldn't it be great for theater to help audiences explore whether they would want to know a genetic test result—and share it with their family?"

"Theater has a long history of addressing social, political and cultural issues," said Jacqueline Lawton, a D.C.-based playwright. "The sciences—especially the intricate, rich, deeply personal and ethical complexities of genomics and genetics—have an enormous impact on our daily lives. When theater artists and scientists work together, we can help break down the barriers that exist between scientists and the public. We can encourage learning and curiosity."

After the workshop, many participants went to the Smithsonian's S. Dillon Ripley Center in Washington, D.C., to take in scenes from four plays and to discuss the illustrated ethical and societal implications. The evening performance was organized in conjunction with the Smithsonian Institution's National Museum of Natural History-NHGRI exhibition, *Genome: Unlocking Life's Code*. ●

Deisseroth To Give Nirenberg Lecture, June 11 in Masur Auditorium

Dr. Karl Deisseroth of Stanford University will deliver the fourth annual Marshall Nirenberg Lecture as part of the 2013-2014 Wednesday Afternoon Lecture Series. Deisseroth's talk, "Optical Deconstruction of Fully Assembled Biological Systems," will be held on Wednesday, June 11 at 3 p.m. in Masur Auditorium, Bldg. 10.

Deisseroth is a Howard Hughes Medical Institute investigator and D.H. Chen professor of bioengineering and of psychiatry and behavior-



al sciences at Stanford. He received his undergraduate biochemical sciences degree from Harvard University. He obtained both his Ph.D. and his M.D. (neuroscience) from Stanford. His current research develops optical methods for high-resolution investigation of intact biological

systems. His group has pioneered optogenetics, a technology that uses light to control millisecond-precision activity patterns in defined cell types in the brains of freely moving mammals, and CLARITY, a chemical engineering technology that enables high-resolution structural and molecular access to intact brains. A practicing psychiatrist, Deisseroth has also applied his technologies to study anxiety, depression and social dysfunction.

The lecture, established in 2011, recognizes Nirenberg for his work to decipher the genetic code, which resulted in his receiving the 1968 Nobel Prize in physiology or medicine. Nirenberg's research career at NIH spanned more than 50 years; his work also focused on neuroscience, neural development and the homeobox genes. The Nirenberg lecture recognizes outstanding contributions to genetics and molecular biology.

For lecture information and reasonable accommodation, contact Jacqueline Roberts, (301) 594-6747.

August To Give WALs Lecture, June 10

Dr. Avery August will discuss "Nature vs. Nurture: Tuning CD8+ T cell Responses" on Tuesday, June 10 at 3 p.m. in Masur Auditorium, Bldg. 10. His presentation is a special Tuesday version of the NIH Director's Wednesday Afternoon Lecture Series (WALS).

August has made critical discoveries in the area of T cell signaling. His work has focused on the Tec family of non-receptor tyrosine kinases in T cell function in the development of allergies and asthma and in the development of specific T cell populations. He has also made important discoveries on the function of eosinophils in regulating the development of allergic asthma.

For the WALs lecture, he poses the question: Are T cell immune responses more dependent on the properties of the antigen-specific receptors generated in the thymus during their development or the amount of signal that the T cell receives when the T cell receptor interacts with MHC complexes?

Since 2010, August has held the position of professor of immunology and chair of the department of microbiology & immunology at Cornell University College of Veterinary Medicine. Prior to Cornell, he was a distinguished professor of immunology in the department of veterinary & biomedical sciences and director of the Center for Molecular Immunology & Infectious Disease at Pennsylvania State University, where he started as an assistant professor in 1999.

There will be a reception and an opportunity to talk with the speaker in the NIH Library following the lecture.



20th Police Awareness Day Draws Crowd

The NIH Police hosted NIH's 20th annual Police Awareness Day on May 13 on the lawn in front of Bldg. 1. As grill smoke filled the air and popular music played, attendees enjoyed lunch (r), a pretty day and a variety of exhibits put on by local law enforcement agencies. Among the attractions

were horses used by U.S. Park Police. Children from the NIH preschool program found them irresistible. There was a serious side to the BBQ as well; the names of 105 officers who were killed in the line of duty in 2013 were listed on a plaque and solemnly recalled. Below, Chief Alvin Hinton (l) and Lt. Udon Cheek remember fallen officers.

PHOTOS: CHRIS JONES





FESTIVAL

CONTINUED FROM PAGE 1

Above, from l:

At the NIH Pavilion at the USA Science and Engineering Festival, NIDDK's Diane Tuncer (l), deputy director of the National Diabetes Education Program, helps children "Be a Sugar Detective."

The 3-D Print Exchange team included (from l) Meghan Coakley, Katie Rush, Damien Terry, Sybil Philip, Jeremy Swan and Meredith Daly. The team showed visitors 3-D printers at work and hosted interactive activities for kids, showing them how to build scientific models from objects made with the printers.

PHOTOS: JEREMY SWAN, JESSICA MEADE

don't celebrate science and engineering," said Larry Bock, co-founder of USASEF. He added, "Strengthening the STEM educational foundation of our nation is vital to our future economy and the health, safety and well-being of America's families."

Since USASEF's inception, NIH, a 2014 sponsor, has had widespread involvement. Last February, NIDDK director Dr. Griffin Rodgers spoke at Buck Lodge Middle School in Adelphi, Md., as part of the Nifty Fifty Speaker program. Nifty Fifty is one of the national STEM initiatives organized before the festival for 180,000 students and teachers. NIH's involvement continued at the Walter E. Washington Convention Center on Apr. 24-27 for the X-STEM Extreme STEM Symposium, Sneak Peek Friday, Meet the Scientists and the Grand Finale Expo.

Attracting more than 325,000 people, the Convention Center was filled every day during the festival with enthusiasts—young and old—learning, creating and exploring the wonders of STEM. On Apr. 24, more than 5,000 students participated in the Extreme STEM Symposium, which offered presentations from a group of visionaries who aimed to empower and inspire youth about careers in STEM. NIH director Dr.

Francis Collins was one of the speakers who addressed a standing-room only crowd.

NIH hosted a 5,600-square-foot anchor exhibit in the Health and Medicine Pavilion where children and families journeyed through an interactive obstacle course of 25 hands-on activities led by 20 institutes and centers. In the NIH Pavilion, participants were able to find out how researchers are advancing science with new 3-D printers that transform digital files into physical objects; explore DNA and the human brain; and measure lung capacity. Also, attendees studied how the body works by learning about eyes, ears, joints and skin; found out how much sugar is really in foods and drinks; and tested their knowledge of regenerative medicine and biomedical imaging.

At the USASEF Career Pavilion on Apr. 26, attendees were able to "Meet the Scientists," during a 1-hour networking extravaganza where students met NIH staff representing many different career fields.

The NIH Office of Administrative Management and Communications thanks the hundreds of NIH staff who worked, volunteered and otherwise supported efforts to make the NIH footprint at USASEF a success.



At left, children and parents played an iPad game "Who Wants to be a Bioengineer?" and racked up points while learning about bioimaging, robotics and bioengineering. At right, visitors are fascinated by a 3-D printer as it turns a digital file into a physical object right before their eyes.



Maddox Takes Helm at NIMHD

Dr. Yvonne Maddox has been named acting director of the National Institute on Minority Health and Health Disparities. NIH director Dr. Francis Collins announced her selection recently, following NIMHD director Dr. John Ruffin's retirement in March.

"I commend Dr. Ruffin for his years of service to the NIH and the community that is so in need of the research supported by NIMHD," Maddox said. "I am looking forward to working with NIMHD staff and my other colleagues at the National Institutes of Health and Department of Health and Human Services to continue to advance the programs of the institute. In addition, I look forward to listening and working with the many stakeholders to assess and identify the needs of the various populations that we serve."

Prior to joining NIMHD, Maddox served as deputy director of NICHD. She has also served as acting deputy director of NIH from January 2000-June 2002 and co-chaired the first NIH Strategic Plan to Reduce and Ultimately Eliminate Health Disparities.

Maddox has also served as executive director of the HHS cancer health disparities progress review group and co-chaired the HHS Initiative to Reduce Infant Mortality in Minority Communities. She has also served on many public service and academic boards.

Maddox first came to NIH in 1985 as a health scientist administrator at the National Institute of General Medical Sciences. Before that, she was a research assistant professor in the department of physiology and biophysics at Georgetown University Medical Center. As a cardiovascular physiologist, Maddox has served in several scientific roles at NIH and has authored numerous scientific papers and review articles and delivered keynote scientific lectures domestically and internationally. She has received many honors and awards.

Maddox received her B.S. in biology from Virginia Union University and her Ph.D. in physiology from Georgetown University.

As acting director, Maddox will oversee the NIMHD budget of approximately \$268 million. Additionally, she will assist in providing leadership for the minority health and health disparities research activities of NIH, which constitute an annual budget of about \$2.8 billion.—**Cherie Duvall Jones and Gerda Gallop-Goodman**



Seto Named NEI Deputy Director

By Daniel Stimson

Dr. Belinda Seto joined NEI as its deputy director on Apr. 7. She comes from NIBIB, where she served as deputy director for 11 years, starting just 3 years after the institute was established.

Her professional career—and lifelong passion—in biomedical research actually started at NIH. After earning her Ph.D. in biochemistry from Purdue University, she came here in 1974 as a postdoctoral fellow working with Drs. Earl and Thressa Stadt-

man at NHLBI. The Stadtmans—who are the namesake of the Stadtman Tenure-Track Investigators Program—led a world-class biochemistry lab. Their research helped establish some of the basic principles found in today's biochemistry textbooks, including enzyme function and regulation.

The pair was also famous for a mentoring style that became known as the Stadtman Way. Seto said the Stadtmans treated their lab like a family, but that they were also tough and could deliver rapid-fire critiques to their students and postdocs. "They fostered rigorous scientific debates. I learned that criticism should not only be accepted but appreciated," Seto said. "They also taught me to take risks and not be afraid of failed experiments and that negative experiments are often as informative as those that worked as predicted."

After completing her postdoc, she took those critical thinking skills to the FDA to conduct research on hepatitis B and vaccine development. About 10 years later, she returned to NIH and soon took a position at the Office of Extramural Research, where she oversaw analysis and reporting of NIH grants data. She ultimately became deputy director and then acting director of OER before moving to NIBIB.

The skills she applied in her research have served her well in analyzing trends, needs and opportunities in the extramural research world, Seto said. "Whether you're doing research or in a position to guide research policies, you always need to think about what's going to yield the most productivity," she noted.

While at NIBIB, she began helping steer the institute's management of "big data," which refers to the ballooning volumes of data produced in research, especially through medical imaging. She continues to serve on the executive committee of the NIH Big Data to Knowledge (BD2K) initiative and its oversight body, the NIH scientific data council, which are providing researchers with better tools and training to deal with big data.

Seto is also continuing the tradition of mentorship she learned in the Stadtman lab. She has chaired the NIH working group on women in bioengineering, which aims to recruit and advance women in the bioengineering field, and she is a recipient of the Ruth Kirschstein mentoring award.

She was attracted to NEI, she said, because the vision research community has been at the forefront of pioneering areas such as stem cell therapy and gene therapy. This was a fortuitous time to join the institute, she said; the NEI Audacious Goals Initiative recently launched and will seek ways to regenerate damaged nerve cells within the visual system. "My biggest challenge is to help NEI reach that goal," she said.

BRAVEMAN

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Right:

The obligation of a just society is to focus on those with the greatest social and economic obstacles to fulfilling their rights, Braveman said.

PHOTOS: BILL BRANSON

shows, not all health differences are unfair. Braveman favors a definition of disparity enunciated by British social scientist Dr. Margaret Whitehead, who says we ought to focus not just on any differences in health status among any groups, but on those that are “unfair, avoidable and unjust.”

Braveman acknowledged that the National Institute on Minority Health and Health Disparities is faced with a dizzying array of needs, difficult to balance. Should NIMHD focus on autism? People with catastrophic genetic diseases? Veterans? Men, who have a shorter life expectancy than women?

Human rights principles provide guidance, Braveman said. She argues that people have the right to attain the highest possible standard of health, the right to education, the right to a decent standard of living (needed for health), to the benefits of progress, to non-discrimination and to equality of rights.

Proceeding from these rights, which are globally accepted even if not always achieved, are economic, social and cultural rights that cannot be separated from the civil and political rights with which most of us are more familiar, e.g., freedom of speech.

“A group’s history of exclusion and marginalization,” from such rights should be an important factor in defining a disparity, she said.

Braveman proposes a human rights-based definition of health disparities, which are closely linked to social and economic disparities. We need to focus on those disparities that adversely affect groups who have experienced greater obstacles to health, she said.

“Not all health differences are health disparities,” she said. “The key is ‘What adversely affects socially disadvantaged groups?’ When you put already socially disadvantaged groups at further disadvantage with respect to health, that’s a double-whammy.”

Braveman’s talk, “Health Disparities: The Issue Is Justice,” made the case that equity is justice. “Disparities or inequalities are the metric we use to assess progress toward equity.”

The obligation of a just society is to focus on those with the greatest social and economic obstacles to fulfilling their rights, she said.

Braveman acknowledged that the causes of



many health disparities are unknown, “including many important ones.” She also noted that if you count up all the vulnerable groups within the United States, it turns out to include “most of the population,” which is clearly untenable as a focus for NIMHD.

She called for a focus on groups that have historically experienced discrimination or marginalization. We should consider the depth and duration of the disadvantage, including which groups have experienced atrocities, slavery, Jim Crow and intergenerational poverty.

“There are measurement challenges, too,” she said. What is the reference group for comparison? She set a high bar—the health of the most socially privileged group, i.e., those with the greatest wealth, power and prestige, arguing that that indicates what should be biologically possible for everyone.

Braveman’s espousal of human rights values and concepts springs from both the accumulated gravity of ideas accepted around the world and from a sense that such principles conceive of health equity as an entitlement, not as a charity.

Only a values framework that sets its benchmark at the highest attainable standard of health can hope to interrupt a vicious cycle of harmful exposures, vulnerability and unequal consequences, she maintains.

“Pursuing equity requires swimming against prevailing tides,” she concluded. “We will encounter resistance. We therefore need to be very clear about where we are headed and why.”

NIEHS Reflects: Four Years After Deepwater Horizon

Apr. 20 marked 4 years since the Deepwater Horizon oil spill in the Gulf of Mexico. The

NIH response included worker training and research into potential health effects of that work. NIEHS took the lead in that effort, training more than 100,000 clean-up workers and initiating the GuLF Study, the largest study ever conducted on the potential health effects of an oil spill.

At a recent media teleconference, NIEHS presented preliminary observations from the ongoing GuLF Study and urged participants to stay involved.

The study enrolled more than 33,000 people, each of whom completed a telephone interview. A subset of 11,000 completed home exams. Dr. Dale Sandler explained that researchers are now contacting all participants to interview them regarding current health status. Participants living within 60 miles of New Orleans or Mobile, Ala., are invited to take part in more detailed clinical exams.

Sandler, lead researcher for the GuLF Study and head of the NIEHS Epidemiology Branch, reported that preliminary observations indicate clean-up workers were about 30 percent more likely to have moderate to severe depression than residents who did no clean-up work. Results were similar for anxiety.

"It's important that the 33,000 people enrolled in this study stay involved, because these early findings need to be followed up over time," said Sandler. "At this point, it is hard to know if the increased frequency of depression and anxiety in workers is because of exposure to oil and dispersants or something else about the oil spill experience and its aftermath," she said.

"If participants haven't already done so, we encourage them to call 1-855-NIH-GULF (1-855-644-4853) to participate in the health exam and other study activities," Sandler said.—Robin Mackar



Participating in the roundtable were (from l) Dr. Laurel Northouse of the University of Michigan; Dr. Laura Gitlin of Johns Hopkins University; NINR director Dr. Patricia Grady; ONS president Dr. Mary Gullatte; Dr. Michael Irwin of UCLA; and Dr. Kathleen Knafl of UNC-Chapel Hill.

NINR, ONS Co-Host Roundtable on Science of Caregiving

NINR and the Oncology Nursing Society (ONS) recently co-hosted the 2014 National Nursing Research Roundtable. Since 1987, the annual event has brought together an interdisciplinary group of clinicians, scientists, educators, scholars and policy leaders from across the country to discuss priorities in science, practice and policy. The focus of this year's roundtable was "The Science of Caregiving," an increasingly important subject given the increase in the incidence of chronic illness and aging of the population.

"Managing chronic illness is increasingly shifting from health care providers to individuals, their families and the communities where they live and there is increasing awareness that the responsibilities of caring for family members or friends can have a significant impact on the health of lay caregivers," said NINR director Dr. Patricia Grady during opening remarks. "This is an area where the nursing community is ideally positioned to design and test caregiver health interventions and translate research findings into clinical and community health practices."

The keynote address was delivered by Dr. Michael Irwin, a professor and researcher at the University of California, Los Angeles, who discussed health issues faced by caregivers of persons with dementia. Because many older adult caregivers report sleep disturbances, Irwin also discussed sleep as a modifiable risk factor for fatigue, depression and other health issues. He concluded by recommending future research directions, such as further studies that address the association between sleep disturbance and inflammation that may contribute to cardiovascular disease and increased mortality.

ONS president Dr. Mary Gullatte described current activities at ONS and Grady provided an NINR update, in which she summarized studies focused on caregiving. The scientific presentations also targeted caregiver health.

"Nursing is interlinked with caregiving," Grady said, noting that caregiving is encompassed by self-management, which is one of NINR's four scientific areas of emphasis for implementing the institute's strategic plan. "It is through these research efforts that we may advance caregiver health and thus promote its critical role in supporting the management of chronic conditions."—Natalie Zeigler

Researchers Discover Key Factor in Early Auditory System Development

Researchers at NIH have uncovered a molecule in an animal model that acts as a key player in establishing the organization of the auditory system. The molecule, a protein known

as Bmp7, is produced during embryonic development and acts to help sensory cells find their ultimate position on the tonotopic map, which is the fundamental principle of organization in the auditory system. The tonotopic map groups sensory cells by the sound frequencies that stimulate them. The study is the first to identify one of the molecular mechanisms that determines position.

Findings from the study, led by Drs. Zoe F. Mann and Matthew W. Kelley of the Laboratory of Cochlear Development at NIDCD, were published in the May 20 issue of *Nature Communications*. The research was performed in collaboration with scientists from the University of Virginia School of Medicine and Imperial College in London. The American Hearing Research Foundation also provided support.

An additional study, appearing in the same edition, is led by NIDCD-supported researchers Dr. Benjamin R. Thiede and Dr. Jeffrey T. Corwin of UVa. Working in collaboration with Mann and Kelley, the researchers reveal that another signaling molecule, retinoic acid, acts in concert with Bmp7 to position cells.

“The findings could open doors to therapies that take advantage of Bmp7’s navigational talents to direct the formation of regenerated sensory cells that are tuned to respond to a specific frequency,” says NIDCD director Dr. James F. Battey Jr. “Since many forms of hearing loss are limited to specific frequencies, this approach could lead to replacement sensory cells that are tailored to individual needs.”



Researchers at NIH have uncovered a molecule in an animal model that acts as a key player in establishing the organization of the auditory system.

Study Links High Cholesterol Levels to Lower Fertility

High cholesterol levels may impair fertility in couples trying to achieve a pregnancy, according to a study by researchers at NIH, the University at Buffalo and Emory University.

Couples in which each partner had a high cholesterol level took the longest time to reach pregnancy. Moreover, couples in which the woman had a high cholesterol level and the man did not also took longer to achieve pregnancy when compared to couples in which both partners had cholesterol levels in the acceptable range.

“We’ve long known that high cholesterol levels increase the risk for heart disease,” said the study’s first author, Dr. Enrique Schisterman of NICHD, which led the study. “In addition to safeguarding their health, our results suggest that couples wishing to achieve pregnancy would improve their chances by first ensuring that their cholesterol levels are in an acceptable range.”

The study findings were published online in the *Journal of Endocrinology and Metabolism*.

Single Episode of Binge Drinking Linked to Gut Leakage, Immune System Effects

A single alcohol binge can cause bacteria to leak from the gut and increase levels of bacterial toxins in the blood, according to an NIH-funded study led by Dr. Gyongyi Szabo of the University of Massachusetts Medical School. Increased levels of these bacterial toxins, called endotoxins, were shown to affect the immune system, with the body producing more immune cells involved in fever, inflammation and tissue destruction. The article appears online in *PLOS ONE*.

Binge drinking is defined by NIAAA as a pattern of drinking alcohol that brings blood alcohol concentration to 0.08 g/dL or above. For a typical adult, this pattern corresponds to consuming 5 or more drinks for men, or 4 or more drinks for women, in about 2 hours.

“While the negative health effects of chronic drinking are well-documented, this is a key study to show that a single alcohol binge can cause damaging effects such as bacterial leakage from the gut into the bloodstream,” said NIAAA director Dr. George Koob.—**compiled by Carla Garnett**

feedback

Have a question about some aspect of working at NIH? You can post anonymous queries at www.nih.gov/nihrecord/index.htm (click on the Feedback icon) and we'll try to provide answers.

Feedback: So where exactly does the money for the lunch that accompanied the tent show go? We used to be able to attend for free and now it costs \$7/10. I decided this year that my money was better spent elsewhere. The last time I went (and paid), there were way fewer people than when it was free. This means those food vendors who do this get less exposure which means less people will know about them and frequent their businesses.

Response from Christopher Wanjek, Office of Intramural Research: I agree that, this year, the Taste of Bethesda lunch was not the deal it used to be. The event certainly no longer can be free; that's a violation of government rules. The money from customers now goes directly to the vendors and to the cost of the tent. The Technical Sales Association (TSA) and the NIH R&W help support the event. The TSA helped us keep the ticket prices lower in recent years, but the organization suffered from the government shutdown last year. Many customers this year paid in advance; so for \$7 they received two entrees, a dessert and a drink, which was indeed less money than a comparable meal on the NIH campus.

Feedback: Are there enough handicapped parking spaces for NIH employees? Answer: No! I broke my leg and am temporarily restricted in my mobility. My husband accompanied me to work on my first day back. Although we arrived at 8 a.m., there was no available employee handicapped parking in the Bldg. 10 parking garage or in MLP-9 just behind Bldg. 10. We had to do stacked parking in MLP-9 and then have my husband push me in a wheelchair through the garage to the elevator, which did not have a curb cut so I had to hop up a high curb just to use the elevator. This is totally unacceptable and I am sure that it is in violation of the ADA, which NIH is supposed to abide by. I'm sure I'm not the only NIH employee with mobility issues (permanent or temporary) who has had a similar issue with parking. While parking is always tight at NIH, those who need handicapped parking should not be required to improvise just to fulfill the NIH mission.

Response from ORS: Currently, the NIH main campus has a total of 9,889 parking spaces available for employee use. Based on current ADA regulations, NIH must provide a minimum of 109 accessible parking spaces solely for handicap parking. As of this response, there are 371 designated handicap parking spaces on campus, which is more than three times greater than required by minimum ADA standards.

In addition, Manual Chapter 1410—Parking Policy also allows for disabled persons with a valid handicap parking permit or a state-issued handicap placard to park in the long-term visitor lots or metered spaces without paying. By adding these 855 visitor spaces that are on the main campus to our 371 designated handicap spaces, NIH has a total of 1,226 parking spaces available to disabled persons with properly issued handicap permits. Thus, the available number of accessible spaces is more than 10 times required by the latest ADA requirements set forth in 2010.

Concerning your issue about the curb cut, a work order has been entered requesting an assessment of MLP-9's elevator access to ensure ADA compliance. 📧

Executive Leadership Program Alumni Visit 'Robot Lab'

Graduates of the NIH Executive Leadership Program recently had an opportunity to tour a lab featuring NCATS' ultra-high-throughput screening robotic system. ExLP alumni spent a morning learning about cutting-edge research at NCATS and exploring some of the promising translational drug discovery and development taking place at NIH.



Ceremony Launches Child Care Bldg. Construction

Ground was broken for the new Northwest Child Care Center on Apr. 29. The facility is scheduled to open in 2015 with room for 170 children ages 6 weeks to 5 years. On hand at the ceremony were (from l) Brian Rabin and Dr. Sheri Schully of the NIH child care board; Dr. Alfred Johnson, director of the Office of Research Services; Colleen Barros, NIH deputy director for management; and Tony Clifford, chief engineer for the Office of Research Facilities. The project officer for the new building, also known as Bldg. 23, is Thor Sigfusson.

PHOTO: ERNIE BRANSON



Heavy rain limited attendance at 2014 Bike to Work Day, but the NIH Bicycle Commuter Club and its volunteers nonetheless welcomed the hearty on May 16 in front of Bldg. 1. Registrants (above, l) received event T-shirts. NIAID's Dr. Bernard Moss (c) was among the undeterred riders. At right, ORS's Joe Cox (l) receives the Carl Henn Award from R&W President Randy Schools for efforts on behalf of NIH cyclists.

PHOTOS: BILL BRANSON

Bike to Work Day Gets Drenched

Just a week before NIH observed Bike to Work Day on May 16, the U.S. Census Bureau reported that the number of people who traveled to work by bike increased roughly 60 percent over the last decade.

But those statistics were of no avail on BTWD, when torrential early morning rains dampened attendance at what is usually a robustly supported event. Ironically, skies cleared around 9:30 a.m., precisely the time when the three NIH pit stops closed up shop for the day.

The Census Bureau says that bicycle commuting increased from about 488,000 in 2000 to about 786,000 during 2008-2012. "This is the largest percentage increase of all commuting modes tracked by the 2000 Census and the 2008-2012 American Community Survey," the bureau said.

But rain is no respecter of statistical trend. According to Michelle Mejia, transportation quality assurance specialist with the Division of Amenities and Transportation Services, "We had 531 people register for [BTWD] and 155 passionate cyclists showed up in the rain to obtain their BTWD T-shirts."

That means that only around 30 percent of the NIH'ers who expected to ride that morning actually did so. The rest, according to Mejia, need not despair of receiving their 2014 BTWD commemorative shirts. Those who registered for the event can obtain their shirts on Sept. 22 at NIH's observance of Car Free Day.

According to the Census Bureau, while bicyclists still account for just 0.6 percent of all commuters, some of the nation's largest cities have more than doubled their rates since 2000. Portland, Ore., had the highest bicycle-commuting rate at 6.1 percent, up from 1.8 percent in 2000. The rate in Washington, D.C., is 3.1 percent.



NIMH's Jules Asher (l), decked out in rain gear, prepares to videotape BTWD proceedings.



The rain did not dampen riders' moods, as this participant proves.

Below, a representative of Proteus Bicycles prepares fruit smoothies by using pedal power to run a blender.

Bicycle Commuting Data from the Census Bureau

- The West had the highest rate of biking to work at 1.1 percent and the South had the lowest rate at 0.3 percent.
- The median commute time for those who bike to work was about 19.3 minutes.
- Men were more likely to bike to work than women were. The rate of bicycle commuting for men was more than double that of women, 0.8 percent compared with 0.3 percent.
- Those with a graduate or professional degree or higher and those with less than a high school degree had the highest rates of biking to work, at 0.9 and 0.7 percent, respectively.

