PUSHING AT THE EDGES
‘Digital Summit’ Explores New Ways to Communicate Health, Science
BY CARLA GARNETT

Here’s looking at you, alpha geeks. We’re counting on you to help us tell the stories of science and medicine in the years ahead. That’s what one keynote speaker, HHS Chief Technology Officer Susannah Fox, told attendees at the first NIH Digital Summit on Oct. 19.

“My mission and purpose in life is to stay close to the edges of medicine and science,” she said, describing the 15 years she’s spent following people who are living with life-changing diagnoses and rare conditions. “Because I really believe they are the alpha geeks of health care. When you follow the alpha geeks of any industry, you’re following the hackers. You’re following the people who are pushing on every tool, pushing at the edges of medicine...This way I can bring back reports from the future, so we can better think about where things are headed in terms of health and technology. That’s our shared mission. That’s what you do here at NIH, push at the edges of medicine and science in treatment and in the labs and in the research you do.”

The summit brought “together communicators, patients, researchers and health professionals from inside and outside government to talk about the most effective ways to communicate on digital platforms,” said John Burklow, NIH associate director for communications and public liaison, opening the event. Two keynote lectures, 4 panels, an exhibit/demo area and several topic tables comprised the day-long summit. More than 1,400 people registered to attend the event, either in Masur Auditorium or online. A screen featuring a real-time...
DDM Seminar Series Announces 2015-2016 Lectures

The Deputy Director for Management (DDM) Seminar Series is set to offer another round of exceptional leadership and management presentations beginning this December.

The 10th annual series will host dynamic, experienced public speakers known for delivering meaningful insights into workplace concepts, challenges and solutions. The seminars will provide NIH employees the opportunity to advance their knowledge of best practices in a variety of leadership and management issues.

The first seminar will feature Avish Parashar, “Improve, Adapt and Innovate in an Ever-Changing World” on Thursday, Dec. 3 from 11 a.m. to 12:30 p.m. in Masur Auditorium, Bldg. 10. The series continues into 2016 with three more Thursday seminars: Howard Ross, “Unconscious Bias” on Feb. 11; Cy Wakeman, “Reality-Based Leadership” on Apr. 14; and Daniel Pink, “The Puzzle of Motivation” on June 16.

Presentations will be available at http://videocast.nih.gov/ for those who cannot attend or when Masur Auditorium reaches capacity. Sign language interpreters will be provided. Individuals who need reasonable accommodation to participate should contact the NIH Training Center at (301) 496-6211.

For more information about the series and to view previous videocasts, visit www.ddmseries.od.nih.gov/.

This Thanksgiving, Celebrate Family Health History Day

This Thanksgiving, cook up your unique recipe for wellness and disease prevention and create a family health portrait using the Family Health History tool created by the U.S. surgeon general with help from the National Human Genome Research Institute.

Why is it important to discuss your family’s health history? Diseases such as cancer, diabetes and heart disease are often inherited, meaning they run in families. Tracing illnesses suffered by your parents, grandparents and other blood relatives can help your health care practitioner predict your risk for specific diseases and make vital screening and treatment decisions before any disease is evident.

Precision medicine is an emerging approach for health promotion and disease prevention that takes into consideration the genes, environment and lifestyle of each person. Many efforts are under way to help make precision medicine the norm in everyday clinical practice. However, there will always be a place for family health history as a no-cost component of your personalized health care.

With the surgeon general’s online tool My Family Health Portrait (https://familyhistory.hhs.gov), people can record their family health history before going to medical appointments. In addition, the tool allows users to save family history information to their own computer and share health history with other family members. The tool is available in English, Spanish, Italian and Portuguese.

Before using the tool, ask family members for details about their health histories as well as the health histories of older relatives. Ideally, a family health history should contain information about at least three generations, listing the diseases and conditions that have affected family members, the age a disease was diagnosed and, in the case of deceased family members, the cause of death. The most important relatives to include are parents, siblings and children. Tips on starting the conversations are available at www.hhs.gov/familyhistory/start/startenglish.pdf.

NIDA, NIAAA Host Mini-Convention

NIDA and NIAAA hosted the annual 1-day mini-convention Frontiers in Addiction Research, a satellite event of the Society for Neuroscience annual meeting, on Oct. 16 at McCormick Place Convention Center in Chicago. NIDA- and NIAAA-supported scientists from around the world presented on the neurobiological and behavioral consequences of drug and alcohol use during development. Event highlights included an overview of the development of the brain and the corresponding development of behavior; and a look at the genetics of human thought, behaviors and psychiatric disorders. NIDA director Dr. Nora Volkow (c) also announced the 2015 winner of the Jacob P. Waletzky Award, which recognizes scientists for innovative research on substance use or addiction. It went to Dr. Yan Dong (second from l) of the University of Pittsburgh. Also on hand were (from l) NIDA’s Dr. Roger Sorensen, NIAAA director Dr. George Koob and Dr. Jeremy Waletzky.

NCI’s Rosenberg Wins Honors

It has been an exciting fall season of awards for Dr. Steven Rosenberg, chief, Surgery Branch, National Cancer Institute. He received the 6th annual Betty Ford Lifetime Achievement Award from the Susan B. Komen Foundation on Sept. 26 for his commitment to working with breast cancer patients and educating communities on this type of cancer. On Sept. 30, he was recognized for his leadership and dedication in cancer immunotherapy advancements by receiving the American Cancer Society Medal of Honor for Basic Research. And finally, on Oct. 7, Rosenberg won the Samuel J. Heyman Service to America Medal (“Sammie”) for Federal Employee of the Year. Rosenberg pioneered what is now mainstream immunotherapy for patients and has spent more than 40 years as chief of surgery at NCI, developing treatments that seek to harness the power of the immune system to fight cancer.
New Mental Health Initiative Reaches Out to African-American Men

NIMHD and the Omega Psi Phi Fraternity, Inc., have launched an educational outreach initiative titled Brother, You’re On My Mind (BYOMM): Changing the National Dialogue Regarding Mental Health Among African-American Men. The focus is to raise awareness about the mental health challenges associated with stress and depression that affect African-American men and their families.

Omega is the first international fraternal organization to be founded on the campus of a historically black college (at Howard University) and has 750 chapters throughout the United States and internationally.

While African-American men are as likely as anyone else to have mental illness, they are less likely to get help. Depression and other mental illness can be deadly if left untreated. Suicide is a leading cause of death among African Americans ages 15 to 24. Untreated mental illness can also make African-American men more vulnerable to substance abuse, homelessness, incarceration and homicide.

"We greatly appreciate this partnership with NIMHD and are looking forward to a long-term relationship to have the impact we know is needed in our chapters and the communities we serve for years to come," said Omega’s Antonio F. Knox, Sr.

Omega members have taken a pledge to help change the national dialogue in underserved communities about mental illness; to become more knowledgeable about mental health; to educate other men and their communities about mental health; and to partner with other organizations to help reduce the stigma of mental illness. Through educational awareness programs, they also disseminate evidence-based public educational materials.

As part of a recent Omega leadership conference, NIMHD hosted an information session with remarks by NIMHD chief of staff Dr. Courtney Ferrell Akin and a keynote address by former Surgeon General David Satcher on men’s mental health and the importance of the partnership between NIMHD and Omega. NIMHD also hosted a health fair with materials from NIH.

"I believe this is a wonderful collaboration that has already paid dividends in reducing the stigma attached to mental illness in the African-American community," said Omega’s Dr. David Marion, who is leading the initiative.

For more information about the BYOMM Initiative, visit www.nimhd.nih.gov/programs/collab/BYOMM.html.—Gerda Gallop-Goodman

OSA Honors Gandjbakche

Dr. Amir H. Gandjbakch, head of NICHD’s section on analytical and functional biophotonics, was elected a fellow of the Optical Society (OSA) at its recent meeting in San Jose. He was recognized for leadership and research in areas of non-invasive optical imaging of biological targets, devising quantitative theories, development of methodologies and designing instrumentation to study biological phenomena. Founded in 1916, OSA is the leading professional association in optics and photonics.

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Wednesday Afternoon Lecture on Oct. 7.
“Multidrug resistant tuberculosis is quite widespread. TB is now the lethal disease that it was in the pre-antibiotic years.”

Paradox because you could drop a bucket of TB-infected material on a person and not transmit the disease. It is the tiny, aerosolized particles of perhaps 1 to 3 bacteria-laden droplets that get into the alveolar spaces of the deep lung that transmit TB. The bacteria enter macrophages, where the bug has learned how to survive, causing pneumonia in the lymphoid tissues of the lungs. From there, it can proceed to other organs in the body.

The worst outcome is when TB migrates to the base of the brain, causing TB meningitis—death is the result in between 20-40 percent of cases.

Now at Cambridge University in the U.K., Ramakrishnan, who is a past winner of an NIH Pioneer Award, almost accidentally discovered zebrafish as a model for studying TB pathogenesis.

She was poolside with a clinical mentor during an infectious diseases fellowship at

“TB is now the lethal disease that it was in the pre-antibiotic years.”
-DR. LALITA RAMAKRISHNAN

the University of California, San Francisco, when he suggested that zebrafish, which are susceptible to Mycobacterium marinum—the closest genetic relative of the human TB pathogen—might be a good model organism for studying the TB lifecycle and how to interrupt it.

M. marinum had been identified in 1926 when fish in the now-defunct Philadelphia Aquarium began dying of a TB-like disease. It can infect humans, too, but only causes skin lesions and soft-tissue infections. “But in fish, it looks very much like the human disease,” said Ramakrishnan.

During the first 2-3 weeks of life, zebrafish go through a transparent phase. Ramakrishnan recognized this as a perfect opportunity to conduct real-time analysis of the pathogenesis process in live animals.

“Can we study infection in great depth, from the first phase onward.”

There were technical hurdles to surmount. Pull out a penny and observe the size of Lincoln’s cravat. That is the size of a zebrafish. Ramakrishnan’s colleagues learned to microinject M. marinum into the hindbrain ventricle of the fish, then observe, under high-magnification, the bug’s penchant for invading specific macrophages.

Ramakrishnan has learned much about TB’s evolutionary strategy, which has been successful enough that an estimated one-third of the global population carries latent TB infection. “It’s a good example of pathogen-host co-evolution,” she said. Her work has been like precision medicine in action—there is a high-inflammatory (increased production of tumor necrosis factor) genotype, for which the appropriate therapy is steroids, and a low-inflammatory genotype, for which the leukotriene-inhibitor zilueton is effective, at least in zebrafish.

In an effort to understand why it takes 6-9 months to treat TB, Ramakrishnan and her team learned that bacteria have efflux pumps that get activated when they are inside macrophages and that pump out administered antibiotics.

During a brief Q&A session, Ramakrishnan divulged that her mother was infected with TB, but was eventually treated successfully with rifampicin.

She also noted, “The TB control program in India is a disaster.”

Social problems confound not just TB programs, but many interventions in global disease. Concluded Ramakrishnan, “If we didn’t have poverty, I’d be out of business.”


Workshop on ‘Total Worker Health,’ Dec. 9-10

The NIH Office of Disease Prevention, NHLBI and the National Institute for Occupational Safety and Health are sponsoring the NIH Pathways to Prevention Workshop: Total Worker Health—What’s Work Got to Do With It? It will be held Dec. 9-10 in Masur Auditorium, Bldg. 10, starting at 8:30 a.m. both days.

P2P workshops identify research gaps in a selected scientific area, identify methodological and scientific weaknesses in that area, suggest research needs and move the field forward through an evidence-based assessment of the issue.

A Total Worker Health (TWH) approach is defined as policies, programs and practices that integrate protection from work-related safety and health hazards with promotion of efforts to prevent injury and illness and advance worker well-being. NIOSH launched the TWH program to improve worker health and workplace safety.

In 2007, it is estimated that more than 53,000 deaths were caused by work-related illnesses; the estimated total cost of occupational injuries, illnesses and fatalities was $250 billion. In 2013, more than 4,500 U.S. workers died from work-related injuries and more than 3 million had a nonfatal occupational injury or illness.

To better understand how TWH promotes bringing together the diversity of relevant programs—occupational safety and health, worksite health, disability management, workers’ compensation and human resource benefits—NIH has engaged in an assessment of the scientific evidence. This process will culminate in a second workshop that will focus on key questions in the TWH field.

Attendees will have an opportunity to ask questions and provide comments during open discussion periods. After weighing the evidence, an independent panel will prepare a report addressing the questions.

The workshop is free and open to the public. Sign language interpreters will be provided. Those who require reasonable accommodation to participate should contact Deborah Langer at langerdh@od.nih.gov.
NIH.gov Goes Mobile

The next time you visit the NIH.gov web site (www.nih.gov), you may notice some changes; the slideshow on the homepage is larger, the section pages have a more graphical orientation and some of the site content has been moved to more logical locations. But the largest and most significant change is that NIH.gov has gone mobile.

NIH.gov has adopted a “responsive design,” which allows the web site to dynamically change and shift, depending on the size of the visitor’s screen. No matter what size screen is used, the text, images, navigation and graphics will re-size fluidly. When you visit the site using a smartphone or tablet, the links will now be organized in a mobile-friendly menu in the upper right corner.

The new site has been designed with a Drupal back-end, an open source content management platform that can be used to create and manage many types of web sites. This new software allows NIH.gov to deliver structured content that can be easily shared across different platforms. The transition was managed by the Online Information Branch, Office of Communications and Public Liaison, OD, which is responsible for NIH's home page.

In addition to the new mobile design, NIH is launching a Spanish-language health information web site, Portal de Información de Salud de NIH (www.salud.nih.gov). The web page offers free, evidence-based health information from across NIH on topics ranging from child health to aging. The mobile-friendly site includes translations of many health articles from the NIH News in Health publication, popular for its clear and to-the-point content. Another element is clinical trials information from the Clinical Research Trials and You web site. The new site will also feature a monthly column called Ask Carla (Pregunta a Carla), designed as an opportunity for readers to learn about Spanish-language resources available from NIH.

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The NIH web site was first launched in 1993 and has been through several significant redesigns since that time. The goal of NIH.gov is always to provide an excellent user experience and provide visitors with the highest quality medical research and health information.

New Health Newsletter for Native Americans Launched

A new online newsletter called Honoring Health: Resources for American Indians and Alaska Natives debuted recently. NIAMS, in collaboration with NIDCR and NIA, led development of the newsletter, which features health topics relevant to Native people and highlights health-related resources, events, training and funding opportunities from across NIH and other federal agencies.

The November issue, featuring content from NIDDK, focuses on diabetes, in recognition of Diabetes Awareness Month and American Indian Heritage Month. Diabetes is one of the leading causes of morbidity and mortality among Native people. The disease can cause devastating complications, including heart disease, stroke, blindness and chronic kidney disease, and can lead to amputations. The newsletter features culturally appropriate materials for American Indian and Alaska Native patients with diabetes and people at risk, including ways to control the disease and lower the risk for complications. The November issue also includes a toolkit to help community health workers teach about kidney disease; links to children’s storybooks about nutrition, physical activity and diabetes prevention; and media resources to raise public awareness about diabetes in local communities.

Honoring Health: Resources for American Indians and Alaska Natives is produced by the trans-NIH American Indian/Alaska Native health communications and information work group, in partnership with the Indian Health Service and the Administration for Community Living’s Administration on Aging. To subscribe to this free e-newsletter, visit www.niams.nih.gov/News_and_Events/AIAN_Honoring_Health.
Twitter feed using #NIHDigital kept in-person and online attendees engaged in the conversation.

Setting the day’s agenda, Fox wondered aloud, “How might we connect the edges of science to the majority? How might we use digital tools to engage and educate individuals?”

She talked about what she considered the two major eras of Internet connection so far: “The first—connecting documents—was dominated by Google,” she said. The second—“connecting people—is dominated by Facebook. What I think is next is unleashing empathy.”

Fox recalled that in 1996, when the Pew Research Center began tracking Internet usage, 14 percent of U.S. adults had Internet access; today it’s 9 in 10 U.S. adults. It’s important, she pointed out, to “remove false boundaries between discovery and practice.”

Tapping into digital delivery of information can help with that.

“The Internet has allowed us to crack open the funnel of information previously available only to experts,” she said. But, we can do even better. What if our electronic medical records data were more portable? What if we had full and open access to all medical journals? What if we had true “nothing about me, without me” access to data?

In addition, Fox said, the desktop and landline eras are coming to a close. “We should expect the majority of households to be mobile-only in 5 years,” she predicted.

As for the current social media revolution, Fox said 6 in 10 adults use social networking, and the trend is gaining strength.

“People turn first to a clinician for diagnosis and treatment,” Fox said. “But just as quickly they turn to friends and family, and community of fellow health advocates, community leaders and patients who follow him. “FIT” became a buzzword at the summit. “I think open communication is huge when it comes to doctors and us,” said Rebecca Spencer White, whose young son has Niemann-Pick Type C, a rare neurological disease. Their family learned about NIH through social media, which continues to play an essential role in how they live with the disorder. “We have amazing doctors here at NIH,” she said, “and they read our Facebook and they read our blogs. They can find out things that I forgot to tell them.”

As for anticipating the next cutting-edge tool, Fox said she’s considering virtual reality. By donning VR headsets, users can explore the environment and experiences of other people, without travel. “It is a tool for empathy,” she concluded. “How might we use this new way of understanding someone’s real lived experience? What if we could create a virtual reality experience where scientists and researchers understood really what it is to live with a condition?”

Fox also encouraged summit participants to see the full potential of interacting online. “How might we use social media to open even more doors and windows into our work, to inspire new generations of scientists who ask new questions and discover new pathways?” she asked.

The summit’s afternoon sessions tackled...
digital communication from the science and medical professional point of view.

Keynote speaker Dr. Richard Besser, chief health and medical editor at ABC News and former acting CDC director, described using social media both to explore general health topics daily and to report news. Showing slides and video, he talked about “Reaching People Where They Are: Using Social Media to Promote Health” and interacting in real time with the public.

“I think social media is critically important if we want to reach our audience and get our health messages to people and hopefully have a positive impact on their lives,” he said. “I use social media every day. I share my perspectives on the news…I use Twitter and Facebook a lot to solicit viewer questions. It really helps in terms of connecting with an audience when they feel they are a part of the show, when they tweet us a question.”

One of Besser’s favorite things at ABC News is the weekly Twitter Chat he has conducted since 2011.

“What I love about it is the direct contact with some of our audience,” he noted. “I love engaging with experts from around the country. But I also love that I can do any topic I want.” Unlike a network news broadcast in which stories must be pitched for approval to executive producers/decision-makers, a Twitter Chat topic doesn’t have to win anyone else’s enthusiasm beyond Besser’s.

He discussed the immediacy of posting to Facebook and not having to wait for a news broadcast to report on Ebola in Africa last year.

“By using social media to report the news, it helps us connect with a much younger audience and it helps people connect with me as a trusted news source.”

Besser’s talk gave a broad overview for the panels that followed. Discussions focused on specific devices, applications and practices that communicators are using to connect with people digitally—from interactive tracking tools that allow health professionals to draw behavioral data directly from users remotely to interagency collaboration on emergency preparation.

In a presentation by Dr. John Didion of NHGRI’s Collins Lab, for example, the traditional pen & paper “laboratory notebook” evolved to a digital format using “SmartPen” technology. Didion shared findings from a 3-month study that included NIH researchers and showed how smartpens potentially could change the way scientists solve problems, record their research and share data.

“We really hope to continue this conversation,” concluded Scott Prince, chief of the Online Information Branch in NIH’s Office of Communications and Public Liaison, which hosted the summit. “Continue to use the hashtag ‘NIHDigital.’ We want to hear about the ways you’re going to integrate some of the things you’ve learned about today.”

View the entire day’s event at http://1.usa.gov/1GyKISn.
The dates and speakers are:
- Dec. 16—Dr. Roberta Diaz-Brinton, R. Pete Vanderveen chair in therapeutic discovery and development, University of Southern California, is a recipient of the Presidential Citizens Medal by President Obama for her advocacy in increasing the number of minority students pursuing STEM. She has demonstrated that loss of ovarian hormones leads to activation of a sequence of compensatory responses that ultimately lead to the development of Alzheimer’s pathology.
- Mar. 23—Dr. Brigid Hogan, professor and chair, department of cell biology, Duke University, is an HHMI investigator, NAM member and fellow of the Royal Society. Her research focuses on stem cell techniques and transgenic technology. She is a leader in mammalian embryo manipulation techniques through her publication Manipulating the Mouse Embryo: A Laboratory Manual. Her current focus is the cellular and genetic mechanisms underlying the development, maintenance and repair of organs derived from embryonic foregut endoderm.
- Apr. 13—Dr. Paula Hammond, head of the department of chemical engineering and David H. Koch chair professor of engineering, Massachusetts Institute of Technology, is a member of the 2013 class of the American Academy of Arts and Sciences, recipient of the AlChE Charles M.A. Stine Award and fellow of the American Physical Society. Her group focuses on the self-assembly of polymeric nanomaterials, with an emphasis on the use of electrostatics and other complementary interactions to generate functional materials with highly controlled architecture.
- May 4—Dr. Vivian Cheung, geneticist, University of Michigan, is an HHMI investigator and National Academy of Medicine member. Her research with Dr. Richard Spielman characterized changes in DNA sequence and the effect on gene expression. They mapped and catalogued genetic differences among people from Asia, Africa and Europe; this analysis cemented the importance of regulatory or “junk” DNA.
- May 11—Dr. Yang Dan, professor of neurobiology, University of California, Berkeley, is a Howard Hughes Medical Institute investigator. Her research elucidates how visual information is encoded and processed in the mammalian brain and how neural circuits are shaped by visual experience.
- June 8—Dr. Marie Bernard, committee co-chair. “We of the women of color committee are honored to facilitate their engagement with the NIH community.”

Lectures occur from 3 to 4 p.m. in Masur Auditorium, Bldg. 10.

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“NIH is working hard to address a range of factors related to the research enterprise that affect women in the scientific workforce.”

-DR. JANINE AUSTIN CLAYTON

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The dates and speakers are:
- Jan. 27, 2016—Dr. Yang Dan, professor of neurobiology, University of California, Berkeley, is a Howard Hughes Medical Institute investigator. Her research elucidates how visual information is encoded and processed in the mammalian brain and how neural circuits are shaped by visual experience.
- Mar. 2—Dr. Vivian Cheung, geneticist, University of Michigan, is an HHMI investigator and National Academy of Medicine member. Her research with Dr. Richard Spielman characterized changes in DNA sequence and the effect on gene expression. They mapped and catalogued genetic differences among people from Asia, Africa and Europe; this analysis cemented the importance of regulatory or “junk” DNA.

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Fall Open Enrollment for NIH Leave Bank

Fall open enrollment for the NIH Leave Bank is now available. The enrollment period began Nov. 9 and goes through Dec. 14. The membership period will begin on Jan. 10, 2016.

The Leave Bank is a pooled bank of donated annual and restored leave available to eligible members. It acts like insurance for your paycheck and amounts to paid leave for members who have exhausted all of their leave and are affected by a personal or family medical emergency.

The Leave Bank differs from the Voluntary Leave Transfer Program (VLTP) in that the bank is a depository of leave and leave is distributed to members who are approved to be leave recipients. The VLTP, on the other hand, requires a direct donation from a donor to a recipient. An advantage of the Leave Bank is that eligible members may receive leave from the bank to cover time out of the office without awaiting donations from co-workers.

To become a Leave Bank member, access the Integrated Time and Attendance System (ITAS) during open enrollment and enroll under “Leave Bank Membership.” If you are currently a 2015 Leave Bank member, your membership will automatically continue into 2016, unless you take action in ITAS during open enrollment to opt out. The membership contribution is 1 pay period’s worth of annual leave accrual. The contribution will automatically be waived if you lack sufficient leave to make it.

A list of upcoming free Leave Bank events may be viewed at http://hr.od.nih.gov/benefits/leave/vlbp/important.htm. More information about this benefit can be found at http://nihleavbank.od.nih.gov. Questions may be directed to (301) 443-8393 or LeaveBank@od.nih.gov.
Nonprofit Forum Urges Collaboration

BY SHANNON E. GARNETT

“Progress through Partnership,” NINDS’s ninth nonprofit forum, drew its largest crowd as 145 participants—including representatives from 69 patient advocacy groups—gathered to network with colleagues, learn the inner workings of NIH and NINDS and participate in discussions with staff.

“This is an interactive meeting with patients and their representatives that we are serving,” said NINDS director Dr. Walter Koroshetz in opening remarks. “It is our relationships with the patient organizations that make NINDS hum. These groups also give the people who work at NINDS a real sense of the importance of NIH’s research. We are all motivated by the patients you represent.”

The forum officially kicked off with a plenary talk on patient registries by Dr. Joe Selby of the Patient-Centered Outcomes Research Institute (PCORI). The panel that followed featured six nonprofit representatives sharing case studies in working with patient registries. Panelists covered a wide range of expertise—from those involved in small, low-tech registries to those working with larger, research-level registries.

Co-moderator Dean Suhr of the MLD Foundation—a small 2-person organization he runs with his wife that serves families affected by metachromatic leukodystrophy—talked about the registry he designed to capture data about MLD families.

“Families are our mission but they are also our currency,” he said. “We have to know our families because we are here to serve them but that’s also the source of value we bring to every contact that we make with industry or regulatory agencies.”

Suhr’s foundation now has teamed up with a PCORI-funded Patient-Powered Research Network, which allows them to collaborate and share data and resources with other groups in the network.

NINDS acting deputy director Dr. Alan Willard provided “NIH 101”—how funding decisions are made and priorities set, how the budget affects the payline, what role the National Advisory Neurological Disorders and Stroke Council plays in funding and other fundamental grant information. He concluded with suggestions on how individual groups can contribute to NINDS’s process by providing comments to requests for information, helping principal investigators recruit for clinical studies and recruiting young investigators to the field.

Day two focused on ways patient advocacy organizations can work with partners in industry, academia and government to nurture research on particular diseases. Dr. Paul Scott, director of the NINDS Office of Science Policy and Planning, reviewed the NIH Strategic Plan. Three panels representing major research areas—basic, translational and clinical—followed his talk.

Co-moderators Ronald Bartek of the Friedreich’s Ataxia Research Alliance and NORD, and Ilene Miller of Hope for Hypothalamic Hamartomas, led “Strategies for Stimulating a Basic Research Portfolio.” Panelist Dr. Laura Mamounas, NINDS program director in the neurogenetics cluster of the Division of Extramural Research, gave five defining principles for advancing research:

- Partnerships are critical
- Fund only the best science
- Feed the pipeline
- Diseases are not silos
- Invest in the future workforce

“We need to ensure that rigor and reproducibility are second nature to us,” she said. “NIH can’t do it alone. We have to have journal editors, we have to have patient advocates and we have to have the investigators really understand the importance of conducting only the most rigorous reproducible work. Whether a target or a drug is successful or not, that research has to provide a solid foundation so that the next investigator and the next project can build upon it.”

In the second panel, co-moderators Dr. Amir Tamiz, program director in NINDS’s Office of Translational Research, and Susan Dickinson of the Association for Frontotemporal Degeneration, explored the value of working with government and industry partners on translational research. Dickinson emphasized to her fellow advocates the importance of knowing the science of the disorder they represent.

“You have to understand your science,” she said. “There is this huge pressure to jump toward the clinic and create the animal models...and to develop compounds and get them tested, but unless you understand the basic mechanisms you’re not going to do that successfully.”

Dr. Elizabeth McNeil, acting director of the NINDS Office of Clinical Research, and Cynthia Rothblum-Oviatt of the A-T Children’s Project, co-moderated the panel on partnering effectively with industry in clinical trials.

“At NIH we think a lot about how we can involve the patients as well as industry and academia,” said McNeil. She used the NeuroNEXT (NIH Network for Excellence in Neuroscience Clinical Trials) program—NINDS’s initiative to conduct exploratory trials in neurological conditions—as an example. “The patients help us write the protocols, they serve on the protocol steering committee for grants that are funded and they sit on the data safety and monitoring boards,” she concluded. “So they are involved throughout the entire process.”

PHOTOS: DANIEL SOÑÉ
Americans Who Practice Yoga Report Better Wellness, Health Behaviors

People who practiced yoga or took natural products (dietary supplements other than vitamins and minerals) were more likely to do so for wellness reasons than to treat a specific health condition, according to analysis of data from the 2012 National Health Interview Survey (NHIS). Yoga users reported the most positive health benefits, compared to users of natural products and spinal manipulation. The analysis by the National Center for Complementary and Integrative Health was published in a National Health Statistics Report by the National Center for Health Statistics.

“Though yoga seems to play the biggest role, people who use a variety of complementary health approaches reported better well-being,” said Dr. Josephine Briggs, director of NCCIH. “This may suggest that people perceive more wellness benefit when they are actively involved in their health, for example by practicing yoga. More research is needed to better understand the ways yoga and other approaches impact overall health.”

The NHIS is an annual study in which thousands of Americans are interviewed about their health- and illness-related experiences. The 2012 NHIS asked participants about their use of complementary health approaches and whether they used them to treat a specific health condition or for any of five wellness-related reasons. Participants were also asked whether this use led to any of nine desirable health-related outcomes. The survey results are based on data from 34,525 adults ages 18 and older.

Brain Stimulation Limits Calories Consumed in Adults with Obesity

An NIH study found that non-invasive brain stimulation decreased calorie consumption and increased weight loss in adults who are obese. The findings suggest a possible intervention for obesity, when combined with healthy eating and exercise. Results were published in Obesity concurrent with a presentation at the 2015 Obesity Society meeting.

Led by scientists at the Phoenix Epidemiology and Clinical Research Branch, part of the National Institute of Diabetes and Digestive and Kidney Diseases, the team studied a total of 9 men and women with obesity who resided in the branch’s metabolic ward on two separate visits, each for 8 days. On each visit, the participants ate a weight-maintaining diet for 5 days. Then for 3 days, they unknowingly received either active or sham (fake) transcranial direct current stimulation, or tDCS. Participants then ate and drank as much as they wanted from computerized vending machines. Applied to the scalp, the active tDCS targeted the brain region controlling behavior and reward.

The 4 people who got the sham stimulation during both visits consumed the same number of calories from the vending machines on each visit and did not lose weight. But the 5 people who got active stimulation on the first visit and active tDCS at the brain target on the second visit, consumed an average of 700 fewer calories and lost an average of 0.8 pounds on the second visit.

Next, researchers will compare a group getting only active tDCS with a separate group getting only sham stimulation. More study is needed to confirm the safety and effectiveness of tDCS for weight loss.

In-House Test Kits Motivate Parents to Reduce Allergens in Their Homes

In-home test kits, coupled with patient education, help parents reduce allergen levels in their homes, according to scientists from NIH. The researchers found that parents may become more motivated to participate in allergen-reduction interventions when they can actually see results for themselves. The scientists specifically looked at dust mites, microscopic relatives of the spider, that live in dust on mattresses, bedding, upholstered furniture, carpets, curtains and other soft furnishings. Dust mites contain allergens known to trigger symptoms in people who are allergic to them, and especially those with asthma.

“This is the first study to demonstrate that the use of an in-home test kit can lead to a reduction in dust mite allergen levels in the home,” said Dr. Darryl Zeldin, scientific director at the National Institute of Environmental Health Sciences and a study author. “It’s important to know what motivates people to adapt certain behaviors or attitudes, so we can develop more effective asthma prevention strategies.”

“Parents of asthmatic children have an extra-long list of things to do to keep their kids healthy,” said Dr. Paivi Salo, an NIEHS researcher involved in the study. “We wanted to see if having an easy-to-use kit, where parents could actually monitor allergen levels, would help parents start and maintain allergen-reduction strategies, and our results suggest that it actually did.” The results were published in the Journal of Asthma.
MILESTONES

NIH Library Mourns Murgolo

Betty Beall Murgolo, document delivery specialist at the NIH Library in Bldg. 10, passed away on Oct. 8 after a long battle with cancer.

Murgolo had a long history of exemplary and dedicated service to library customers. She was well-known for being able to locate elusive and difficult-to-find documents. In her 32 years with the library, Murgolo developed a vast network of professional and personal contacts that were an invaluable resource and enabled her to fill even the most complex requests. She was the “go to” person for items that no one else could find. Her colleagues and customers thought of her as the document delivery guru. They knew if the item was out there, Murgolo would find it.

Her sheer perseverance and never-give-up attitude were evident when Murgolo obtained two rare books from 1571 and 1611 that were extremely important for Dr. David Morens to complete his NIAID project on pandemic influenza. Morens said, “I considered her a part of our research team, and state clearly that we could not have done all of the scientific work we have done, including some of our most important achievements, without her. She would figure out a way to get the information the customer needed, no matter where it was and no matter how long it took.”

Another example of Murgolo’s professional expertise and can-do spirit was her ability to track down a French dissertation from the author himself, who said, “Ms. Murgolo had to go to great lengths to obtain the dissertation, as I had the only copy.”

Throughout the years, Murgolo was acknowledged in numerous scientific papers. Hardly a day passed that she did not receive an email, a note of appreciation or a call from an elated customer, expressing gratitude for her hard work, tenacity and perseverance.

According to her supervisor Ben Hope, “Betty strove to constantly improve and enhance the document delivery team to make it the best it could be. She exemplified not only an outstanding commitment to customer service, but also exceptional technical competency and a unique ability to adapt to changing needs. She will be sorely missed by her library colleagues and anyone who had the fortunate opportunity to know her.”

She is survived by her husband John; two sons, John and Stanley; and two grandchildren, William and Wyatt. Expressions of sympathy may take the form of contributions to the Melanoma Research Foundation, P.O. Box 759329, Baltimore, MD 21275.

Former NIH Parasitologist Cheever Dies

Dr. Allen W. Cheever, who devoted his 35-year career in the Public Health Service to conducting research at NIH, died Aug. 29 after a long illness of cardiac amyloidosis.

Cheever joined the Laboratory of Parasitic Diseases at the National Institute of Allergy and Infectious Diseases in 1964 after graduating from Harvard Medical School. In medical school, he developed what would become a lifelong interest in schistosomiasis, a disease caused by parasitic worms that affects more than 200 million people worldwide.

At NIH, Cheever quickly established himself as a leading expert in schistosomiasis, and he worked to understand the biology of the parasite that causes the disease. He was particularly interested in the later stages of the disease, in which schistosomiasis progresses from an acute infection to a chronic and deadly stage. Cheever studied how schistosomiasis can cause liver fibrosis, or scarring, and lead to hemorrhaging and death in some patients. He served as assistant chief of the Laboratory of Parasitic Diseases from 1969 to 1995.

In one of the most significant scientific papers in the field, Cheever demonstrated that the severity of schistosomiasis symptoms and the probability of developing liver fibrosis correlated directly with the number of worm pairs present in people infected with the parasite. His work led to targeted treatment regimens to prevent patients from developing severe forms of the disease.

Cheever was instrumental in establishing ultrasonography, an alternative to surgical biopsy, as the safest and best way to determine the presence and extent of liver fibrosis. In addition, he made important discoveries on schistosomiasis while spending several years in Brazil and Egypt, two regions affected by the disease.

“Allen is best known for two heroic autopsy studies, one performed in Cairo and the second in Salvador, Brazil, that defined forever the quantitative role of parasite burden on the major tropical disease schistosomiasis,” said Dr. Alan Sher, chief of NIAID’s Laboratory of Parasitic Diseases, who worked with Cheever for many years.

Throughout his time at NIH, Cheever was a highly sought collaborator and educator. He was known for his prodigious intellect, dry wit, sage advice and tremendous passion for Brazil, its language and its culture. After retiring from NIH in 1996, he continued his work as a senior investigator at the Biomedical Research Institute located in Rockville.

Born in Brookings, S. Dak., Cheever was a 55-year resident of Bethesda. He is survived by Jane Gilkerson Cheever, his wife of 62 years, with whom he had four children, Carol Ladlow, Erik Cheever, Laura Cheever and Angela Bishop. He is also survived by 11 grandchildren.—Emily Mullin

CSR Review Officer Rosen Remembered

Dr. Lee Rosen, long-time scientific review officer of the biomedical imaging and technology study section at the Center for Scientific Review, died at Johns Hopkins Medical Center on Oct. 22 after a battle with acute myeloid leukemia.

Rosen had been an SRO for 26 years and had been the inspiration and mentor for his colleagues and also a close friend to many at CSR.

Surpassing his devotion to work was his love for his family and friends and his determination to lead a balanced and fun life, remembers colleague John Firrell. “An example of this was a daily game of bridge in the Rockledge II cafeteria, which he organized. He also was an avid diver, which he took up later in his life, and arranged dive trips with friends to the Caribbean, Gulf and elsewhere.”

His colleagues Dr. Eileen Bradley considered Rosen not only an outstanding SRO, but also a close friend. She recalls, “He had been known to immediately jump in to take over someone else’s study sections in an emergency right at the very last minute and to go the extra mile to get things done the right way. In the scientific community, he was extremely well respected among applicants and reviewers alike. They knew Lee would find the appropriate reviewers for their applications and they could count on a fair review. His ability to find and train the right reviewers was recognized worldwide in the medical imaging community."

When word of his death was announced, there were moments at scientific conferences and ongoing review meetings—as far away as Taipei—when participants stopped their proceedings and took time to recognize and mourn his passing, Bradley added.

She concluded, “Those within the NIH and the extramural community will miss his expertise, inspiration, hard work, judgement, organizational skills, leadership and willingness to help anyone in need.”
Late October featured two entertaining events designed to bring attention to the 2015 Combined Federal Campaign.

On Oct. 22, NIH staff enjoyed beautiful autumn weather as NIDCD hosted the NIH CFC Directors’ Challenge—a Frisbee Golf Throwdown. Teams of institute and center directors competed in a friendly game of Frisbee golf. Team members, including NIH director Dr. Francis Collins, landed their Frisbees inside metal basket targets to score points. The final Frisbee was the $1 Frisbee, worth 10 points, to demonstrate that when an employee donates $1 per pay period through payroll deduction, the contribution, while small, adds up to make a big difference to those in need. Sure enough, the team that got the $1 Frisbee into the target won the tournament.

Dr. Michael Gottesman, NIH deputy director for intramural research, kept score and announced the victors. The winning team included NCCIH deputy director Dr. David Shurtleff, NIAMS director Dr. Stephen Katz, FIC senior scientist Dr. Josh Rosenthal and NIDCD director Dr. Jim Battey. The event, held in front of Bldg. 1, drew an enthusiastic crowd of NIH staff who cheered on their directors in support of the CFC.

A week later, the patio outside the Bldg. 31 cafeteria came alive with fantastic and frightening creatures, including NIH’s very own “Cereal Killer” and various assorted wizards, witches, cartoon and storybook characters and superheroes. NIH staff had a howling good time posing for photos in the R&W’s free photo booth. Employees also enjoyed trick or treating with representatives from CFC charities and competing in a costume contest during the event.

Battey came out to enjoy the spectacle and NIDCD Executive Officer Tim Wheeles and HHS CFC Campaign Manager Dan Dodgen awarded trophies for best costumes. Shirley Flottum of OD was awarded a trophy for her “Cereal Killer” costume. OD’s Erin Butler won for her “Neapolitan Ice Cream” costume and ORS/ORF’s Pam Jenkins won a trophy for her “Little Red Riding Hood” costume after judges were terrified by the big bad wolf in her basket.

For more photos of NIH’ers in costume, visit the NIH CFC Twitter feed at https://twitter.com/NIH_CFC. NIDCD partnered with R&W in sponsoring the event.

CLOCKWISE (from above, l): NINR director Dr. Patricia Grady proves Frisbee golf is all in the wrist. NIH director Dr. Francis Collins takes a turn. Cheered on by his teammates, NIDCD director Dr. Jim Battey takes aim at the target. NIDCD CFC steering committee members (from l) Jean Tiong Koehler, Lonnie Lisle and Laura Cole take on alter egos for Halloween. NIH staffers show off their costumes.

Above, Shirley Flottum won a trophy as “Cereal Killer.” Below, judges select winners of the Halloween costume contest.