

NOT 'BUSINESS AS USUAL'

Biden Inspires 'Moonshot' Cancer Effort at NIH

BY RICH MCMANUS

Putting his considerable political capital behind fresh opportunities to make progress against cancer, Vice President Joe Biden is to run "mission control" at an NIH and National Cancer Institute-led "moonshot" effort, said President Barack Obama at his Jan. 12 State of the Union address.

Two days later, NIH director Dr. Francis Collins and NCI acting director Dr. Doug Lowy briefed reporters on fuels for the rocket, including recent success with immunotherapy; lowered costs of genetic sequencing, which will permit faster,

finer and cheaper analysis of the genomic glitches that lie behind the hundreds of diseases known as cancer; the promise of scalable, effective cancer vaccines based on abnormalities in specific tumors; and an aggressive "combination therapy" approach, to "hit [cancer] with everything we've got," Collins said.

"This coalescence of events suggests there is a pathway here," he added. "And we have a very motivated and passionate individual to lead us...He will build a bold, coherent and milestone-driven program. This is the moment to pull out all the stops."

Lowy said that the mortality

SEE MOONSHOT, PAGE 4



In his final State of the Union Address, President Barack Obama calls on Vice President Joe Biden to run "mission control" for an NCI-led "moonshot" to cure cancer.



NIH welcomes Israeli Minister of Health. See p. 12.

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'Databrary' Promotes Sharing, Reuse of Video for Researchers

BY ERIC BOCK

"If a picture is worth a thousand words, then a video is worth a thousand pictures." That's how important video is to developmental research, said Dr. Karen Adolph, professor of psychology and neural science at New York University.

Video gives researchers the opportunity to watch what happens in the blink of an eye—and the ability to repeat that instant, over and over again if



Dr. Karen Adolph

SEE DATABRARY, PAGE 6

HEART HEALTH

Advances in Clinical Research Have Made HCM Highly Treatable

BY DANA TALESNIK

Cardiac arrest hits without warning and is particularly tragic when it kills a seemingly healthy young person. One underlying cause of sudden cardiac death is hypertrophic cardiomyopathy (HCM), a genetic disease that is highly treatable today. Yet HCM remains the most common cause of sudden cardiac death in young people, including competitive athletes.

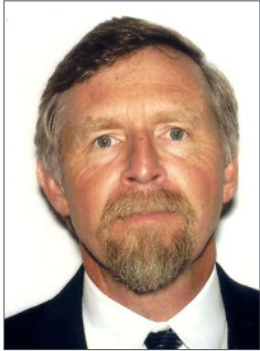


Dr. Barry Maron

SEE MARON, PAGE 8

Clegg To Give NEI 'Audacious Goals' Initiative Seminar, Feb. 11

Stem cell biologist Dr. Dennis O. Clegg will present "Vision for the Future: Cell Therapy for Ocular Disease," as part of the National Eye Institute Audacious Goals Initiative (AGI) Seminar Series in Neuroregeneration. His talk takes place Thursday, Feb. 11 at 4 p.m. in Lipsett Amphitheater, Bldg. 10.



Clegg is a professor at the University of California, Santa Barbara, department of molecular, cellular and developmental biology. He is also founder and co-director of the UCSB Center for Stem Cell Biology and Engineering and a co-principal investigator of the

California Project to Cure Blindness. His research centers on neural development and regeneration with a focus on stem cell therapies for eye disease. Clegg has served on advisory boards for the California Institute for Regenerative Medicine and the NIH Center for Regenerative Medicine.

The AGI series explores topics relevant to regenerative neuroscience and medicine, with special emphasis on the visual system. The AGI is a sustained effort by NEI to catalyze research toward new therapies for disorders that affect the retina and its connections to the brain.

Author Ross To Speak at DDM Seminar

The Deputy Director for Management (DDM) announces the second DDM seminar of the 2016 series "Management and Science: Partnering for Excellence." The event on Thursday, Feb. 11 from 11 a.m. to 12:30 p.m. in Masur Auditorium, Bldg. 10, will feature Howard Ross, who will discuss "Unconscious Bias." He will focus on identifying and navigating unconscious judgments in our daily lives.

Videocasting and sign language will be provided. Individuals who need reasonable accommodation to attend should contact the NIH Training Center at (301) 496-6211 or the Federal Relay Service at 1-800-877-8339.

For more information about the series, visit www.ddmseries.od.nih.gov or call (301) 496-3271.

Bldg. 1 Coffee Bar in Flux

The Bldg. 1 Coffee Bar was closed indefinitely on Jan. 8. The Coffee Bar's food service provider, affiliated with the Maryland Business Enterprise Program for the Blind, made the decision to cease its operations in this location.

The Coffee Bar was a new addition to Bldg. 1 and opened for business in June 2015. The Office of



U.S., Mali Cooperate on Tropical Diseases

U.S. ambassador to Mali Paul A. Folmsbee (l) and Malian Minister of Higher Education and Scientific Research Moutaga Tall recently signed a memorandum of understanding to promote research on and training in tropical and infectious diseases. The United States and the Republic of Mali most recently collaborated on containing the spread of the Ebola virus epidemic outbreak in Mali last year. NIAID maintains an International Center for Excellence in Research (ICER) in Mali to develop and sustain research programs through partnerships with local scientists. Read more about the Mali ICER Program at www.niaid.nih.gov/about/organization/dir/Pages/maliICER.aspx.

PHOTO: U.S. EMBASSY, BAMAKO, MALI

Research Services, Division of Amenities and Transportation Services, is currently exploring other options, with the goal to secure a food service provider who will enhance menu options, increase healthy food choices and provide excellent customer service. ORS seeks to install a new operator as soon as possible. For questions, contact John Crawford, food services manager, (301) 496-8180.

NIH To Host Rare Disease Day, Feb. 29

Rare diseases affect an estimated 25 million Americans. On Monday, Feb. 29, NIH will host an event designed to raise awareness about rare diseases, the people they affect and current research collaborations.

Sponsored by NCATS and the Clinical Center, Rare Disease Day at NIH will take place from 8:30 a.m. to 3:30 p.m. in Masur Auditorium, Bldg. 10. Speakers include Rep. Leonard Lance (R-NJ); NIH director Dr. Francis Collins; NCATS director Dr. Christopher Austin; Clinical Center director Dr. John Gallin; and NCATS Office of Rare Diseases Research and Division of Clinical Innovation director Dr. Petra Kaufmann. The event will feature presentations, posters and exhibits, tours of the Clinical Center and an art show. Admission is free and open to the public. In association with Global Genes, participants are encouraged to wear their favorite pair of jeans.

Prior to the event, on Feb. 22, NIH will host a Twitter chat on rare diseases from 2 to 3 p.m. with Collins and Austin. Join the conversation by following #NIHChat.

Learn more about Rare Disease Day at <https://>

ncats.nih.gov/rdd or visit https://events-support.com/events/NIH_Rare_Disease_Day to see the agenda and to register. You can follow the event on social media at #RDDNIH.

Supervisory Workshop on Work/Life, Well-Being

In collaboration with the Office of Research Services, the Office of Human Resources is launching a new, free supervisory workshop titled Work/Life@NIH: A Supervisor's Guide to Enhancing Workforce Well-being. It will provide an overview of workforce well-being and how it can benefit your organization; highlight the policies and programs NIH offers to promote workforce well-being; and provide supervisors with strategies to manage the use of various workplace flexibilities. The workshop is led by NIH subject matter experts and has been approved for 2 Continuous Learning Points for supervisory refresher purposes.

Registration is available now in the Learning Management System. You may register by searching for course ID #NIHWRD1003. Upcoming sessions are scheduled for:

- Feb. 17, 9-11:30 a.m., 31/6C10
- May 17, 9-11:30 a.m., 31/6C10
- July 14, 1-3:30 p.m., 10/FAES classroom 3
- Nov. 9, 1-3:30 p.m., RKL II/9100-9104

Limited space is available, so register now. For more information, email Courtney Bell (bellcd@mail.nih.gov) or Kelly Peralta (peraltakl@nih.gov).

Guidelines Help Caregivers Meet Cancer Patients' Needs

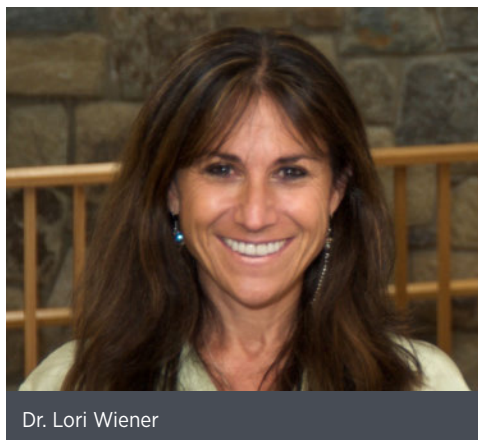
BY ERIC BOCK

Dr. Lori Wiener has witnessed the importance of maintaining a child's emotional well-being during cancer treatment.

Her experiences led her to be a senior leader of a project that developed the first-ever evidence-based clinical standards that provide strong recommendations to support pediatric cancer patients' psychosocial well-being. The standards were recently published in a supplemental issue of *Pediatric Blood and Cancer Journal*.

"The goal of these standards is to enhance [children's] experience not only for their medical care but also their emotional and psychological well-being from the time of a cancer diagnosis through survivorship," said Wiener, co-director of the behavioral health core and head of the psychosocial support and research program of the Pediatric Oncology Branch at NCI's Center for Cancer Research.

For 30 years, Wiener has worked at the Clinical Center, where she is a principal investigator and



Dr. Lori Wiener

psychological and psychiatric follow-up care once treatment ends; all patients should be introduced to palliative care concepts to reduce suffering; and if a child passes away, families should be contacted by a member of the health care team to assess family bereavement needs.

"If you talk with grieving parents, they talk about how disconnected and lost they felt after the intimate and extensive contact with staff who became like a pseudo family," she said. "Not only do they go home without their child, but [also] they

their families. The process included reviewing existing standards and guidelines, surveying experts on their opinion on the most essential services for psychosocial care, gathering feedback from oncologists, psychiatrists, psychologists, social workers, nurses and patients, organizing two "think tank" conferences that included consensus sessions and conducting monthly teleconferences. Eighty-five professionals from 44 institutions were involved.

Wiener called the process "highly unusual" because everyone who participated volunteered their time except for one part-time staffer from the foundation.

Going forward, Wiener predicts "the next phase will be challenging." This will entail learning about models of care, funding models and potential barriers, each of which is essential for integration of the standards on a broad scale. Nevertheless, she said, with evidence that such care contributes to positive quality of life outcomes, the standards are an important first step in meeting the emotional needs of pediatric cancer patients and their families. **R**

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"If you talk with grieving parents, they talk about how disconnected and lost they felt after the intimate and extensive contact with staff who became like a pseudo family."

-DR. LORI WIENER

• • •

also provides therapeutic interventions to pediatric oncology patients and their families on ways to cope and adapt to their diagnosis and treatment.

Previous psychosocial guidelines lacked widely accepted, up-to-date evidence supporting them. The new standards recommend that every patient and family member receive regular psychosocial assessments during treatment, from diagnosis through remission or bereavement.

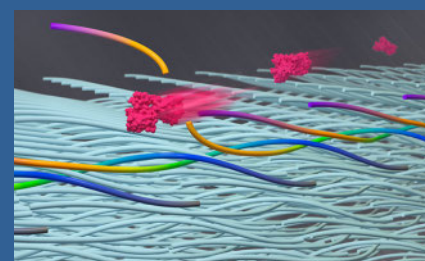
Additionally, some of the other 14 standards are: patients should receive age-appropriate psychoeducation and anticipatory guidance related to their treatment; long-term cancer survivors should receive

lose the staff who they talked to and who provided them support on a daily basis."

Wiener said some hospitals already have psychosocial programs for pediatric patients. The hospitals that don't have them may lack the funds and staff to put such programs in place. These standards include basic elements of psychosocial care and are sufficiently general to be tailored to the resources of individual sites that treat children with cancer, she noted. "We kept the bar low because we wanted something that was digestible and implementable in all health care settings."

The development of the standards is the result of efforts by the Mattie Miracle Cancer Foundation. Established by Vicki and Peter Brown after their son Matthew died from a rare, aggressive form of bone cancer, the foundation advocates for addressing the emotional needs of patients and their families.

To address this critical need, the originators of the foundation asked Wiener to help lead the effort to create evidence-based standards for meeting the psychosocial needs of pediatric cancer patients and



ON THE COVER: A model for collagenase movement and degradation of collagen fibrils based on single-molecule tracking of collagenase enzymes.

IMAGE: MEDICAL ARTS

The NIH Record

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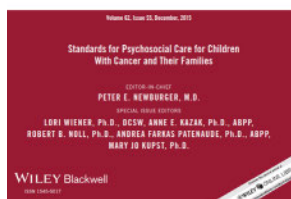
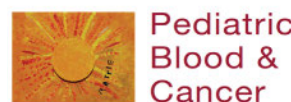
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The *NIH Record* is recyclable as office white paper.





Two days after President Obama announced that Vice President Biden would lead the new initiative to cure cancer, NIH director Dr. Francis Collins (l) and NCI acting director Dr. Doug Lowy discussed the effort with reporters. "...We have a very energized, remarkably creative group of scientists here who are champing at the bit and will rise to the occasion," Collins said. "Given the vice president's support and leadership, I think this is going to be amazing."

Moonshot

CONTINUED FROM PAGE 1

rates for most cancers have gone down in the past 20 years and applauded the recent \$2 billion addition to NIH's FY 2016 appropriation, NIH's biggest increase in more than a decade. "This is building on strength," he stated.

"The notion of a moonshot should be seen as aspirational and not business as usual,"

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"The notion of a moonshot should be seen as aspirational and not business as usual. The opportunities are enormous at this time."

-DR. DOUG LOWY

★ ★ ★

Lowy said. The Biden-led effort will enable faster progress, he predicted. "The opportunities are enormous at this time." But he cautioned that no cure is expected within the next few years.

Lowy also announced creation of a Genomic Data Commons to debut at midyear, housing data for up to 50,000 patients. It will include detailed genomic analysis and annotation of how patients have responded to various therapies. It will rely not just on NCI trial results, but other sources as well, largely due to Biden's influence in the philanthropic community, he said.

"We believe the vice president can enhance this effort," Lowy added. "This kind of database has enormous potential."

Biden, who lost his son Beau to brain cancer last year, has been a keen advocate for cancer research, meeting with more than 200 scientists recently to learn where opportunities against the disease may lie.

His advocacy, rooted in a 36-year Senate career prior to becoming vice president, is seen as assuring more robust private-public partnering and a willingness to share data on an unprecedented scale.

Collins said that NIH's 2-year record of success with the Accelerating Medicines Partnership, which he chairs, is evidence of NIH's ability to navigate public-private partnerships in unique and effective ways. "People were skeptical at first," he said, "but we are now quite excited about that model."

Lowy emphasized, "Patients are absolutely critically important to any initiative. Having more people on clinical trials is a

really key issue and can be improved. People all over the country need access to the latest and best treatments."

Lowy predicts the Biden-led effort will improve basic scientific understanding of the immune system, which is key to creating vaccines, and will boost combination therapies "that might come in various guises—chemotherapy and immunotherapy, or immunotherapy plus radiotherapy... Having more funding will make it possible to explore more avenues more quickly. We have much more to learn about the immune system through basic research. We could have new and important clues not only for cures, but also for prevention."

Noted Collins about the precise new classes of drugs such as helped put former President Jimmy Carter's cancer into remission, "We have educated immune cells to go to college, now it's time to take them to graduate school, where we can explore even finer details."

Noting that Biden is calling for a decade of advances within 5 years, one reporter asked Collins how NIH would know when that milestone was met.

"It's not like turning a crank and getting a predictable result," he explained. "Science is not like that. We are not talking about just a little tweak here or there. This is expected to have a major impact."

Asked what the biggest obstacle facing the moonshot is, Collins responded, "Based on my 23 years [at NIH], I can tell you that it won't be an absence of ideas or talents. It will be a limitation of resources. But we have a very energized, remarkably creative group of scientists here who are champing at the bit and will rise to the occasion. Given the vice president's support and leadership, I think this is going to be amazing." **B**

Liver Disease Patients Needed

An NIDDK research team seeks people with fatty liver disease to participate in a study. Researchers are looking at a breath test to measure how the body breaks down food in people with fatty liver disease. If you have been diagnosed with non-alcoholic fatty liver disease or steatohepatitis, you may be interested in participating. Compensation is provided. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 15-DK-0080.

NIEHS Partners Meet on NIH Campus

BY KELLY LENOX

The NIEHS Partners is a group of education and advocacy organizations concerned with disease, disability and the environment. Together, the members provide a grassroots perspective on the NIEHS research agenda and serve as a key contributor to the translation of research findings for the public, policymakers and private foundations. The group held its annual meeting recently on the NIH campus, fostering a fruitful two-way exchange of information among members and NIEHS leadership and staff.

Representing interests as diverse as asthma, breast cancer, wildlife, children and health professionals, members of the group share a common concern with environmental health. In monthly conference calls, an institute scientist or staff member discusses research in areas such as mercury and fish, nanotechnology, exposure biology as well as other NIEHS activities.

Annual meetings with Dr. Linda Birnbaum, director of NIEHS and the National Toxicology Program, are informal by design. “These meetings are wide



The NIEHS Partners meeting included (from l) Karen Miller of the Huntington Breast Cancer Action Coalition; Karin Russ of the Collaborative on Health and the Environment; Steve Kette of SafeMinds; Kari Christianson of DES Action USA; Eric Uram of Headwater; NIEHS/NTP director Dr. Linda Birnbaum; John Schelp of NIEHS; Lynne Cannon of the Learning Disabilities Association of America; Dr. John Balbus of NIEHS; Mary Lou Ballweg of the Endometriosis Association; Dr. Tony DeLucia of Tennessee State University; and Lisa Wiederlight, also of SafeMinds.

PHOTO: HELEN NOBLE

open—there’s no script, so everyone can share their concerns,” said John Schelp, NIEHS special assistant for community engagement and outreach. “Anything can and does come up, in a real back-and-forth conversation.”

Partners co-chair Karen Miller, who represents the Huntington Breast Cancer Action Coalition, reflected on the significance of the event. “The

NIEHS Partners came prepared to share a diverse range of health concerns our communities face,” she said. “And once again we witnessed through our discussions common threads of toxic environmental exposures and the onset of disease.”

Birnbaum’s penchant for listening to concerns and responding with specific information from relevant research was remarked upon by Dr. Tony DeLucia from Tennessee State University and former head of the American Lung Association. “She riffed like a jazz musician,” he said. The discussion eventually turned toward the developmental origins of disease. “I am convinced that our focus needs to be on early exposure,” Birnbaum said, striking a chord that resonated for all the groups represented.

For Birnbaum’s part, the NIEHS Partners provide a solid grounding in the concerns of a broad range of groups. “I appreciate the opportunity to hear from these different groups from all around the country,” she said.

Staff of the Bethesda office of NIEHS also participated, presenting an overview of their roles on various White House and other governmental committees. Topics they addressed included toxicology, disaster response research and health impacts of climate change. **R**

Campaign Offers Palliative Care Resources for Families

What types of resources do families of children with serious illnesses need? How can palliative care, comprehensive treatment of the discomfort, symptoms and stress of serious illness help them? What is most important to these families? These are questions that drove NINR to create evidence-based materials for parents and families who have a child living with a serious illness.

“When families have a child with a serious illness, pediatric palliative care can be a key part of the care plan to improve quality of life for the child and the family,” said NINR director Dr. Patricia Grady. “It is NINR’s hope that offering evidence-based resources for families will help them access pediatric palliative care services earlier in the course of their child’s illness.”

NINR designed the materials—part of the Palliative Care: Conversations Matter campaign—based on feedback the institute collected from families of seriously ill children. The materials include a resource on finding support, a series of family stories and a fact sheet.

The “Pediatric Palliative Care at a Glance” fact

sheet provides a brief overview of information on how such care works, who provides it and next steps families can take to get this type of care. The “Finding Family Support” resource card outlines different types of support that families may want to access—sibling support, respite care and school resources. Families also told NINR that they want to hear about the experience of others. In “A Family’s Perspective,” four families share their experiences with pediatric palliative care and how the care they receive affects their children and their lives. One parent noted that they “had no idea that the main goal of palliative care is assuring quality of life with a focus on living.” The materials can be used as stand-alone pieces or together to form a family information kit.

First launched in January 2014, the Palliative Care: Conversations Matter campaign aims to increase the use of such care for children with serious



Pediatric palliative care can take place in various settings including the hospital, at home or in outpatient clinics.

illness. The previous phase of the campaign offered materials for health care providers. The campaign’s current phase focuses on resources for patients and families, which includes a care brochure in English and Spanish and outreach items such as web banners, web badges, newsletter articles, an infographic and social media postings.

To download free copies of the materials and learn more about the campaign, visit www.ninr.nih.gov/conversationsmatter or call (301) 496-0207. **R**

Databrary

CONTINUED FROM PAGE 1

need be, she said at a recent Behavioral and Social Sciences Lecture in Natcher Bldg.

Researchers have been using video and film to record infant behavior since Arnold Gesell and Myrtle McGraw pioneered the practice in the 1920s and 1930s. Video allows researchers to gain “new insights into the causes and consequences of learning and development,” Adolph said. “It’s the cheapest, easiest and most effective way to record what people do.”

Video plays an important role in her lab, where she studies how infants, children and adults interact with their surroundings. The lab features specially designed playground equipment where infants can walk across bridges, use handrails to steady themselves and climb over gaps, for example. Recently, her lab helped develop head-mounted eye-trackers for mobile infants and children. These trackers make it possible to record

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“...Most developmental research concerns the kinds of behavior that parents are posting on YouTube and Facebook already.”

—DR. KAREN ADOLPH

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what babies see as they crawl, walk and climb and how a baby’s view of the world differs from the view of their mothers.

“Video allows us to see the extraordinary in behaviors that otherwise seem ordinary and to see the ordinary in what may seem at first glance to be extraordinary,” she said. “Behavior is always rich, complex and organized. And it’s often surprising.”

Researchers, however, rarely share their research videos. Once an investigator completes a study and publishes a journal article, the video just sits on a computer or hard drive. No one ever watches it again.

That’s why Adolph helped to build Databrary, a digital library for sharing and reusing videos. Currently, 350 scientists from 144 research institutions all over the world have uploaded more than 3,500 hours

of video to the library. Most of the data is already coded for behavioral observations using a free, open source program called Datavyu that Adolph also helped to develop or using similar academic or commercial video coding tools. Sharing video excerpts for educational purposes, she noted, is another benefit of Databrary.

To protect research participants’ privacy, only authorized investigators are allowed access to Databrary. Authorized investigators must sign an agreement, show that they have training in human research ethics and work at a facility with an institutional review board. To share video footage with the Databrary community, researchers must get participants’ permission to do so.

Asking for consent is easy, Adolph said. Databrary provides template language that researchers can adapt for their own use and videos that show researchers how to request permission. “We recommend that researchers ask for permission to share videos after the study is over,” said Adolph, “so it’s really clear to the participant what exactly happened and what behaviors were recorded.”

Most parents, she said, are happy to let researchers share videos with other researchers because “most developmental research concerns the kinds of behavior that parents are posting on YouTube and Facebook already.” Most parents of children with disabilities are also eager to share because they hope to speed progress and understanding about developmental disabilities.

Adolph frequently reuses videos for her own research. For example, she and her colleagues collected videos of infants during free play to discover the quantity of locomotion infants spontaneously produce. Babies were recorded in a lab playroom.

Based on these data, she concluded that toddlers, on average, take 14,000 steps and fall 100 times per day. She submitted these findings to a high-impact research journal. The paper was initially rejected



“All behavior is good behavior,” Adolph said of the Databrary.

PHOTOS: ERNIE BRANSON


because a peer reviewer questioned whether babies moved so much because they were in a novel environment. So Adolph reused videos collected for a completely different study of infants playing in their own homes. She counted steps and falls and found no differences between how much babies move in the familiar environments of their homes and the novel environment of the lab. She resubmitted the paper and it was published.

“Infants fall just as much in their homes as they do in the lab,” Adolph said. “By reusing videos collected for a completely different purpose, we were able to answer a new question from old data.”

No researcher has enough expertise to answer important developmental questions alone, Adolph noted. As a motor development expert, she can’t write scientific articles about how motor development affects social interaction, for instance, without collaborators.

However, if she has access to videos coded by language or social development experts, “I think I’m smart enough to relate how those ideas [apply to] motor development—where I have expertise,” she said. “Imagine how much we will discover when it is easy for researchers across the globe to share videos with one another.”

“All behavior is good behavior,” Adolph concluded. Even though it may not be interesting to one researcher, it is likely to interest another.

Databrary is funded by NICHD and the National Science Foundation. Visit <https://databrary.org/> for more information. 



Dr. David Fargo
PHOTO: STEVE MCCAWE

Fargo Named First NIEHS Scientific Information Officer

Dr. David Fargo, NIEHS's first scientific information officer (SIO), will direct development of the infrastructure needed for scientific big data. "David's

office has a broad mission to advance NIEHS scientific information technology and research computing," said NIEHS scientific director Dr. Darryl Zeldin. "He will work across divisional lines in a number of critical areas to ensure that our science IT needs are met."

According to Fargo, his office will make it easier to use available scientific data, while improving research efficiency and enabling new and expanded investigations. "The amount of available data to query is growing much faster than the computational infrastructure," he said.

Fargo, former director of the NIEHS integrative bioinformatics core, has long been interested in designing ways to empower high-performance scientific computing. He said there is a great need for infrastructure that gives researchers access to and understanding of the scientific data deposited in large public databanks. "I'm interested in creating systems and algorithms that empower broader use of large consortia data," he said, describing a scenario in which researchers can query large datasets without having to individually download or reformat raw data.

Fargo would also like the new office to improve management of data generated by NIEHS researchers. Data needs to be trackable, he said, providing a more transparent process and more options for use by scientists. For laboratories that use computers associated with specialized equipment, Fargo envisions customized support and continuity of care—a clear advantage for researchers at the institute.

"Increasingly, the expectation among trainees is to have the opportunity to ask big questions," said Fargo. Through the SIO office, NIEHS will be able to provide the infrastructure and parallel training to support those needs.—Shannon Whirlledge **R**

NINR Highlights Aging Research

The National Institute of Nursing Research recently participated in the Gerontological Society of America's 68th annual meeting, which brought together more than 4,000 gerontologists and interdisciplinary scientists.

NINR director Dr. Patricia Grady moderated both a presidential symposium and an interest group on nursing care in older adults that highlighted the work of NINR-funded researchers. "We are committed to supporting research on health and illness across the lifespan," said Grady. "Nursing science has made significant contributions to the field of aging."

The "Advancing Science and Improving the Lives of Older Adults and Caregivers: 30 Years of the National Institute of Nursing Research" symposium recognized the anniversary of NINR and contributions of researchers it supports. Dr. Rita Jablonski-Jaudon of the University of Alabama talked about her studies in improving oral care for dementia patients. Dr. Joseph Gaugler of the University of Minnesota shared his research in the development of a care coordination tool for dementia caregivers. Dr. Marilyn Rantz of the University of Missouri discussed her research in the use of technology to promote successful aging in place. Dr. Debra Moser of the University of Kentucky presented her work on interventions to improve self-management in heart failure patients.

Grady and Dr. Pamela Cacchione of the University of Pennsylvania were discussants in a symposium on nursing care of older adults.

NINR also joined 100 other exhibitors including publishers, government, pharmaceutical companies, universities and associations. NINR showcased materials such as its strategic plan, research results and training opportunities.



Kandel Speaks on Art History

Nobel laureate Dr. Eric Kandel (l) of Columbia University laid aside his scientific work and spoke instead on art history in the opening Demystifying Medicine talk Jan. 5 in Masur Auditorium. He was introduced by NIH director Dr. Francis Collins (r). Kandel spoke on "The Age of Insight: The Quest to Understand the Unconscious in Art, Mind and Brain from Vienna 1900 to the Present," which is also the title of his recent book. The talk can be seen at <http://videocast.nih.gov/launch.asp?19409>.

PHOTO: ERNIE BRANSON



"I believe very strongly that this is a clinical initiative," said Maron. "The clinicians have saved a lot of lives."

Maron

CONTINUED FROM PAGE 1

"HCM has become a treatable disease, compatible with low mortality and extended, normal longevity," said Dr. Barry Maron, a leading expert on HCM and director of the Hypertrophic Cardiomyopathy Center at the Minneapolis Heart Institute Foundation. He spoke at a recent Grand Rounds Great Teachers lecture in Lipsett Amphitheater. "This is a source of reassurance to patients who have this disease who very often still believe that it's grim, unrelenting and ultimately going to kill them."

HCM thickens the heart walls, restricting blood flow. Some who have it are asymptomatic; others may experience dizziness, shortness of breath, chest pain and/or arrhythmias.

The disease affects at least 1 in 500 Americans. While some 700,000 people in the U.S. have HCM, including some who may be at increased risk of progressive heart failure and sudden death, many are unaware they carry the gene. But many patients with HCM lead long lives without incident or intervention.

"If you've reached the age of 60, 65 and nothing has happened, it's as if the disease

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"If you've reached the age of 60, 65 and nothing has happened, it's as if the disease has declared itself at this point and the event rate is very low, in fact less than the general population."

—DR. BARRY MARON

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has declared itself at this point and the event rate is very low, in fact less than the general population," said Maron, a former senior investigator at NHLBI. "Sudden death due to HCM is rare in this age group, particularly not after age 70, and there's little reason to consider primary intervention."

For those who require treatment, the range of options includes implantable cardioverter defibrillators (ICD) that abort life-threatening arrhythmias; septal myectomy to surgically reduce muscle thickening; medications; and

transplant. These treatments can reverse heart failure and often allow patients to return to normal activity, said Maron.

Septal myectomy is a procedure developed at NIH 55 years ago. "The mortality rate deserves comment because myectomy operations have become the safest open-heart procedure we have, in experienced hands," said Maron. The operation improves quality of life, survival and possibly decreases risk for sudden death.

Scans such as MRI and CMR (cardiac MRD) can show morphology and help identify patients who need intervention. Still, HCM is heterogeneous and highly unpredictable, said Maron. One 18-year-old asymptomatic patient seemed low-risk though a CMR showed some wall scarring, which can be a source of arrhythmias. His mother insisted her son get an ICD implant. Then, 9 months later, the device stopped an arrhythmia and saved him.

Another example highlighting the unpredictability of HCM and the value of primary prevention is a patient who got an ICD implant after his brother died of the disease. During sleep 5 years later, only seconds after

an episode of tachycardia, a shock restored the patient's heart rhythm. Then 9 years later, at age 50, he received a second life-saving shock and has lived without incident for the past decade.

"There's a certain degree of predictability for which patients are at risk," said Maron, "but the timing for these events is unpredictable."

Patients have a higher mortality risk if they have a family history of HCM, wall scarring or massive hypertrophy (thickness). Patients with left ventricular aneurysms represent another high-risk group. And while younger people tend to have a more progressive form of HCM, today's treatments end up creating a low mortality rate for younger patients as well.

Fifty years ago, the mortality rate for HCM patients was 6 percent per year. Today, if patients receive proper treatment, said Maron, the mortality is less than 1 percent.

Genetic research has played a role in understanding HCM. Investigators have identified 11 genes and nearly 2,000 mutations, said Maron. But given the disease's heterogeneous properties, even using genetic markers makes it hard to predict risk. Maron credits decades of clinical research with reducing HCM mortality rates and extending healthy lifespans.

"I believe very strongly that this is a clinical initiative," said Maron. Genetic research has contributed to understanding the basic molecular substrate for the disease and genetic testing can help exclude some family members from further evaluation. "But in terms of prognosis and treating patients, the clinicians have saved a lot of lives." **B**

Trying to Conceive Soon After a Pregnancy Loss May Increase Chances of Live Birth

Couples who attempt to conceive within 3 months after losing an early pregnancy, defined as less than 20 weeks gestation, have the same chances, if not greater, of achieving a live birth than those who wait for 3 months or more, according to an NIH study.

The finding, published Jan. 11 in *Obstetrics & Gynecology*, questions traditional advice that couples should wait at least 3 months after a loss before attempting a new pregnancy. The World Health Organization, for example, recommends waiting a minimum of 6 months between a pregnancy loss and a subsequent attempt.

“Couples often seek counseling on how long they should wait until attempting to conceive again,” said Dr. Enrique Schisterman, chief of NICHD’s Epidemiology Branch and senior author of the study. “Our data suggest that women who try for a new pregnancy within 3 months can conceive as quickly, if not quicker, than women who wait for 3 months or more.”

Previous studies of pregnancy spacing have focused on when women should become pregnant after experiencing a loss, but few have addressed the question of when couples should start trying to conceive.

“While we found no physiological reason for delaying attempts at conception following a pregnancy loss, couples may need time to heal emotionally before they try again,” said Dr. Karen Schliep, a postdoctoral fellow in the NICHD Epidemiology Branch at the time of the study and primary author of the study. “For those who are ready, our findings suggest that conventional recommendations for waiting at least 3 months after a loss may be unwarranted.”



An eye exam can help in the diagnosis of glaucoma, a common cause of vision loss.

PHOTO: NEI

Three Glaucoma-Related Genes Discovered

An analysis funded by the National Eye Institute has identified three genes that contribute to the most common type of glaucoma. The study increases the total number of such genes to 15.

“Just in time for Glaucoma Awareness Month, this unprecedented

analysis provides the most comprehensive genetic profile of glaucoma to date,” said NEI director Dr. Paul Sieving. “These findings open avenues for the pursuit of new strategies to screen for, prevent and treat glaucoma.”

Glaucoma is a group of conditions that damage the optic nerve, the bundle of nerve fibers connecting the eye to the brain. Primary open angle glaucoma, the most common type, was studied in this analysis. In the majority of cases, pressure inside the eye is increased. Glaucoma affects side vision first, often going unnoticed for years. If detected early, vision loss can often be prevented with surgery or eye drops to lower pressure. The most common culprit of irreversible vision loss, glaucoma affects about 2.7 million Americans and 60 million people worldwide.

Some rare types of glaucoma are inherited via a single gene. The underlying causes of primary open angle glaucoma remain poorly understood, but likely involve the interaction of many genes with environmental influences.

The report appeared online Jan. 11 in *Nature Genetics*.

Diet, Exercise Improve Exercise Capacity in Certain Heart Failure Patients

A randomized clinical trial of 100 patients found that diet and exercise—alone or combined—improved exercise capacity in obese older patients with a particular type of heart failure. The trial is the first to show that this dietary intervention was effective in improving exercise capacity and reducing symptoms in patients with heart failure with preserved ejection fraction (HFPEF). The results appeared in the Jan. 6 issue of the *Journal of the American Medical Association*. The study was supported primarily by NIA.

HFPEF is the most rapidly increasing form of heart failure, especially in older adults. It occurs primarily in overweight and obese older women and is associated with high rates of morbidity, mortality and health care expenditures. Exercise intolerance—fatigue and shortness of breath with exertion—in HFPEF patients was recently shown to be associated with increased body weight.

Dr. Dalane Kitzman and colleagues at Wake Forest University School of Medicine randomized trial participants to four groups: diet alone, exercise alone, diet and exercise together or control. After 20 weeks, people in the three intervention groups showed improved exercise tolerance, measured by peak exercise oxygen consumption. The diet and exercise groups both showed improvement; however, the combination group had almost twice the improvement in oxygen consumption. In addition to improving exercise capacity, diet and exercise decreased the amount of fat cells within the leg muscle, the researchers found; fat, which infiltrates leg muscle, contributes to reduced exercise capacity in heart failure.

This is the first randomized controlled trial of calorie restriction in this patient population. While the researchers noted that follow-up studies are needed to investigate the loss of muscle mass associated with weight loss, this research supports a treatment for heart failure that relies on diet and exercise, unlike previous treatments which focused on regulating heart function through medication.

Scientific Review Officer, Mentor Khan Bids Farewell

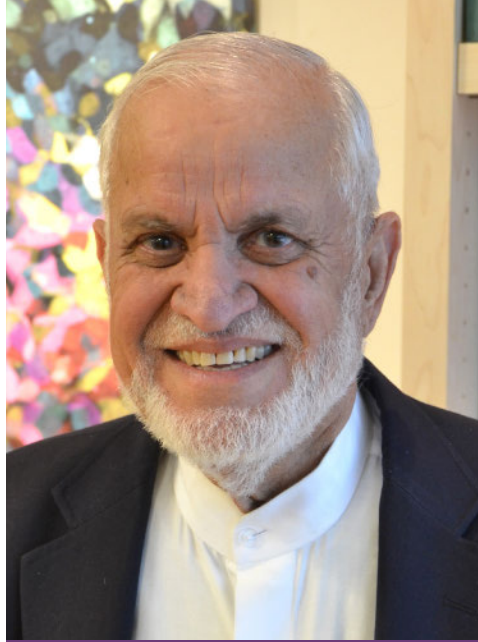
BY PAULA WHITACRE

Dr. Mushtaq Khan lives by the creed “Live to Give.” It guided him through 38 years of federal service, including 27 at NIH supporting the review process with a focus on digestive disease research. It led him to mentor numerous NIH colleagues and extramural researchers. And it has guided him in the creation of a nonprofit organization that provides water pumps and other services in his native Pakistan and elsewhere.

Khan retired in January as scientific review officer (SRO) of the clinical, integrative and molecular gastroenterology study section. “He has guided us by example,” said Dr. Patricia Greenwel, an SRO whom he mentored when she first came to the center. “He has impacted the life of many people at NIH and he has been the face of NIH to the gastroenterology field.”

Khan grew up near Faisalabad. At age 13, he was selected for a highly competitive program toward a career as an air force officer. He changed directions, however, and studied veterinary medicine at the University of Panjab in Lahore. There, a professor of physiology influenced his eventual life choices.

“I remember him walking around the classroom, hands in his pockets, lecturing



Dr. Mushtaq Khan leaves NIH following 38 years in federal service.

at the Food and Drug Administration. At both institutions, he conducted research in nutritional toxicology.

He came to the Division of Research Grants (now CSR) in 1988. He played a leading role in a reorganization to better review gastrointestinal research. From 1997 to 2013, he was chief of the digestive, kidney and urological systems integrated review group.

“I am not retiring, I’m changing focus. Live to give, that is the most important thing in my life right now.”

—DR. MUSHTAQ KHAN

without notes about the thyroid gland,” Khan recalled. “I realized—this is what I want to do.”

Khan received a master’s in animal nutrition at Montana State University. Through a U.S.-Pakistani exchange program, he then earned his Ph.D. in the School of Veterinary Medicine at Washington State University, with a major in physiology and minor in nutrition.

After teaching for 6 years at the University of Maryland Medical School, Khan served as head of perinatal toxicology

“Mushtaq’s ‘glass-half-full’ philosophy to life has a profound impact on those around him,” said Dr. Richard Hodin, a surgical leader at Massachusetts General Hospital and former study section chair. Khan was particularly known for his support of early career investigators. As Dr. Michael Martin, a former CSR division director, said, “There was never any concern when Mushtaq was involved. When he said he could get [something] done, he did.”

Khan, his wife and their four children have often visited Pakistan, but the country’s

devastating 2006 earthquake led to a new direction. He and his wife volunteered in a field hospital to assist with relief efforts. He learned about a low-tech solution to the lack of clean water affecting many villages—a community hand-pump and filter. When he returned to the U.S., he set up his charity, which has provided 600 pumps to date. The charity also has contributed to post-disaster relief in Japan and Haiti.

“I am not retiring, I’m changing focus,” Khan stressed. “Live to give, that is the most important thing in my life right now.” He will spend more time on his charity when he leaves NIH, beginning with a trip to Pakistan in February.



Karen Chandler of NIGMS says so long after a 30-year career at NIH.

PHOTO: SOMA CHOWDHURY

Chandler Retires After Three Decades in NIGMS Budget

Karen Chandler’s first step toward her 30-year career at NIGMS came on her last day of a family vacation. It was 1985, and she was ending a week in Ocean City, Md., with cousins. At one cousin’s prompting, she decided to take the civil service test at NIH before returning home to Toledo, Ohio. But Chandler wasn’t sure how she’d fare. “In my town, having a government job was something you could only dream of.”

Within a month of the exam, she was seated in the NIGMS Budget Office in her

★★★
“I’ve had a stellar career that surpassed all my dreams. Now it’s time for new dreams.”

-KAREN CHANDLER

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new position as a clerk-typist. After rising to the level of a senior budget analyst in this same office, Chandler recently realized another dream—retirement.

Chandler says that when she began working at NIGMS, the Budget Office had the institute’s only fax machine and computer. Her early assignments included typing up budget analyses that were given to her on graph paper or as handwritten notes.


Before retiring, Chandler’s many responsibilities included playing a leading role in budget execution, which at NIGMS entails allocating resources to each funding component. In recognition of her outstanding contributions, she received numerous awards, including NIH Merit Awards in 2004 and 2015.

NIGMS Budget Officer Tony Moore, who

worked with Chandler for the past 17 years, says, “In addition to excelling at her own work, Karen was extremely generous with her time in training other analysts.”

Chandler says that she especially treasures the relationships she developed with her coworkers. “When I moved here 30 years ago, I left my parents and my high school friends and my office mates became my family,” she says.

Chandler is already settling into retirement at her log cabin nestled into the woods at the edge of the George Washington National Forest in West Virginia. She looks forward to spending hours gazing out at bears, deer and birds.

“I’ve had a stellar career that surpassed all my dreams,” she says. “Now it’s time for new dreams.”—Carolyn Beans 



Dr. Patricia Grady

Grady Discusses Aging’s Effects on Society


National Institute of Nursing Research director Dr. Patricia Grady recently spoke at the annual meeting of the National Academy of Medicine (formerly the Institute of Medicine) of the National Academy of Sciences in Washington, D.C. The meeting’s theme was Aging: Complexities, Opportunities and Impacts on Society.

Grady participated in the panel Our Aging Society: Influences, Interventions and Impacts, which addressed the economics and demographics of aging, health disparities and inequalities, as well as biological influences on aging.

She discussed challenges and opportunities related to health care and caregiving among the elderly. She noted that a significant amount of caregiving for the elderly in the United States is provided informally, often by family members. Such care is an important component of a system to help the elderly age in place. However, caregivers can face stressors that affect their own health, as well as that of those they care for. Grady discussed new technologies and other interventions—such as caregiver training and methods of stress management—that could help older adults age in place and enhance quality of life.

She stressed that clear communication will remain essential for reaching the elderly and their caregivers. It is vital, she noted, that we “communicate health messages in very clear, very plain language, in ways that will reach all populations, so that care will be improved for everyone.”

During the panel discussion, Grady responded to a query about issues of financial security and their impact on caregiving for the elderly. She discussed low-cost interventions, such as easy-to-access programs where caregivers and patients can get information and ask questions, noting that such programs can help reduce costly and time-consuming appointments with health professionals.

Grady also touched on issues of the health care workforce, including shortages in caregivers and the effects of education on patient morbidity and mortality. Her remarks can be viewed at https://www.youtube.com/watch?v=NnkThgxt3_c. 

Have a question about some aspect of working at NIH? You can post anonymous queries at <https://nihrecord.nih.gov/Feedback.aspx> and we’ll try to provide answers.

Feedback: There seems to be a persistent disregard for pedestrians on campus during construction. One example is the near constant closure of the sidewalk on Center Drive near Bldgs. 12 & 22. This closure requires pedestrians to cross the road twice, which is very dangerous. This could easily be remedied by simply moving the fence inside the sidewalk. Alternatively, simply narrowing the driving lane by a few feet would also work and would help to slow traffic. Prioritizing car traffic over pedestrians, and making it easier on the construction contractor, is outdated thinking and needs to change. At least make the contractor move the fence when they are done working for the day—there’s no reason for the sidewalk to be closed when no construction activity is going on, which is most of the time.

Response from the Office of Research Facilities: Thank you for your observations regarding pedestrian safety. Our employee and visitor safety is a high priority, as evidenced by our investment in improved campus lighting and construction of pedestrian-activated crosswalks. In addition to such crosswalks in the vicinity of Bldgs. 3 and 35, we plan on awarding the construction of 8 additional ones this fiscal year.

Regarding pedestrian safety in the vicinity of construction sites, it is, indeed, a balancing act. We don’t want to force pedestrians to cross the street unnecessarily, but at the same time we don’t want to expose pedestrians to construction risks. Your suggestions are helpful and we will do our best to manage both categories of risks facing pedestrians—vehicular and construction.

Feedback: The parking lot next to Bldg. 45 often has vehicles (e.g., the NCI Frederick shuttle, taxis, caterers, police) parked in the outbound lane. They do not park next to the building where the shuttles pick up/drop off because that area is marked as a fire lane. However, when vehicles are parked in this very narrow lane (that is also on a curve), it makes exiting the parking lot very difficult. There is a No Parking sign posted, but enforcement is lacking. Can ORS start monitoring this area and ticketing offenders?

Response from the Office of Research Services: The NIH Police have increased monitoring of the area and will take action as appropriate. If you see a vehicle improperly parked in a fire lane or “no parking” area anywhere on campus, call the NIH Police non-emergency line at (301) 496-5685 to report the violation.

Israeli Minister of Health, Ambassador Visit

PHOTOS: ERNIE BRANSON

Israeli Minister of Health Yakov Litzman and Israeli Ambassador to the U.S. Ron Dermer visited NIH on Jan. 4, following a memorandum of understanding signing with HHS Secretary Sylvia Burwell. The MOU emphasized increased cooperation in the fields of health, medicine and science. While at NIH, Litzman and Dermer and their delegation met with NIH senior leadership, including NIH director Dr. Francis Collins,

principal deputy director Dr. Lawrence Tabak, deputy director for intramural research Dr. Michael Gottesman and deputy director for extramural research Dr. Michael Lauer. Later, the group toured the Clinical Research Center and visited a patient unit with Dr. William Gahl, director of the NIH Undiagnosed Diseases Program. Rounding out the afternoon, the group met with NCI leaders, including acting director Dr. Doug Lowy, and attended a Q&A session with Israeli scientists who discussed the importance of NIH, its contribution to health and research in the U.S. and the possibilities of building a similar institution in Israel.



Israeli Minister of Health Yakov Litzman (l) and NIH director Dr. Francis Collins



Dr. William Gahl (second from l), director of the NIH Undiagnosed Diseases Program, describes a treatment protocol involving the drug EPI-743. Also shown are pediatric nurse practitioner Lynne Wolfe (seated) and research nurse Ashley Rice.

Preparing for a tour of the Clinical Research Center, the Israeli minister of health is greeted by several NIH leaders including (from r) deputy director for extramural research Dr. Michael Lauer, acting deputy director for administration Dr. John McGowan, deputy director for intramural research Dr. Michael Gottesman and FIC director Dr. Roger Glass.

At right, NIH leaders gather with the Israeli delegation in the Clinical Research Center's Medical Board Room.

Below, at a Q&A session, NIH scientists (from l) Dr. Ofer Zimmerman of NIAID and Drs. Sigal Shachar and Dr. Jasmin Leshem, both of NCI, talk about the researcher/clinician fellowship that allows physicians to conduct research in the U.S. and see patients related to their research at the same time. "We discussed the significance of this program, how it contributes to advancing and improving medical practice and how we should try and implement a similar program in Israel," said Shachar.

