

Survivors Discuss Suicide's Stubborn Persistence, Mismanagement

BY RICH MCMANUS

Suicide is one of the leading causes of death in the United States, remaining stubbornly high on the list of medical causes of mortality even as deaths from stroke, AIDS, heart disease and leukemia have fallen.

Two people who have survived encounters with this wily enemy of life led off the 12th season of the NIMH Director's Innovation Speaker Series on Oct. 5 at the Neuroscience Center.

Dr. Kay Redfield Jamison, Dalio professor in mood disorders and co-director of the Mood Disorders Center at Johns Hopkins



Dr. Kay Redfield Jamison of Johns Hopkins

University School of Medicine, lamented medicine's disinterest in lithium, the only drug that has yet proven effective in significantly decreasing suicide attempts and completed suicide in patients with manic depression/bipolar illness such as herself.

Jamison says she never misses a day's dose and is baffled by the fact that medical residents today are largely unaware of the drug's effectiveness in many patients.

Joining her in a discussion of suicide was Dese'Rae L. Stage, an artist and activist who knew by the age of 15, when her own suicidal thoughts were exacerbated by a friend who took her own life, "that this was going to be my field for the rest of my life."

Stage was 23 when that life nearly ended. She had "run away to New York City to join the circus" when, despondent over a physically and emotionally abusive relationship, she tried to kill herself.

In an attempt to get past the trauma of the experience, to surmount the "invisibility and erasure" one feels in the aftermath, she set out to find others like herself. That led to creation of the web site Live Through This (livethroughthis.org), a gallery of portraits

SEE SUICIDE, PAGE 4



Lori Stokes with NIH director Dr. Francis Collins

'GENTLEMANLY, BUT ALSO TOUGH' Stokes Family, NIH Director Honor Congressman's Legacy

BY CARLA GARNETT

An hour could not contain all of the fond remembrances that NIH and its broad community holds for the late former Congressman Louis Stokes, who died in 2015

SEE STOKES, PAGE 6



Dr. Alan Leshner touts communication at NIH.

Scientists Need Public's Support to Continue Progress, Leshner Says

BY ERIC BOCK

Science has made fantastic progress on virtually every front and, to continue, scientists need the public's support, argued Dr. Alan Leshner.

"We need the public badly. They are the ultimate receptors for the products of our

SEE LESHNER, PAGE 8



Institute directors support CFC. See p. 12.

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Open Enrollment for NIH Leave Bank

Fall open enrollment for the NIH Leave Bank runs until Dec. 11. The membership period will begin on Jan. 7, 2018.

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 own sick and annual leave and are affected by a personal or family medical condition.

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

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 a 2017 Leave Bank member, your membership will automatically continue into 2018, unless you opt out. The yearly membership contribution is one pay period's worth of annual leave accrual. The membership contribution will automatically be waived if you lack sufficient leave.

For more information visit <http://hr.nih.gov/leave-bank> or contact (301) 443-8393 or LeaveBank@od.nih.gov.

Gail Receives ASA's Karl Peace Award

Dr. Mitchell H. Gail, senior investigator in the Biostatistics Branch of NCI's Division of Cancer Epidemiology & Genetics, received the 2017 Karl E. Peace Award for Outstanding Statistical Contributions for the Betterment of Society from the American Statistical Association at the recent Joint Statistical Meetings in Baltimore.



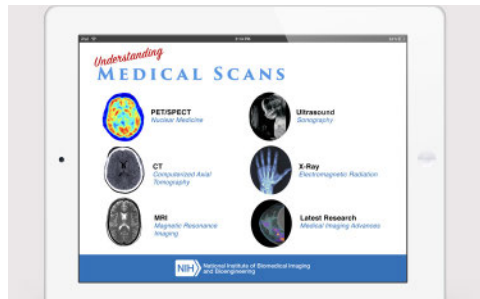
The award recognizes Gail's seminal contributions to the development of statistical methodology and their application to epidemiology and clinical medicine, particularly risk prediction, HIV incidence estimation, genetic epidemiology and the design, execution and analysis of cancer treatment and prevention trials. Notable is his work to develop the landmark Breast Cancer Risk Assessment Tool, also known as the Gail Model, which is widely used in counseling women on their risk of breast cancer.

In addition, Gail's contributions have been recognized with his election to the National Academy of

Medicine and the Marvin Zelen Leadership Award in Statistical Science. He is also an ASA fellow.

In August—with coauthor Dr. Ruth Pfeiffer, also a senior investigator in the Biostatistics Branch—Gail published a new book as part of the Monographs on Statistics and Applied Probability Series by CRC Press. *Absolute Risk: Methods and Applications in Clinical Management and Public Health* draws on the investigators' expertise and seminal achievements in modeling absolute risk.

Established in 2012, the Peace award is given yearly to a statistical scientist who has made seminal contributions with important societal impact.



NIBIB Mobile App Explains Scans

Understanding Medical Scans is a free app for mobile devices that offers helpful explanations of common medical imaging procedures. Developed by the National Institute of Biomedical Imaging and Bioengineering, the new tool's goal is to explain to patients what to expect during a medical scan and how each type of scan can help with both diagnosis and treatment.

Five types of medical scans are described in the app: positron emission tomography (PET), computerized tomography (CT), magnetic resonance imaging (MRI), ultrasound and x-ray imaging. The app uses question-based navigation, images and videos to highlight each of these state-of-the-art technologies. An additional topic within the app is the role of imaging in biomedical research. Developed with the layperson in mind, it may be helpful for patients and family members in formulating questions about pending procedures.

The app can be downloaded onto an Apple or Android device, making medical imaging information easily available anywhere. Visit <https://www.nibib.nih.gov/> or search Understanding Medical Scans at the Apple store or on Google Play to download the app.

NIH Community College Day, Nov. 21

NIH Community College Day will take place on Tuesday, Nov. 21 from 8 a.m. to 4 p.m. at Natcher Conference Center. To register and for more information visit www.training.nih.gov. The event will provide community college students and faculty an opportunity to visit campus and learn about careers and training opportunities in biomedical and health care fields.

Three NIH'ers Elected to NAM

Three NIH scientists are among 80 new members elected to the National Academy of Medicine. Election is considered one of the highest honors in the fields of health and medicine and recognizes



Dr. Christine Grady

individuals who have demonstrated outstanding professional achievement and commitment to service.

Dr. Christine Grady is chief of the department of bioethics at the Clinical Center. Dr. George Koob is director of the National Institute on Alcoholism and Alcohol Abuse. Dr. John Mascola is

director of the Vaccine Research Center.

"These newly elected members represent the most exceptional scholars and leaders in science,

medicine and health in the U.S. and around the globe," said Dr. Victor Dzau. "Their expertise will help our organization address today's most pressing health challenges and inform the future of health and health care to benefit us all."

New members are elected by current members through a process that recognizes individuals who have made major contributions to the advancement of the medical sciences, health care and public health.



Dr. George Koob



Dr. John Mascola

Established originally as the Institute of Medicine in 1970 by the National Academy of Sciences, NAM addresses critical issues in health, science, medicine and related policy and inspires positive actions across sectors.

Mother of Patient Runs 10K for Son, Children's Inn at NIH

BY ERIC BOCK

In September, Carly Israel-Agin was passing through airport security when her son's school called. Her 8-year-old, Desi Borstein, had a rapidly increasing fever. She went straight to his school and administered a painful shot that broke the fever.

The next morning, Israel-Agin did something she'd never done before: she ran a 10K.

"Desi's super brave and I figured if he could withstand the pain, so could I," the Ohio mother of three explained. "It felt amazing to push myself and it's because of the example I have in my little guy."

Running that distance was important to Israel-Agin because she's part of the Children's Inn at NIH's #RunINN4Kids Marine Corps race team. On Oct. 22, she ran in the MCM (Marine Corps Marathon) 10K, a 6.2-mile race that passes by some of the most recognizable landmarks in Washington, D.C., and Arlington, Va. To join the team, runners must raise at least \$600 for the inn. She raised more than \$7,000.

Israel-Agin joined because she and her son are one of more than 13,000 families with children participating in clinical studies at NIH who have stayed at the inn, for no charge, since 1990. She doesn't know where her family would be if it wasn't for NIH and the inn. So she wants to help others in her position.

Desi doesn't have a diagnosis. He was born with a complete blockage of a vein that normally circulates blood from the brain to the heart. As he grew, new veins formed and bypassed the blockage. However, the veins prevent the bones in the back of his head from closing. He also repeatedly gets unexplained high fevers that can rise above 107 degrees if left untreated.

Desi first came to NIH when he was 3 years old at the suggestion of a local immunologist who believed NIH was his best chance, since no one could figure out what was wrong with him.



Carly Israel-Agin with her son Desi Borstein

"We are so grateful when doctors are willing to admit they need help," Israel-Agin said.

He was enrolled in a study sponsored by NHGRI's Dr. Daniel Kastner and underwent a week of extensive testing. Since then, he's been under the care of several specialists at NIH including NHGRI's Dr. Amanda Obrello, nurse practitioner Patrycja Hoffmann and NIAID's Dr. Juan Ravell.

Desi's doctors, despite lacking a diagnosis, have found a medication that has kept him out of the hospital for the past 10 months. He's kept busy during that time. Israel-Agin said he's begun to write stories with his best friend from home. He and his family like to watch cartoons and Cleveland Cavaliers games, play video games, soccer and kickball, bake cookies and crack jokes.

At the inn, Desi has found a place like home. His mom said he especially enjoys checking his inn mailbox every day for a special treasure. When he's there, he sleeps on a pillowcase that a volunteer made.

"It's his place," his mom said. "He also loves the air hockey table and the fact that he knows his way around."

And what's Desi's favorite part about the inn? "Everything!"

In early October, Israel-Agin said one of Desi's doctors at NIH asked him to come back.

"We no longer expect a magical solution, but I heard words I have never before heard," she said: "We found someone who closely resembles your son."

Doctors have identified a new lead that might provide more insight into Desi's condition. It could one day lead to a diagnosis. **R**



NICHD's Basser Honored

Dr. Peter Basser (l), senior investigator who heads the section on quantitative imaging and tissue sciences at the National Institute of Child Health and Human Development, accepted the Victor M. Haughton Award for his groundbreaking work on diffusion tensor imaging at the October annual meeting of the American Society of Functional Neuroradiology in Portland, Ore. Congratulating Basser is society president Dr. Christopher G. Filippi.



ON THE COVER: NCI scientist holds three test tubes containing (from l) healthy T-lymphocytes, T-cells infected with HIV/AIDS virus and T-cells exposed to HIV but protected by AZT.

IMAGE: JOHN CRAWFORD, MAPB

The NIH Record

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Suicide

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and true stories of nearly 200 suicide attempt survivors across America.

Jamison was 17 and in high school when she suffered her first psychotic breakdown and depression. In that condition, she learned how to load her father's gun.

By graduation, the dark mists had lifted, but her mania and depression "got much worse over the years." At age 28, following a bout of mania and depression, she took what she knew—being a lithium researcher—was enough lithium to kill her.

"I unambivalently wanted to die."

But she didn't. "Being in a coma is an eye-opener, it turns out," she observed drily.

Jamison was eloquent in her description of the self-deception she and others with her condition are capable of, recounting a pact she made with Jack, a friend and erstwhile suitor who also suffered from bipolar illness.

The two, both prone to skipping their medication, made a blood oath that they would meet at Jack's house on Cape Cod to walk the beach—they called it "Hostage Week"—should one feel on the verge of suicide.

"We figured that a week was long enough to make the argument for life," Jamison recalled. "We agreed not to buy guns or let anyone else have them in the house. Still, I had my doubts. Who are we kidding? It wasn't in me to call for help, let alone arrange travel to Massachusetts."

Her skepticism was fulfilled when Jack, a successful Yale grad and holder of some 1,000 patents for everything from toys, to missiles, to household products, shot himself in the head.

"I was shaken, but not surprised," said Jamison. "Suicide is not beholden to an evening's promises."

Suicide, with 1 million deaths annually worldwide, "is a huge problem and it's only getting worse," she said.

Almost diabolically, the average age of onset of the most common causes of suicidal thoughts—depression, manic depression and schizophrenia—is the late teens and early twenties, a time when this population is least likely to be in treatment, said Jamison. "It is a very difficult clinical problem."

It frustrates her that lithium, the gold standard for bipolar illness, is not often enough used nowadays.



"Lithium is the only drug we know that works well in preventing suicide and severe attempts, but few prescribe it."

Acknowledging that it doesn't work for everybody, Jamison is nonetheless concerned about lithium's non-use. Part of the problem is that the drug has gone off patent and is no longer a money-maker. It also means more work for physicians—blood draws and follow-up.

"No one defends or makes the case for it anymore," she said. "Residents are not taught to use it. Why don't we do more about that? I don't understand. Why doesn't the community use it more?"

She suggested a campaign to persuade physicians to rediscover lithium. Anything to thwart "the pain, the guilt, the agonizing 'What could I have done differently?'"

Des Stage has lots of ideas about what can be done differently.

While an undergraduate at East Tennessee State University, Stage, who by then was already a suicide loss survivor, was discouraged from pursuing suicide as



Dese'Rae L. Stage offers views on care of suicidal people.

PHOTOS: MARLEEN VAN DEN NESTE

a field of academic study. Nevertheless, she persisted.

In the immediate aftermath of her own attempt—an event that included a surfeit of embarrassments, as Stage was lightly clothed at the time—she had a dream gig of a professional life. She was working for a record label in New York, which gave her access to such heroes as Jay Z, Tori Amos and Amanda Palmer. The job was cool, but not fulfilling.

Stage bought a camera as a healing tool, a coping mechanism. The thing that had been missing from her studies of suicide was finding the humanity in the predicament of a person contemplating such an extreme act.

Seven years ago, she googled "suicide survivor. I was looking for a lived-experience identity. How do you find support groups? How do I get past it? I was already 4 years out from my own suicide attempt. I was unfulfilled in my work with musicians and looking for a personal project that would change that feeling. I immediately thought, 'What if I could do with my camera what I couldn't do in academia?'"

"I set out to find out who these people were," she said, and Live Through This was born.

Her first notion was to use her PR contacts from the rock music world to find celebrities who might open up to her.

"Almost all of them told me to buzz off," she said. "I had no body of work, no credibility."

She posted Craigslist ads in New York, but that site eventually demurred from publishing her posts. In time, though, people found her. A 2013 Kickstarter campaign brought in \$23,000 in 30 days, enough to broaden her recruitment campaign beyond New York City. Within a year, Stage and Live Through This were the subject of a story in the *New York Times*.

A charming, forthright, admitted "over-sharer," Stage has a disarmingly simple m.o.: "I interview people. I just say, 'Tell me your story.' All they know is that I've been there."

Stage takes portraits of survivors, depicting them "in the world they were ready to leave. Just a quiet, honest moment that prompts the viewer to look into our eyes."

There are rules: participants have to be at least 18, they must be willing to use their full names and likenesses and they must be a year out from their most recent attempt.

"This has been such an anonymous and



"I just say, 'Tell me your story.' All they know is that I've been there," said Stage.

marginalized group," Stage says. "I feel that the personal part of suicide is unmined territory."

Before her site began, "We just didn't exist," Stage continues. "We were stuck in a shame closet—let it go, shut up. I was tired of the silence. I've never been a silent person."

Stage is convinced she is changing public attitudes, which was her goal. "Research has shown that ordinary people's stories have the biggest effect, not celebrities." Her mission is to "create connections, even if [people] can't meet face to face."

So far, she has done 182 interviews in 35 cities. Far from the passive recipient of others' wisdom, she has become evangelical about larger themes.

"Health care is a problem" in general, she says. "Suicide is a human experience, but we have a hard time treating it that way."

When she tried to take her life in 2006 in Tennessee, cops pounded on her door and carted her off without allowing her to change clothes.

"It was a humiliating experience, but tame compared to what I've heard," she said. The risk of harm from first responders is an issue, Stage noted, as is the brusque and distant treatment frequently visited on such patients while in the ambulance and at the hospital.

"A person-centered assessment is needed," she argues, not a filling out of rote and somewhat ridiculous, given the situation, forms.

"Not all people who attempt suicide need hospitalization," she continued. "We need to learn to ask these people, 'What do you need?'"

Stage promised herself, in recovery, that she would "change everything about my life."

The opacity and impersonalization of many medical interactions is now an enemy: "It leaves you with nothing to hang your hopes on...It took me until I was 30 to know what questions to ask at intake."

Only 7 states have suicide training programs, she said, calling for a need to prioritize education, especially given that suicidal ideation can occur in children as young as 5.

Stage concluded, "Regular people are the ones who are going to save lives. But we need more resources, not necessarily adhering to the medical world model. One size doesn't fit all."

She warns against platitudes and the retailing of such likely untruths as, "It gets better."

"That contributes to a sense of futility and hopelessness," she said. When Stage interviews people for Live Through This,

she always asks, Is suicide still an option for you? "Most people who share their stories say 'Yes, but I don't want it to be.' The best approach is to find ways to cope."

As taboo as suicide is, "It can't be terrifying to the experts," Stage said. "We can't operate from a position of fear. Fear-driven care isn't care...Talking openly gives other people permission to do so, too. A safe, productive conversation can defuse a crisis and flip the switch.

"People want to tell their stories, but many are afraid," she said. Virtually all of Stage's interview subjects decide to tell their stories because they feel that if they can help just one person, it's worth it.

"Let's do something different," said Stage, "together." **R**

DEC. 5

Ollmann Sapphire To Give Kinyoun Lecture

Dr. Erica Ollmann Sapphire, director of the Viral Hemorrhagic Fever Immunotherapeutic Consortium, will deliver the 2017 Joseph J. Kinyoun Memorial Lecture on Tuesday, Dec. 5 at 3 p.m. in Lipsett Amphitheater, Bldg. 10.

Her talk, "Antibodies Against Ebola and Lassa: A Global Collaboration," will explore the features of antibodies that protect against these deadly viruses and the ongoing need for scientists to collaborate in this research to establish a complete knowledge base. During the past 3 years, consortium researchers from dozens of labs on 5 continents have studied these protective antibodies. The consortium aims to fill critical knowledge gaps and provide a foundation of research that can be used to improve existing vaccines and antivirals and to evaluate the pipeline of candidate countermeasures.

Ollmann Sapphire, who has served as consortium director since 2013, investigates the structural biology of both viruses and antibodies—how viruses like Ebola, Marburg and Lassa infect host cells, what the viruses' weaknesses are and which antibody combinations might defeat them. This work has led to surprising and substantial discoveries in virology: Her team recently found that some viral proteins can change their 3-D structures to play several different roles, allowing more information and more function to be encoded in concise viral genomes.

Ollmann Sapphire received her Ph.D. in macromolecular and cellular structure and chemistry from the Scripps Research Institute in 2000. She has since held a number of positions there, where she is currently a professor of immunology and microbial science. Her work has been recognized by a Presidential Early Career Award for Scientists and Engineers, the Burroughs Wellcome Fund and young investigator awards from the American Society for Biochemistry and Molecular Biology, the American Society for Microbiology and the International Society for Antiviral Research. She is a fellow of both the American Academy of Microbiology and the American Association for the Advancement of Science and serves on the scientific leadership board of the Global Virus Network.

Since 1979, NIAID has hosted an annual public lecture in honor of Dr. Joseph J. Kinyoun. In 1887, he founded the Laboratory of Hygiene—the forerunner of NIH—paving the way for more than a century of groundbreaking medical discoveries since then.



Dr. Erica Ollmann Sapphire



At an NIH event honoring the late Congressman Louis Stokes are (from l) NIMHD director Dr. Eliseo Pérez-Stable; Collins, along with Stokes's children Lori Stokes, Shelley Stokes-Hammond and Chuck Stokes, and former Health and Human Services secretary Dr. Louis Sullivan.

PHOTOS: CHIA-CHI CHARLIE CHANG

Stokes

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at age 90. But an event hosted Oct. 12 by the National Institute on Minority Health and Health Disparities—just one part of NIH he was instrumental in seeing founded and funded—featured as many warm recollections as could fit into 60 minutes.

Fortunately many of those stories—and a lot of shared history—were also documented by the lawmaker himself in a recently released autobiography, *The Gentleman from Ohio*.

Led by former Health and Human Services secretary Dr. Louis Sullivan, NIH director Dr. Francis Collins and NIMHD director Dr. Eliseo Pérez-Stable and attended by several Stokes family members, the occasion billed as a “Fireside Chat” honored the legislator’s legacy in Bldg. 50, which bears his name, the Louis Stokes Laboratories.

A founder of the Congressional Black Caucus (CBC) in the 1970s not long after his election as the first black U.S. representative from Ohio and first chair of CBC’s Health Brain Trust, Stokes served “numerous prominent roles in the House of Representatives throughout his career,” said Pérez-Stable, “but what I believe to be the true essence of his life’s work and why we are here today is the energy he poured into improving the nation’s health. He was an outspoken supporter of biomedical research and led the charge to appropriate billions of dollars to these efforts.”

Stokes was instrumental in launching NIH’s Office of Minority Programs in 1990, which evolved into a center in 2000 and eventually became NIMHD in 2010.

A member of Congress’s appropriations committee, Stokes was known for helping direct millions in funds to NIH for research

on health conditions that disproportionately affect minority populations and to training programs for minorities underrepresented in biomedical science careers.

“A champion of legislative prowess, Congressman Stokes carved out a path for us to address health disparities,” Pérez-Stable said.

Long-time Stokes friend Sullivan, who served as HHS secretary 1989-1993, recalled meeting the lawmaker in fall 1975 and “immediately formed a great relationship that lasted a number of years.

“All of us went to Lou Stokes,” Sullivan remembered. “We were not in Ohio, not in Cleveland, so we couldn’t vote for him...but he would really respond to us whether we were from Georgia or from Nashville or from New Orleans because the issue of minority health and minority professionals was very close to him.”

According to the former HHS head, Stokes “helped get appropriations year after year for scholarship support, for research and teaching facilities, including NIH’s Research Centers at Minority Institutions,” which still exists.

“He played a very critical role not only for the health of minorities in general but also for minority institutions,” Sullivan said. “He was a very good friend...Lou Stokes represented an idealist, worked very hard, came along at a special time, accomplished much and all of us are better off for what he contributed to us.”

Collins and 3 of Stokes’s 4 adult children then took to armchairs set on a platform that temporarily transformed Bldg. 50’s science conference space into an informal, cozy living room.

The NIH director’s laboratory, which focuses on diabetes, is located on the 5th floor of the Stokes Bldg. and Collins said he

often thinks about the legislator when going to work there.

“He was the gentleman from Ohio and he was always gentlemanly,” Collins recalled, “but he was also tough. He wanted, when he asked a question, that somebody might actually provide an answer. He would occasionally remind us that while our eloquence was impressive, what he was really looking for was substance...I always admired his fairness, his generosity of spirit, but [more] his principled way of handling the responsibilities he carried on his shoulders and carried them well, representing his district but really the whole nation in a way that was truly remarkable.”

Collins, along with Stokes’s daughters Shelley and Lori and son Chuck, reflected for the next hour on the impact their dad’s career and character had on improving the health and well-being of people nationwide through his promotion of laws and initiatives at NIH especially but also in the biomedical research community at large.

With a mixture of humor and emotion, the group described many Stokes anecdotes, priorities and values: the importance of family, principles in the political environment, Stokes’s appreciation for a good-natured prank by his brother as well as his devotion to justice and law.

“Thanks for remembering my father in such a beautiful way,” concluded Shelley Stokes-Hammond.

After the chat concluded, Stokes’s family lingered for a while, signing copies of the book and reminiscing with a crowd of the congressman’s admirers.

See the entire event online at <https://videocast.nih.gov/summary.asp?Live=26485&bhcp=1>. **R**



NIH recognized the work of physician assistants at an event that included speakers (from l) Dr. Richard Childs, NHLBI clinical director; Deputy Surgeon General Sylvia Trent-Adams; and keynoter Clinical Center CEO Dr. James Gilman. At right, PAs assemble for a photo after the event.

PHOTOS: JEFF ELKINS

NIH Recognizes Work of Physician Assistants

NIH recognized the contributions physician assistants (PAs) have made on campus, in the military and the Public Health Service on Oct. 12 in the Clinical Center’s southeast patio room. The event was held during PA Week.

“PAs play a vital role in the care of patients across the nation and, in particular, in the care of patients here at NIH,” said Dr. Richard Childs, NHLBI clinical director and a senior investigator in the Laboratory of Transplantation Immunotherapy.

He said NIH employs about 40 PAs. On campus, they take care of patients, help conduct clinical and scientific research and mentor staff, from nurses to physicians to fellows. He first began working with PAs 15 years ago. Right now, he works with two. “These two PAs are the best clinicians I’ve ever worked with,” Childs said.

The profession has military roots. In 1965, Dr.

Eugene Stead founded the first PA education program at Duke University, said Clinical Center CEO Dr. James Gilman during the event’s keynote address. The first students were four Navy corpsmen. They graduated in 1967, marking the beginning of the profession.

Before he came to the CC, Gilman worked extensively with PAs. During his 35 years in the U.S.



“...The future of your profession looks very, very bright.”

-DR. JAMES GILMAN



Army, he learned how valuable they are. In the military, he explained, they provide routine care, train medics and, when deployed, provide advanced trauma and life support skills. These responsibilities “illustrate the flexibility and adaptability of PAs as a profession and as individuals.”

Gilman noted, “The future of your profession looks very, very bright. I’m very proud to work with all of you.”

PAs in the PHS have shown their ability to provide health care and leadership, noted Deputy Surgeon General Sylvia Trent-Adams. They’ve responded to natural disasters like Hurricanes Katrina and Sandy and participated in the response to the Ebola outbreak in West Africa.

Trent-Adams concluded with a challenge: “You have done a lot, you continue to do a lot, but there’s a lot more for you to do.”—Eric Bock

Stanford’s Quake Lectures at NIBIB Council

Dr. Stephen Quake, the Lee Otterson professor of bioengineering, physics and applied physics at Stanford University, recently gave the fourth annual Lopez lecture at NIBIB’s September council meeting. He described how he, his colleagues and students have employed “precision measurement in medicine” to develop and exploit the properties of microfluidic chip and sequencing technologies—creating paradigm shifts in crystal formation, single cell genomics and non-invasive prenatal diagnosis.

One of the first successes of microfluidics was that the physical properties of reagents at nanoliter volumes allowed crystal formation of important biological proteins that would not crystallize under standard conditions. The study of the structure of these proteins dramatically advanced our knowledge of their roles in human health and disease and the subsequent development of medical treatments.



Dr. Stephen Quake (l) with NIBIB director Dr. Roderic Pettigrew

Another breakthrough enabled by microfluidics was single cell genome analysis. One of the initial studies tracked gene expression as cell types differentiated in the developing lung to create alveoli. Large sets of transcripts were found that defined each cell type of the differentiating lung.

Another early study used microfluidics and single cell genomic amplification to follow the changing patterns of gene expression in individual clonal lines of cells in childhood acute lymphoblastic leukemia. The researchers tracked patterns of emergence of mutated genes in individual cells of the tumor population. Each patient presented with distinct patterns of combinations of mutated genes. However, the analysis revealed commonly mutated genes in many clones, suggesting common targets for therapies despite the polyclonal nature of the disease.

Quake concluded with examples of how the lab adapted single molecule sequencing and precise counting of amplified molecules of cell-free DNA in blood to eliminate risky, invasive diagnostic procedures.

Quake’s take-home message is that nearly all the technologies he described have become commercially available and have significantly improved public health.—Thomas M. Johnson

Leshner

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work,” said Leshner, chief executive officer emeritus at the American Association for the Advancement of Science and former NIDA director, during an Oct. 19 NCCIH lecture in Lipsett Amphitheater on communicating science to the public. “The public only supports science because they think it’s good for society and that it serves society.”

Overall, the public approves of scientific research. Support depends on how productive scientists are, the quality and trustworthiness of “science, the enterprise, not just science, the project,” and what the public learned about science in school.

Despite progress, Leshner, who has also served as deputy director and acting director of the National Institute of Mental Health and in several roles at the National Science Foundation, has never felt “as uneasy as I do now about the way the public relates to science. They seem ambivalent, indifferent,

for example, that when one scientist is found guilty of conflict of interest, it tarnishes the reputation of thousands of other scientists. Even though these are rare events, the “effect is incredibly pervasive.”

Another reason for mistrust is when scientific findings contradict a group’s core values.

“People don’t make decisions based on science. They bring science into the context of their own goals, knowledge, values and beliefs,” Leshner said. Researchers and the public may have different opinions.



“People don’t make decisions based on science. They bring science into the context of their own goals, knowledge, values and beliefs.”

—DR. ALAN LESHNER



or, in some cases, hostile to much of science.” Over the past few decades, polls suggest certain demographic segments have lost trust in science.

Certain events, such as scientific misconduct, can damage that trust. He said,

To rebuild trust, he advised scientists to engage with the public at every level by talking with them, not at them.

Engaging the public effectively requires one to think about context—What does the public need to know in order for them to understand the finding? Who is the scientist speaking to and what do they care about? What is the scientist trying to accomplish? Is a scientist, for instance, trying to explain a topic, make an argument or tell a story? These considerations will shape the communication strategy.

Some of the best communicators use images and graphics, he said. Recently, NASA ran a “pretty picture” to illustrate what happens when two neutron stars collide. Without that photo, the collision is just a “theoretical concept” and “you need a whole lot of background to get it.”



A question posed by audience member Dr. Jack Stein of NIDA earns a response from Leshner (below, l) that cracks up the crowd.

PHOTOS: CHIA-CHI CHARLIE CHANG

Leshner weaves narratives into his scientific talks. He believes stories are the most effective way to communicate science.

“A lot of what we do feels esoteric and is difficult to bring into a personal context. Often, we can do that by talking about the story of discovery. And then people go, ‘Aha, that’s interesting,’” he said.

Leshner avoids hyperbole, which can “damage the credibility of science.” He’s also learned to speak in soundbites. He once told a reporter that ““addiction is a brain disease, expressed in behavioral ways and in a social context.” However, the only thing people ever heard was “addiction is a brain disease, because they don’t hear the clauses or caveats.”

Although communicating science is difficult, Leshner said the public must be involved in shaping the research agenda. During his time as NIDA director, he gave talks around the country. At the end of one event, a woman asked him what the difference is between the effect of a drug on a young child’s brain versus an older child’s brain. That question started a research program on the neurological differences between younger and older adolescents.

“NIH has done a great job, I think—better than some other federal agencies—at getting the word out about what it’s discovered. But we need it, and we need a lot more of it,” Leshner concluded. “This stuff that NIH does is fabulous and has tremendous implications and impacts on people.” **R**





At NINDS's recent forum (from l) Lauren Dunlap of the Advocacy & Awareness for Immune Disorders Association discusses her poster with NINDS director Dr. Walter Koroshetz; Janet Hieshetter of the Dystonia Medical Research Foundation leads the "Maximizing Impact in a Tough Budget Era" discussion; and Dr. Margie Frazier of the Batten Disease Support and Research Association shares a success story.

PHOTOS: DANIEL SOÑE

NINDS Nonprofit Forum Explores Progress Through Partnership

BY SHANNON E. GARNETT

NINDS recently held its 11th "Progress Through Partnership" nonprofit forum bringing together more than 130 participants—including representatives from 63 patient advocacy groups from around the country—to learn about NINDS research and funding, network with each other and interact with program staff.

"The purpose of the meeting is two-fold," said NINDS director Dr. Walter Koroshetz. "First, to listen to the nonprofit organizations and get their input and feedback, and second, to inform them about what we are doing here at NINDS and where their tax dollars go."

New this year was a pre-forum orientation session for first-time attendees that featured a primer on NINDS research priority-setting, decision-making and NIH basics given by Dr. David Owens of the Division of Extramural Activities and Dr. Ernie Lyons of the Scientific Review Branch. Also on the bill was "A Day in the Life of a Program Director," by Dr. Jill Morris of the Neurogenetics Cluster.

The forum featured discussions on patient-driven research, access to new drugs for rare neurological disorders, continuity of care and issues and challenges in functional endpoints and neurological scales, which focused on Food and Drug Administration guidance for neurological clinical trials.

"There is no other area I can think of besides neurology that is so rich with opportunities but so devoid of beneficial therapies," said panelist Dr. Billy Dunn of FDA's Center for Drug Evaluation and

Research, describing how difficult neurological disorders are to treat. "To be an effective drug, we [at FDA] evaluate how it makes the patient feel, function and survive."

Throughout the 2-day meeting, nonprofit representatives shared lessons as well as success stories, which ranged from discovering new treatments to achieving therapy readiness.

Dr. Anne Pariser of NCATS and Ron Bartek of the Freidreich's Ataxia Research Alliance led a presentation on the new, web-based NCATS Toolkit for Patient-Focused Therapy Development. The toolkit, which debuted in September, was created as a one-stop resource to guide patient groups through the therapy development process.

"Patient involvement is critical and necessary at every stage of rare diseases research and therapy development," Pariser said.

Eric Dishman, director of the All of Us Research Program, provided an in-depth look at NIH's newest research initiative. All of Us is an effort to gather data from 1 million or more people living in the United States to accelerate research and improve health.

"I became a patient advocate because patient advocates helped me understand what was happening to me," said Dishman, a 23-year kidney cancer survivor. "At the heart of the All of Us Research Program is a participant-centeredness that undergirds all that we do."

During the meeting, nonprofit representatives also informally met with NINDS program staff and attended a session featuring 25 posters on key nonprofit initiatives involving the institute.

Forum Session Emphasizes Importance of Continuity of Care

Continuity of Care—one of the many patient-centered topics presented during NINDS's nonprofit forum—explored transitional care, which is the process beginning in early adolescence to prepare children with chronic illness and their families for adult care.

"From the perspective of the young adult, it is a challenge to shift from a long-standing family-based medical relationship to what can be an alien adult

medical system that is individual-based, often narrowly focused and with fewer supports like social workers, therapists or special education resources," said Dr. Lawrence Brown of Children's Hospital of Philadelphia (CHOP).

Brown focused on the neurologist's role in transition. He discussed barriers to as well as core elements of good health care transition.

"Little attention was ever directed on what we as pediatric specialists and primary care providers could do to ensure that all youth—especially those with special health care needs—would reach their full potential in terms of

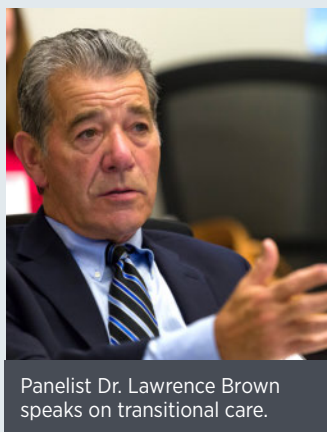
knowledge of their medical condition, ability to manage their condition and enjoy the best quality of life," he said. "Only in recent years has transition been understood as a process that takes many years of preparation."

Ten years ago, Brown started a program to help families whose children with Lennox Gastaut syndrome, a severe form of epilepsy, were aging out of CHOP. The program grew to include all adolescents and youth with neurological disorders and became a national project later adopted by the Child Neurology Foundation (CNF).

After organizing a consensus panel that published transition guidelines for youth with neurological disorders, CNF looked for ways to integrate the process into daily practice and to help adolescents understand the importance of preparing for adulthood. This led them to develop resources for neurologists on the CNF web site, projects to incorporate transition into the electronic medical record and a comic book titled *Understanding Transitional Care in Epilepsy*.

Programs like CHOP's are being developed throughout the United States and Canada, but creating a standard plan remains a challenge.

"Clearly, there is no one size fits all," Brown concluded. "The needs within neurology are as variable as those across other specialties. For example, transition preparation for a youth with Duchenne dystrophy is very different than for one with tuberous sclerosis, and what is needed for sickle cell disease is different than for cystic fibrosis."



Panelist Dr. Lawrence Brown speaks on transitional care.

Study Shows How Memories Ripple Through the Brain

Using an innovative “NeuroGrid” technology, scientists showed that sleep boosts communication between two brain regions whose connection is critical for the formation of memories. The work, published in *Science*, was partially funded by the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative.

“Using new technologies advanced by the BRAIN Initiative, these researchers made a fundamental discovery about how the brain creates and stores new memories,” said Dr. Nick Langhals, program director at the National Institute of Neurological Disorders and Stroke.



IMAGE: MAXIPHOTO/ISTOCK

A brain structure called the hippocampus is widely thought to turn new information into permanent memories while we sleep. Previous work by the new study’s senior author, New York University School of Medicine professor Dr. György Buzsáki, revealed high-frequency bursts of neural firing called ripples in the hippocampus during sleep and suggested they play a role in memory storage. The current study confirmed the presence of ripples in the hippocampus during sleep and found them in certain parts of the association neocortex, an area on the brain’s surface involved in processing complex sensory information.

“When we first observed this, we thought it was incorrect because it had never been observed before,” said Dr. Dion Khodagholy, the study’s co-first author and assistant professor at Columbia University.

Using a cutting-edge NeuroGrid system they invented, along with recording electrodes placed deeper into the brain, the researchers examined activity in several parts of rats’ brains during non-rapid eye movement (NREM) sleep, the longest stage of sleep. Their NeuroGrid consists of a collection of tiny electrodes linked together like the threads of a blanket, which is then laid across an area of the brain so that each electrode can continuously monitor the activity of a different set of neurons.

“This particular device allows us to look at multiple areas of the brain at the same time,” said Dr. Jennifer Gelinas, the study’s co-first author and assistant professor at Columbia.

The team was also surprised to find that the ripples in the association neocortex and hippocampus occurred at the same time, suggesting the two regions were communicating as the rats slept. Because the association neocortex is thought to be a storage location for memories,

the researchers theorized that this neural dialogue could help the brain retain information.

To test that idea, they examined brain activity during NREM sleep in rats trained to locate rewards in a maze and in rats that explored the maze in a random fashion. In the latter group of animals, the ripples in the hippocampus and cortex were no more synchronized before exploring the maze than afterwards. In the trained rats, the learning task increased the cross-talk between those areas, and a second training session boosted it even more, further suggesting that such communication is important for the creation and storage of memories.

The group hopes to use the NeuroGrid in people undergoing brain surgery for other reasons to determine if the same ripples occur in the human brain. The researchers also plan to investigate if manipulating that neural firing in animals can boost or suppress memory formation in order to confirm that ripples are important for that process.

“Identifying the specific neural patterns that go along with memory formation provides a way to better understand memory and potentially even address disorders of memory,” said Gelinas.

New Targets Revealed for Anti-Malaria Drugs

The deadliest malaria parasite needs two proteins to infect red blood cells and exit the cells after it multiplies, a finding that may provide researchers with potential new targets for drug development, according to researchers funded by NIH. Their study appeared in *Science*.

Plasmodium falciparum, the species of parasite that causes the most malaria deaths worldwide, has developed drug-resistance in five countries in Southeast Asia.

In the current study, researchers sought to uncover the role of plasmepsins IX and X, two of the 10 types of plasmepsin proteins produced by *P. falciparum* for metabolic and other processes. They created malaria parasites that lacked plasmepsin IX or X under experimental conditions and compared them to those that had the two proteins.

The team found plasmepsin IX in rhoptries, specialized cell structures inside the parasite that help it invade red blood cells. Parasites lacking plasmepsin IX had defective rhoptries. In addition, the team observed plasmepsin X in exonemes—small vesicles (balloon-like structures) that help malaria parasites exit infected cells. The team also discovered that plasmepsin X processes an important protein called SUB1. When deprived of plasmepsin X, the parasites couldn’t process SUB1 and couldn’t infect red blood cells or exit these cells after multiplying.

The researchers also identified three experimental malaria drugs that may work by targeting plasmepsin X. One drug, called CWHM-117, has already been tested in a mouse model of malaria. The new

findings may help researchers modify CWHM-117 to make it more effective. Furthermore, parasites lacking the plasmepsins could potentially be used to screen candidate drugs to identify additional anti-malaria compounds.

Study Identifies Brain Patterns Underlying Moms’ Responses to Infant Cries

Infant cries activate specific brain regions related to movement and speech, according to an NIH study of mothers in 11 countries. The findings, led by researchers at NICHD, identify behaviors and underlying brain activities that are consistent among mothers from different cultures. Understanding these reactions may help in identifying and treating caregivers at risk for child maltreatment and other problematic behaviors.

The study team conducted a series of behavioral and brain imaging studies using functional magnetic resonance imaging (fMRI). In a group of 684 new mothers in Argentina, Belgium, Brazil, Cameroon, France, Israel, Italy, Japan, Kenya, South Korea and the United States, researchers observed and recorded 1 hour of interaction between the mothers and their 5-month-old babies at home. The team analyzed whether mothers responded to their baby’s cries by



IMAGE: NIDERLANDER/ISTOCK

showing affection, distracting, nurturing (like feeding or diapering), picking up and holding or talking. Regardless of which country they came from, mothers were likely to pick up and hold or talk to their crying infant.

Through fMRI studies of other groups of women, the team found that infant cries activated similar brain regions in new and experienced mothers: the supplementary motor area, which is associated with the intention to move and speak; the inferior frontal regions, which are involved in the production of speech; and the superior temporal regions that are linked to sound processing.

Overall, the findings suggest that mothers’ responses to infant cries are hard-wired and generalizable across cultures. The study also builds upon earlier work showing that women’s and men’s brains respond differently to infant cries.

After 20 Years, Edmonds Retires from NIGMS

BY CHRIS PALMER

Dr. Charles G. Edmonds retired from his position as program director in NIGMS's Division of Cell Biology and Biophysics recently, putting a cap on a remarkable globe-trotting, highly interdisciplinary career.



At NIH and beyond, Edmonds is well-regarded for his scientific and administrative contributions in biochemical analysis and structural biology. He is a card-carrying mass spectrometrists and an enthusiastic supporter of what he calls "gizmotronics," the development of new instruments, methods and technologies to solve biological problems.

Edmonds grew up in the Midwest and received his B.S. from the University of Missouri. Military service as a medical laboratory specialist interrupted his graduate studies, but following his service, Edmonds resumed graduate work in Glasgow, Scotland. There, he developed study methods for human steroids and sterol natural products; met his wife, Valerie; and took up the sport of climbing.

He returned to the U.S. to postdoctoral work in geochemistry and renewable energy at UC Berkeley. He then studied natural products from Amazonian plants and animals as an employee of the National Research Council of Brazil. Later, during a second postdoc at the University of Utah, he contributed to the discovery of novel modified nucleotides in transfer RNAs and the development of new methods of mass spectrometry analysis, while pursuing skiing and mountaineering.

Before joining NIH in 1997, Edmonds was a program director with the office of biological and medical research at the Department of Energy and, prior to that, a senior staff scientist at Battelle Pacific Northwest National Laboratory, where he studied how radiation and chemical damage can modify nucleic acids and proteins in cells.

Edmonds played a significant role in the NIGMS program of structural genomics and other trans-NIH initiatives. He was responsible for overseeing the NIGMS (joint with NCI) investment in the GM/CA synchrotron beamline for structural biology at Argonne National Laboratory, which has become one of the most valuable resources for X-ray diffraction studies of molecular structure.

Edmonds frequently organized workshops to share knowledge of the enabling technologies for protein production, crystallization and structure determination. He handled a large portfolio of research grants and showed exceptional initiative in utilizing the SBIR/STTR grant mechanisms to promote innovative science.

Among the many things Edmonds said he will

miss about working at NIH is his "ringside seat for world-class science." He added, "I will also miss my opportunity to interact with the physicians, scientists and engineers supported by NIGMS. I admire and envy them (mostly) and get a vicarious reward from their success."

While at NIGMS, Edmonds pursued his interest in public health, obtained a graduate certificate therein and served on details to Kenya and to the public health laboratory division in the D.C. department of forensic sciences. "I understand and endorse the argument that basic science is necessary to eventually have something to translate into improved diagnosis, treatment and prevention of disease, but I have admired and envied my colleagues in the categorical institutes and elsewhere who are on or near the field of battle," said Edmonds.

"Charles has had an exceptionally interesting life, full of adventure and challenge," said Dr. Peter Preusch, acting director of the Cell Biology and Biophysics Division, NIGMS. "He has been a terrific colleague and friend who will be difficult to replace."

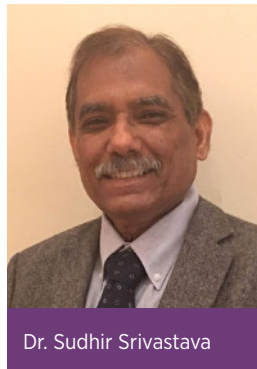
Edmonds is known for a wry wit that reflects his time in the U.K. and his classical education. His colleagues at NIGMS and throughout NIH will miss him. In recent years, he has taken up sailing. Colleagues wish him well as he and Valerie sail off into retirement together.

NCI's Srivastava Wins Proteomics Award

Dr. Sudhir Srivastava, chief of the cancer biomarkers research group, NCI Division of Cancer Prevention, was honored by the Human Proteome Organization (HUPO) with the 2017 Clinical and Translational Proteomics Award Sept. 20 at the group's annual World Congress in Dublin, Ireland.

The group named Srivastava "a visionary and proactive leader who has worked with HUPO since its inception." They cited his "tremendous commitment and leadership" to the NCI Early Detection Research Network, which he has headed from its start in 2000, and which focuses on the discovery and validation of proteomics, genomic, metabolomics, epigenomic and other "omic" markers of cancer detection and prognosis.

In the field of proteomic biomarkers, translational research bridges the gap between basic research discoveries that identify biomolecules involved in or are the result of carcinogenesis and the clinical application of these discoveries.



Dr. Sudhir Srivastava



NIAMS director Dr. Stephen Katz (c) and deputy director Dr. Robert Carter (r) welcome new members to the institute's council. They are (from l) Dr. Michael Yaszemski, Dr. Judith James, Rosemary Markoff and Dr. Michael Econs.

Four Named to NIAMS Advisory Council

Four new members recently joined the National Arthritis and Musculoskeletal and Skin Diseases Advisory Council.

Dr. Michael J. Econs is the Glenn W. Irwin, Jr. professor of endocrinology and metabolism and chief of the division of endocrinology and metabolism at Indiana University School of Medicine. His primary area of research is in the genetic aspects of metabolic bone diseases.

Dr. Judith A. James is vice president of clinical affairs and chair of the arthritis and clinical immunology research program at the Oklahoma Medical Research Foundation. Her research aims to understand the etiology and pathogenic mechanisms of systemic autoimmune, rheumatic diseases, with a special interest in minority groups.

Dr. Michael J. Yaszemski is professor of orthopaedics and bioengineering and director of the tissue engineering and biomaterials laboratory at the Mayo Clinic. His research focuses on the development of biodegradable scaffold polymers to support bone and spinal cord regeneration using tissue engineering strategies.

Rosemary J. Markoff began her career in accounting until a diagnosis of scleroderma led her down a path toward patient advocacy and disease awareness. She became actively involved in the Scleroderma Foundation and has served in numerous leadership roles over the last 15 years.



Fierce competition. NICHD director Dr. Diana Bianchi (l) defends against Joyce Backus of NLM. At center, enforcing “Brooklyn rules,” NIH principal deputy director Dr. Lawrence Tabak serves as referee before an enthusiastic crowd. At right, former NBA star Walt Williams (second from l) and NINDS director Dr. Walter Koroshetz (kneeling) congratulate the victorious Code Red team that included (from l) NIAID director Dr. Anthony Fauci, NEI’s Dustin Hays and Backus.

PHOTOS: MARLEEN VAN DEN NESTE

CFC SLAM DUNK

IC Directors Play Hoops for a Cause

Eight teams that included NIH institute directors vied for the gold at the CFC Directors’ Basketball Challenge Oct. 26 on the Clinical Center’s outdoor court. The event helped launch the Combined Federal Campaign fund-raising drive.

“I’ve seen these guys warm up and you’re gonna get a real treat today,” said University of Maryland basketball legend and former NBA pro Walt Williams, who served as coach and co-emcee.

Every shot earned a point. The first 3-person team to reach 7 points, or whoever led when the 4-minute clock ran out, would win the game. “I anticipate us going to 4 minutes every time,” quipped Williams. The tourney then got under way amid much cheering and laughter from a crowd that had assembled not only courtside but also along a rampart overlooking the court.

Although the hoop was set at 8 instead of 10 feet, the first round began with quite a few air balls



NIMHD director Dr. Eliseo Pérez-Stable (l) finds a way around the defense of Hays.

and attempted layups. Then, NINDS director and CFC co-chair Dr. Walter Koroshetz scored the first basket of the day and made his free throw to break the tie when the clock ran out.

In every round, referee Dr. Lawrence Tabak, NIH principal deputy director, didn’t miss a travel call, blocking violation or foul. Not shy with his whistle, Tabak enforced “Brooklyn rules” for 3-on-3 games,

a few rules on possession, passing and fouling, including “no blood, no foul.”

“After a score, the other team gets the ball,” explained Koroshetz, who along with Tabak and NIAID director Dr. Anthony Fauci, hails from Brooklyn. “The original notes for the CFC had the ball going to the team that scored [also known as “make it, take it” or “winners”] but Dr. Fauci noticed this was incorrect and we changed it.”

Team Code Red had a slight advantage thanks to 6’8” teammate Dustin Hays, NEI’s chief of science communications. Fauci and Joyce Backus, NLM associate director for library operations, had many assists but they left most of the scoring to Hays. In the end, Code Red won the gold.

“This is how the directors demonstrate their support for the CFC in a fun way,” said OD’s Christine Brake, a member of the CFC steering committee. “This event takes them out of their normal business day to do something personal and highlight the campaign.”

For more information about donating to the CFC, visit <https://cfc.nih.gov/donate.html>.—Dana Talesnik

CFC Halloween Sights & Frights

NIH’ers leaped into the Halloween spirit on Oct. 31, as the CFC held its annual costume party on the Bldg. 31 patio. Getups ranged from clever to comedic, menacing to mystifying. Below, we recognized Three Little Pigs (l) and a social (media) butterfly (r). To see more images, visit <https://cfc.nih.gov/index.html>.

