Brain Stethoscope
New Device Listens to Brain, May Help Epileptic Patients
By Dana Talesnik

It was a harmonious pairing. A neurologist and a composer/music researcher teamed up to hear the rhythms of the brain. Their invention, currently in testing, might help diagnose seizures earlier to foster earlier intervention and prevent permanent brain damage.

It all began when Dr. Josef Parvizi, associate professor of neurology and neurological sciences at Stanford University, was enjoying a concert of cosmic sounds: the Kronos Quartet had converted radio waves from outer space into music. He wondered: can we record brain waves as music? So Parvizi contacted Dr. Chris Chafe, director of Stanford’s Center for Computer Research in Music and Acoustics (CCRMA), to find out.

Parvizi and Chafe presented their research at the NIMH Director’s Innovation Speaker Series recently. After years of collaboration, they have

NIH’ers Leave Cars At Home for Bike To Work Day
By Eric Bock

Some NIH’ers actually enjoy their commute. And on May 15, hundreds of bike riders convened at 3 NIH-affiliated “pit stops” to celebrate Bike to Work Day.

A total of 617 cyclists registered for NIH’sobservance of BTWD. At the pit stop in front of Bldg. 1, 338 registrants could pick up snacks, a free T-shirt, enter a raffle and maybe learn a new shortcut or two from a fellow rider. The NIH Bicycle Commuter Club (NIHBCC) organized the annual event.

The other two NIH-affiliated BTWD pit stops were Rockledge Drive at Rock Springs Business Park and Fallsgrove Village Center, near NCI-
**Akil To Give Director's Lecture, June 10**

Dr. Huda Akil, who has made groundbreaking contributions to the understanding of the brain biology of emotions—including pain, anxiety, depression and substance abuse—will deliver an NIH Director’s Lecture titled “The Depressed Brain: Sobering and Hopeful Lessons,” on Wednesday, June 10 at 3 p.m. in Masur Auditorium, Bldg. 10.

Akil is the Gardner Quarton distinguished university professor of neuroscience and psychiatry and co-director of the Molecular and Behavioral Neuroscience Institute at the University of Michigan.

She and her collaborators provided the first physiological evidence for the role of endorphins in the brain and showed that they are activated by stress and inhibit pain. In her current research, she investigates the genetic, molecular and neural mechanisms underlying stress, addiction and mood disorders. She is the Michigan site director of the Pritzker Consortium, which is engaged in large-scale studies to discover new genes and proteins that cause vulnerability to major depression and bipolar illness.

Akil is a member of the Institute of Medicine of the National Academies, the American Academy of Arts and Sciences and the National Academy of Sciences. She is past president of the Society for Neuroscience and serves on numerous boards and scientific councils as well as on organizations that promote scientific and brain health awareness nationally and globally. She is also a member of the advisory committee to the NIH director.

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

**ORS Salutes Safety Award Winners**

The NIH Mission First Alway,s Safety Always award, now in its third year, recently recognized two scientists who have demonstrated leadership, innovation and involvement in their organization’s safety culture. The award—offered by the Division of Occupational Health and Safety (DOHS), ORS—salutes professionals who make a difference in safety.

Dr. Kevin Holmes, chief of the flow cytometry section in NIAID’s Research Technologies Branch, developed new guidance for working safely when performing flow cytometry procedures. His paper “Characterization of aerosols produced by cell sorters and evaluation of containment” (Holmes, 2011) and the “Standard practice for cell sorting in a BSL-3 facility” (Perfetto, et al., 2011) gained worldwide recognition as the safety standards to be used during the cell-sorting process.

Holmes subsequently co-chaired a task force at NIH to develop the NIH Biosafety Policy for Cell Sorters, which was approved in 2012. It established standards for the installation and operation of cell-sorting facilities in NIH intramural laboratories. Holmes also serves as chair of the NIH occupational health and safety committee.

Dr. Kevin Conner of NCI’s Genetics Branch has been proactive in writing standards of procedures for the biosafety manuals in her institute. She was the first researcher at NCI to have her biosafety manual completed and reviewed by DOHS. By sharing her methods and knowledge, Conner helped other labs in the institute stay in compliance with local, state and federal safety requirements by posting a lab-specific biosafety manual in their labs.

Recently, there was a low oxygen level alarm in the freezer farm area of Bldg. 37. Conner was one of a group of individuals who helped keep others safe by restricting access to the area. After the incident, she and others developed signs to instruct people about response to this hazard if it re-occurs.

**Children’s Inn 25th Anniversary Symposium**

The event “At the Intersection of Hope and Science: The Children’s Inn 25th Anniversary Symposium” will be held Thursday, June 18 from 2 to 5 p.m. in Masur Auditorium, Bldg. 10.

It will highlight the history of the inn, especially the role it has played in advancing medical research by providing a free “place like home” for pediatric patients and their families. NIH physicians and families will share their stories and the scientific advances that have been made in the treatment of their diseases. Featured speakers include NIH director Dr. Francis Collins and Clinical Center director Dr. John Gallin.

To register, visit http://conta.cc/1S2kfrS. To watch the symposium online, visit http://videocast.nih.gov.
Summit Explores Creative Arts as Healing Aids in Military

By Ellen O’Donnell

Creative arts therapies are showing promise in clinical settings to help military service members and veterans in healing and health. However, more well designed, rigorous research studies are needed to inform health practices and health care policies. This was a key theme of the recent “Third National Summit: Advancing Research in the Arts for Health and Well-Being Across the Military Continuum” at Natcher Bldg.

NCCIH joined Americans for the Arts, a non-profit organization, and the National Endowment for the Arts to host the summit as part of the National Initiative for Arts and Health in the Military. The initiative is a collaborative effort across the military, government, private and nonprofit sectors to advance the arts and creativity for the benefit of military health.

Researchers, health care providers, creative arts therapists, practicing artists and other attendees learned about cutting-edge research projects and clinical programs, made recommendations for future research and explored potential partnerships.

Dr. Emmeline Edwards, director of the NCCIH Division of Extramural Research, chaired the summit’s scientific planning and one of its symposia. She said, “Non-drug complementary and integrative approaches, including through the arts, are desperately needed to help manage the very complex problems of pain and other symptoms in our service members and veterans and to address problems related to the chronic use of opioids.

“Chronic pain in military service members and veterans is often accompanied by other conditions, including traumatic brain injury, post-traumatic stress, depression and sleep issues. This situation creates very tough challenges,” she added. “At the summit, it was exciting to hear about programs that are already providing much-needed relief to our military populations and their families and to see momentum build and promising directions identified for building the evidence base.”

One speaker, Dr. Donald McGeary, is an NCCIH grantee and assistant professor of psychiatry at the School of Medicine at the University of Texas Health Science Center. His team is evaluating the effectiveness of an integrative pain-management program for combat-injured veterans with multiple traumatic injuries. The hope is to improve participants’ physical function, reduce disability and decrease chronic opioid use. His program, which is being compared to usual care, includes relaxation, biofeedback, guided exercise, imagery, mindfulness meditation and cognitive-behavioral therapies.

McGeary said, “Art and music have been a part of military life for thousands of years. Now research is exploring how they can be integrated into military research on pain, including complex pain accompanied by other trauma conditions. I believe that a complex phenomenon requires a complex intervention—as simple interventions can fail or create additional problems—and that we should emphasize rehabilitation over pain relief for these patients.”

Family Observes ‘Waddle to Work Day’

We didn’t make a fuss about it here at the NIH Record, but Thursday, May 21 was Waddle to Work Day. This lovely family showed discipline and obedience on that morning as they marched from a bivouac on the lawn of Bldg. 1 toward the day’s pasturage. Clearly, they were observing Take Your Child to Eat Day as well.

Question: Which gosling is named Ryan?

Photo: Rich McManus
invented a prototype—the brain stethoscope—that sonifies brain waves. They’re testing this device on seizure patients in the hospital; there’s potential for the portable, simple-to-use gadget to help anyone detect neurological danger, even in non-medical settings such as in the car, at work or at home.

The brain stethoscope uses a patented algorithm that allows slow signals from the brain to be converted to sounds in real time. This process of data sonification and frequency modulation builds on the earlier research of Dr. John Chowning, a pioneer in computer music and founding director of CCRMA. Chafe’s work has effectively created the first sonified seizure.

“It’s so important to have art and artistic activity in an institution that is known to be a home for great engineers,” said Parvizi. “This interdisciplinary work we did took us outside the range of comfort of medical practice and music and created a platform for an innovative way of diagnosing brain conditions.”

Heeding the Warnings of Epilepsy

More than 2 million Americans suffer from epilepsy, a condition characterized by recurring seizures. If untreated, prolonged seizures can cause cognition problems, brain damage, even death.

Many seizures go undetected because most patients don’t exhibit behavioral signs until the seizure becomes severe, said Parvizi. In a condition known as non-convulsive status epilepticus, the brain stethoscope can be especially effective as an early diagnosis device.

In fact, many ongoing seizures even go undetected in the hospital. It can take hours for a technician to arrive, glue on electrodes and record an EEG (electroencephalogram). Then the results must be interpreted by a trained neurologist, said Parvizi. What’s more, it’s costly to have trained technicians and electrophysiologists on staff; many hospitals don’t have EEG machines.

The brain stethoscope incorporates electrode design, microelectronics and sonification bundled into a small, inexpensive device that’s attached to the head. Said Parvizi, “The brain is acting very differently [during seizure] and causes altered mental status, but you need a device where you can hear the tone” for earlier diagnosis.

Parvizi showed a video of an epileptic patient during a seizure. In the early stages, the patient was able to repeat words read to her. Without EEG, we wouldn’t know from her normal behavior that she was having a seizure. But as the seizure progressed, she stopped the task and became increasingly confused and uncommunicative. Chafe played an audio clip of the patient’s EEG during the word-repetition task.

Listening in on the Brain

In the audio clip, we hear a stable tone that soon starts to waver; the sound gets increasingly rapid and eventually becomes frantic. As the seizure migrates from one side of the brain to the other, the device switches to a male voice, representing the other, now dominant hemisphere. “You can hear the rhythms of the seizure, also the magnitude of the signals and the loudness and modulated qualities,” said Chafe. “These are all acoustic parameters being driven by, or performed by, the seizure and it’s something we can do in real time.”

The brain stethoscope instantly recodes brain waves; it takes less than 10 seconds to determine if the patient is in seizure. Computer chips record electrical wave forms from the patient’s head and use Chafe’s algorithms to turn brain signals into sound, complete with voice pitch inflections. The process relates back to Chowning’s method of taking a stable, flat tone that increases in vibrato as it modulates.

As the seizure progresses, the tones become increasingly discordant. Parvizi said, “These are not the most pleasant sounds and we want them to stay unpleasant because we want them to signal danger to someone recording them.”

An Opus of Hope: Potential and Future Applications

The brain stethoscope acts like a cardiac stethoscope. Anyone can use it, even with no medical training. In a recent survey among untrained high school students using the device, there was a near 90 percent accuracy rate in detecting normal vs. abnormal sounds.

The average person can listen to the brain waves of a spouse or child or infant, or even one’s own brain waves, and hear when something’s starting to go awry. The device is cheap to produce and has the potential to help patients in hospitals and doctor’s offices, in homes, schools and offices, as well as in facilities in poorer countries.

“We are really looking forward to a future where this device sees the light of day and becomes available to anyone, anywhere,” said Parvizi.

There may also be additional medical applications including detecting early signs of stroke, abnormal heart rhythms, sleep patterns and psychological disorders.

Though Parvizi and Chafe come from two different disciplines, their combined expertise has created a revolutionary biofeedback tool. “This is an example of how this type of collegiality and collaboration and going outside of the box can lead to a new, innovative way of thinking,” said Parvizi. “Hopefully this will save a lot of lives in the future.”

Drs. Chris Chafe (l) and Josef Parvizi of Stanford are collaborating on what amounts to a “brain stethoscope.”

PHOTO: ERNIE BRANSON

BRAIN MUSIC
CONTINUED FROM PAGE 1
NIH Police Host Cookout for Employees

By Eric Bock

NIH’s bravest protect campus so that employees can safely further NIH’s mission. They also know their way around a charcoal grill.

On May 12, the NIH Police hosted the 21st annual Police Awareness Day on the lawn in front of Bldg. 1. Representatives from several units within the department and from surrounding law enforcement agencies were on hand to talk to staff about their roles, let spectators look at their equipment and, of course, grill lunch for employees.

In addition to a barbecue lunch, the event also included visitor tables for the Montgomery County police and sheriff’s departments, the Maryland-National Capital Park and Planning Commission Police and the NIH Fire Department. A simulated shooting range offered participants a chance to see how they would handle life or death encounters.

“We look forward to this day every year,” said Police Chief Alvin D. Hinton. “It gives us the opportunity to develop a greater rapport with the NIH community outside of our normal duties.”

The NIH Police department is a full-service department, which means it offers the same services that a local police department does. NIH police can, for example, issue traffic and parking citations, patrol campus, investigate crime, detain citizens who have an arrest warrant or respond to reports of an active shooter.

“There are roughly 30,000 people on campus each day,” said Sgt. Clyde Bartz of the special response team. “NIH has a larger population than most small cities. Any offense that happens outside can happen inside. We work 24 hours a day, 7 days a week—holidays included—to keep everyone safe.”

Bartz said that his team is trained to respond to high-risk situations on campus. His unit is equivalent to a local department’s SWAT team. His team can be identified by their olive green uniforms. They undergo extensive training alongside federal, state and local law enforcement agencies. He added that the team also trains closely with the NIH Fire Department. If needed, the team can respond to emergencies involving hazardous materials.

“We’re highly trained professionals. If a call goes out, we can be there almost immediately,” Bartz said. “When seconds count, we can’t be waiting for an outside police department to arrive.”

Later, K-9 unit handlers Cpls. Wallace Carter and Steve Cradlin gave a brief demonstration of how their dogs find explosives. There are 10 other NIH canine teams assigned to the Bethesda area. Each unit is trained to detect either explosives or drugs.

Police Awareness Day is part of National Police Week, which honors police officers killed in the line of duty. In 1962, President John F. Kennedy proclaimed May 15 as National Peace Officers Memorial Day.

Hard-to-Treat Depressive Symptoms?

This inpatient research study is assessing the effectiveness of the oral medication diazoxide (an enhancer of glutamate transporter function) versus placebo to rapidly improve hard-to-treat major depressive symptoms. The study enrolls eligible participants ages 18-65, who are diagnosed with major depressive disorder, have previously failed to respond to treatment and are free of other serious medical conditions. The study can last up to 12 weeks and is conducted at the Clinical Center. There is no cost to participate. For more information, visit www.nimh.nih.gov/labs-at-nimh/join-a-study/index.shtml, call 1-877-666-3644 (TTY 1-866-411-1010) or email moodresearch@mail.nih.gov. Refer to study 14-M-0041.
WEICKER
CONTINUED FROM PAGE 1

a real difference in our ability to understand the
disease and extend the lives of those it struck," 
Collins said. "Buildings come and buildings go,
but reputations—and sometimes, solidly built
historic buildings—actually endure; this one
does. So for all these reasons, the pairing of the
Lowell P. Weicker personality and impact on
history with Bldg. 4 is a very good fit."

The new dedication, Collins declared, transfers
"the Weicker name to one of NIH's oldest and
most distinguished buildings recently renovat-
ed to be made new again, Bldg. 4...one of six
original buildings on the NIH campus." It now
houses NIAID laboratories.

After thanking friends and supporters, the hon-
oree encouraged the audience to consider "your
roles for determining the priorities of the Unit-
ed States" and not to underestimate "the power
of one, as in you.

"My wish for this building," Weicker said, "is
that generations bring their skills, their talents
together in the interest of life."

'Dear Friend, Great Champion'

Earlier, Collins had reminded attendees that in
1940, President Franklin Roosevelt stood just a
few hundred yards away from the newly dubbed
Weicker Bldg. to establish NIH's new home, say-
ing, "In dedicating this institute, I dedicate it to
the underlying philosophy of public health, to
the conservation of life, to the wise use of the
vital resources of our nation)—words that apply
to Lowell Weicker as well as to NIH."

NIAID director Dr. Anthony Fauci, who has
known Weicker for more than 30 years, saluted
the man as "a dear friend and great champion of
biomedical research."

Recalling the early days of the HIV/AIDS pan-
demic when being diagnosed with the disor-
der was a virtual death sentence, Fauci put the
honoree’s NIH legacy in perspective: "Very few
politicians were courageous enough to support
the scientific and public health measures nec-
essary to address a newly recognized disease
that affected mostly the disenfranchised. Sen.
Weicker was one of the few and the brave. At
that time, the leadership on Capitol Hill was
desperately needed and Lowell provided it."

Weicker was one of the first senators to hold
congressional hearings on AIDS and led the call
in the Senate for funding to address the dis-
ease. "Lowell has been truly a unique, visionary
leader and a loyal friend to NIH," Fauci not-
ed. When Weicker served as chair of the Sen-
ate Labor-HHS appropriations subcommittee,
NIH's budget grew from $4.3 billion to $6.7
billion—56 percent—in just 5 years. "A sub-
stantial part of that increase jumpstarted our
research to better understand HIV/AIDS and to
develop the soon-to-be-tested life-saving treat-
ments," Fauci said. "And that's where Lowell
came in."

'Enlightening Way to Proceed'

In 1986, Weicker led the legislative charge to
seek $46 million to test the experimental drug
AZT and to provide it to 10,000 people dying
of AIDS. "At the time, this medicine was the
only glimmer of hope for many patients," Fauci
explained. He recalled Weicker saying, "'We are
confronted with an epidemic the likes of which
this world has never seen and we do not have
time to get into philosophical, academic or mor-
alistic debates. We'd better do exactly what we
have been told to do by those of science and
medicine, which is number one, put our money
into research and number two, put our money
into education.' As these words remind us, Low-
ell has always had a keen grasp of the importance of biomedical research and understanding how sustained investment in NIH ultimately leads to the development of therapy and vaccines for the diseases with important global health implications.”

Now, an AIDS-free generation is within the world’s sights, Fauci pointed out. “This would not have been possible without the political courage that Lowell Weicker demonstrated more than 25 years ago…Lowell’s keen intellect, bipartisanship, independence from political ideology, compassion and tenacity remain the hallmarks of his public service.”

A congressional colleague, former U.S. Sen. Tom Harkin (D-IA), reminisced about the way Senate appropriations hearings were conducted on the NIH budget in 1985 when Weicker was in charge.

Unlike House hearings, where the committee sat high on a rostrum facing testifiers below, with chairman Weicker “we all sat at the same level” around a big table, Harkin said. Each institute director would give a statement and “we’d engage in a kind of open discussion. I thought this was rather an unusual but enlightening way to proceed. It was just intellectually stimulating to engage in that kind of discussion...It was a great learning experience for me to learn about what was happening at NIH.”

‘Foresight & Inspiration’

Harkin also pointed out that Weicker “is a proud parent of the Americans with Disabilities Act and we owe him a great debt of gratitude... That’s why this recognition is timely: to honor a person who did not back down, who supported basic biomedical research through the years, through the thick and the thin, who gave courage to others to continue the fight for the public support of the National Institutes of Health and its mission. Thank you, Lowell Weicker, for your life of courage and foresight and inspiration.”

As the honoree took the podium to a standing ovation, he deflected personal praise in favor of assigning responsibility.

Progress in science, medicine and health happens “not because of buildings named after ex-politicians, but because of the people who reside in those buildings who are plodding along day after day,” said Weicker, “and because citizens participated in their government.”

Recalling the difficulties he and others met while ushering legislation for AZT funding through Congress—all while people were suffering without any real treatments—he said the course of action was clear. He challenged individuals to do likewise, to take active, crucial roles in deciding the direction government moves, based on obvious common principles such as the advance of science and good health for all.

Concluding, Weicker rephrased St. Paul’s oft-quoted observance to the Corinthians, “Faith, hope and love—these three, but the greatest of these is...hope.”

**Federal Employee Viewpoint Survey—There’s Still Time**

NIH employees still have one more week to share their feedback and help make NIH one of the federal government’s best places to work. The theme is “Employees Influencing Change,” and is an opportunity for federal employees to provide feedback on their level of engagement and satisfaction in areas such as work experience, work/life programs, leadership, diversity and inclusion.

In 2014, NIH’s scores improved over 2013, and were higher than government and HHS-wide scores in almost every performance category. NIH ranked 80th in the Partnership for Public Service’s Best Places to Work rankings though, so we still have opportunities for improvement. Help us make NIH an even more engaging and rewarding place to work by sharing your input on this year’s FEVS.

The Federal Employment Viewpoint Survey is easy and only takes about 25 minutes to complete; responses are confidential. HHS is striving to improve its participation rate, which was 46.4 percent in 2014 and 50 percent in 2013. Your input matters. Take a few minutes to share your perspective before June 12.

For questions about the FEVS, contact Evans Aine at ainee@od.nih.gov or Allison Kruszewski at kruszewskial@od.nih.gov.
Shady Grove in Rockville.

Among the riders who stopped in front of Bldg. 1 was NIH director Dr. Francis Collins. He pedaled in with his wife, Diane Baker, from their home in Chevy Chase.

“We are the National Institutes of Health. So it’s good that we actually think about health not only for the rest of the world, but also ourselves,” said Collins. “Riding your bike to work or riding your bike almost anywhere is a great way to do that.”

Collins added it’s important to eat right and exercise despite deadlines and busy schedules. He then urged occasional riders to bike to work more often.

“Make a practice of it. Do it every day,” he said. “I’ll be riding my bike most of this season. As long as it’s not pouring rain, I expect I’ll be rolling up here in the morning.”

After Collins spoke, Joe Cox, ORS’s chief of transportation services, presented Dr. Diane Bolton with the 4th annual Carl Henn Bicycling Advocacy Award. Henn, who passed away in 2010, was a co-founder and president of the NIHBCC and a dedicated environmentalist. The award is given to someone who exemplifies Henn’s values.

Bolton, now a researcher at Walter Reed Army Institute of Research’s U.S. Military HIV Research Program, advocated for bicycle commuters when she was a postdoctoral fellow at NIAID’s Vaccine Research Center. She worked closely with Cox during her time at NIH, providing him with a cyclist’s perspective on transportation issues that affect NIH.

“Diane came to State Highway Administration meetings with me and she organized BTWDs until last year. She energizes everyone around her,” said Cox. “One year, she broke her ankle the day before BTWD. She still worked the registration table.”

He noted that there are bike repair kits and tire pumps available at garage attendant booths and bike racks on campus because of Bolton. One day, she asked Cox if he could store kits and pumps on campus. He agreed. Now, any booth that has a kit and pump inside is marked with a blue sign showing a bike and wrench icon.

Some bikers have substantial commutes. Steve Bourque rides 20 miles from Washington, D.C., to Rockville every day—in rain, snow, sleet or shine.

Biking “is lots of fun,” said Bourque, a system administrator at NIAID. “It’s the best way to get to work.”

The longest commute of the day belonged to NICHD’s Rodney Rivera. His round-trip was 60 miles.

For NCI’s Don White, IT specialist, Bike to Work Day is just like any other day. That’s because he’s been riding a bike to work since 1959.

“I was going green before going green was popular,” he said.

He began biking to work when he was a lab technician at the University of Iowa Medical Research Center because it was affordable. When he arrived at NIH in 1975, he kept it up because “it’s economical, convenient, healthy and good exercise.”

Cpl. Brett Alexander of the NIH Police was on
hand to help employees register their bikes with the department. He said registering a bike makes it easier to identify and recover if a bike is lost or stolen.

BTWD was sponsored by the Office of Research Services, Division of Amenities and Transportation Services and the NIHBCC.

ORS’s Cox introduces Dr. Diane Bolton, recipient of the 4th annual Carl Henn Bicycling Advocacy Award.

IOM Panel Visits NIH for End-of-Life Briefing

The National Institute of Nursing Research recently hosted a briefing on the Institute of Medicine report Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.

NINR director Dr. Patricia Grady noted that end-of-life care is "a topic of great interest across the NIH and across the Department of Health and Human Services and it is reflected by the attendees at today’s meeting."

IOM committee co-chair and former U.S. comptroller general David M. Walker introduced the consensus report findings and themes. He was joined by co-chair Dr. Philip Pizzo of Stanford University School of Medicine, who highlighted the committee’s reasoning for each recommendation. In regard to honoring individual preferences and decisions, Pizzo said, “We were very clear in our work that while we were attentive to cost, we were putting quality first.” He stressed the importance of understanding "what people want...so that they could have the best quality of life and the best quality of death.”

The briefing also included remarks from IOM committee members Dr. James Tulsky, chief of Duke Palliative Care and professor of medicine and nursing at Duke University; Judith R. Peres, an independent consultant; Dr. Pamela Hinds of Children's National Medical Center; and Dr. Adrienne Stith Butler, the IOM study director.

Tulsky spoke on the importance of quality communication between clinicians and patients. “We’re not trying to drive people to a particular kind of care, we’re trying to drive them to the type of care that they want, need and deserve,” he said.

When discussing the social work aspects of palliative care, Peres noted that "we need to know the role of the interdisciplinary team, the role of the family caregiver and...meeting people’s spiritual needs at the end of life.” From a policy standpoint, she emphasized “the role of the integration of medical and social services” as “a critical component to getting people what they need near the end of life.”

Hinds observed, “This is our opportunity to prevent complications for families, when end-of-life care is not the best that can be offered in America. Americans die in many different locations. How can we bring the best of care to all of those locations?” Meanwhile, Butler was adamant about disseminating the report and sharing the committee’s findings with other scientists and health care providers.

After a Q&A session, Pizzo remarked that the questions were “profound and they require clarity from many different disciplines.” He also noted “it’s not typical to prioritize death over life in funding, and yet, if we don’t do that, we are doing a disservice to every single person in this room and every single person on the planet.”
Animals’ Presence May Ease Social Anxiety in Kids with Autism

When animals are present, children with autism spectrum disorders (ASDs) have lower readings on a device that detects anxiety and other forms of social arousal when interacting with their peers.

According to a study funded in part by NICHD, companion animals—such as dogs, cats or the guinea pigs in the study—may prove to be a useful addition to treatment programs designed to help children with ASDs improve their social skills and interactions with other people.

The study, published online in Developmental Psychobiology, was conducted by Dr. Marguerite O’Haire at the Center for the Human-Animal Bond in the College of Veterinary Medicine of Purdue University and colleagues at the University of Queensland in Brisbane, Australia.

"Previous studies suggest that in the presence of companion animals, children with autism spectrum disorders function better socially,” said Dr. James Griffin of NICHD. “This study provides physiological evidence that the proximity of animals eases the stress that children with autism may experience in social situations.”

Scientists Create Mice with a Major Genetic Cause of ALS, FTD

Scientists at Mayo Clinic, Jacksonville, Fla., have created a novel mouse that exhibits the symptoms and neurodegeneration associated with the most common genetic forms of frontotemporal dementia (FTD) and amyotrophic lateral sclerosis (ALS, Lou Gehrig’s disease), both of which are caused by a mutation in the gene called C9ORF72. The study was partially funded by NINDS and published in the journal Science.

“Our mouse model exhibits the pathologies and symptoms of ALS and FTD seen in patients with the C9ORF72 mutation,” said the study’s lead author, Dr. Leonard Petrucelli of Mayo Clinic. “These mice could greatly improve our understanding of ALS and FTD and hasten the development of effective treatments.”

More than 30,000 Americans live with ALS, which destroys nerves that control essential movements, including speaking, walking, breathing and swallowing. After Alzheimer’s disease, FTD is the most common form of early onset dementia. It is characterized by changes in personality, behavior and language due to loss of neurons in the brain’s frontal and temporal lobes. Patients with mutations in the chromosome 9 open reading frame 72 (C9ORF72) gene have all or some symptoms associated with both disorders.

“This is a significant advancement for the field,” said Dr. Margaret Sutherland of NINDS. “Scientists have been trying to create mice that accurately mimic the pathologies associated with these forms of ALS and FTD. This mouse model will be a valuable tool for developing therapies for these devastating disorders.”

Scientists report development of a new way to modify interleukin-2 (IL-2)—a substance known as a cytokine that plays key roles in regulating immune system responses—in order to fine-tune its actions. Harnessing the action of IL-2 in a controllable fashion is of clinical interest with potential benefit in a range of situations, including transplantation and autoimmune disease. The modified IL-2 molecules inhibited the actions of endogenous IL-2, potentially more effectively than existing agents, as well as inhibited the actions of another interleukin, IL-15, with additional therapeutic potential.

The research is published in the journal Immunity. The principal research teams include scientists from NHLBI, Stanford University and the Howard Hughes Medical Institute, with contributions from scientists at NCI and NIAID.

The scientists developed altered forms of IL-2 where activity can be tuned to either boost or block immune responses depending on the desired therapeutic application. In laboratory studies, treatment with one type of modified IL-2 prolonged survival in a mouse model of graft-versus-host disease and blocked the growth in vitro of T-cells from a patient with chronic/smoldering adult T-cell leukemia, a rare form of cancer, researchers note. A similar approach could potentially be used to engineer other immune-system cytokines to generate new molecules with therapeutic potential, the scientists say.
NCI’s Lowy Presents His Vision During Town Hall Meeting
By Viviane Callier

Following in the footsteps of former NCI director Dr. Harold Varmus, who retired Apr. 1 after holding the post for 5 years and also serving as NIH director from 1993-1999, would seem like a daunting challenge for any leader. But new NCI acting director Dr. Doug Lowy certainly appeared ready to assume the mantle during his first town hall meeting at NCI’s Shady Grove campus to share his vision and priorities for the coming year.

After noting the superb leadership of his predecessor, Lowy emphasized his intention to continue many of the initiatives created during Varmus’s tenure, including NCI’s Center for Global Health, the Center for Cancer Genomics, the Provocative Questions Initiative and the Outstanding Investigator Awards for extramural scientists.

He also stressed his own commitment to be an active acting director. Lowy said he was “especially enthusiastic” about the Precision Medicine Initiative (PMI) recently announced by President Obama. NCI has already launched some precision medicine trials, he noted, including the ALCHEMIST and Lung-MAP trials; the MATCH and Pediatric MATCH trials are forthcoming.

The PMI, he said, will continue the momentum toward the development of cancer therapies that are “based on a molecular pathology and a mechanistic understanding of disease so that we can try to give the right kind of treatment to the patients who have the most appropriate catalog of molecular abnormalities.” The PMI also includes a plan to develop better preclinical models to understand and combat resistance to cancer treatment and to create a "cancer data commons" to store and share molecular information about different cancers.

Moreover, Lowy said that he plans to bring NCI’s research activities in several areas into "sharper focus," including cancer prevention and screening, cancer health disparities research and support for basic research.

Having trained and worked at NIH since 1975, Lowy is no stranger to the federal research environment or to groundbreaking scientific achievements. His own research over the years has focused on molecular biology, virology and cancer pathogenesis. Last year, along with his long-time research partner Dr. John T. Schiller, Lowy was awarded the National Medal of Technology and Innovation by President Obama for work that led to the development of human papillomavirus (HPV) vaccines. The HPV vaccine work, he recounted, started 15 years after he became an investigator at NCI.

In the area of prevention and screening, Lowy said that, like cancer treatment, it will benefit from a precision medicine approach. With cancer health disparities, although he said that it’s not possible to address every type of disparity, he hopes to focus on a small number of important disparities or factors that influence them to better understand them and identify and study ways to address them. Finally, he emphasized the need for continued support for basic research. The "word on the street," he said, is that NCI will only fund basic research “that has immediate translational potential.” That is not and should not be the case, he stressed.

“Some of those most important discoveries will come from basic research” that doesn’t have immediate translational potential, he continued. “And I think it’s really important for the NCI to underline, especially for our young investigators, that what we want to see is outstanding research.”

In summing up his comments, Lowy expressed his deep appreciation for “the outstanding individuals at all levels of NCI,” and emphasized that “we all rely on each other. Cancer research is a team sport.”

Lowy also took several questions from staff. One member of the audience asked whether NCI has the leverage to ensure that an invention developed here is made accessible to all who need it. Lowy explained that, although NCI does not have this kind of leverage, it is possible to negotiate licensing agreements favorably. An example of that is the HPV vaccine, which he had a central role in developing and which is now broadly available.

Another question related to the role of epidemiology and health services research. In the exchange that followed, Lowy stressed the importance and benefits of working with other federal agencies such as the Centers for Disease Control and Prevention to have a bigger impact on disease.

In his answer to a final question about balancing his dual role as acting director and lab chief, Lowy stated that he plans to continue to run his lab. He stressed that it’s important that, as acting director, he not lose touch with the problems that investigators face every day in conducting their research for the American people.

“I think it is important for all of us, regardless of where we are in this organization, to recognize what our long-term goals are, to help people live longer, healthier lives by decreasing the incidence of cancer and improving the outlook of cancer for those patients who develop it,” he said.

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Got Data?
How Moving Bits and Bytes Around the Country Benefits Research
By Erin O’Leary
(This is the second of a multi-part series exploring how technology enables NIH’s mission.)

The ability to access and share data is a straightforward concept. Each day at NIH, we log on to computers and personal devices to collaborate with coworkers, peers and friends. What if access to this data meant that a cancer diagnosis could be more easily treated or prevented?

For researchers who use The Cancer Genome Atlas (TCGA) through the Cancer Genomics Hub (CGHub), the ability to share and access data is allowing for a better understanding of cancer development and leading the way to personalized medicine.

TCGA, with more than 30 cancer types, including 9 rare tumors, catalogs an unprecedented amount of data. With one sample generating more than 300 billion bytes of data, a collection hub was required to coordinate geographically dispersed genome sequencers and genome analysis centers. CGHub serves as a central repository for genomics information for three different National Cancer Institute programs, including TCGA.

Located in San Diego, CGHub is managed by the University of California, Santa Cruz, and provides cancer researchers a secure repository for storing, cataloging and accessing TCGA’s lower-level sequence data set.

Accessing and sharing data in real time is only a part of the challenge. As of 2014, CGHub contained approximately 2 petabytes of data; however, long before then, NIH and UC Santa Cruz were concerned with data integrity, and specifically, backups.

“By physically shipping data, we had tapes backed up in San Francisco, closer to Santa Cruz, but we wanted a backup on the east coast, closer to NCI,” said Mathangi Thiagarajan, CGHub project manager. “In 2012, we shipped the first batch of tapes to NCI-Frederick and copied the data to a tape archive.”

After NCI-Frederick caught up with data archiving, they started to explore the possibilities of transferring data across the network.

“In 2012, we started this project and could barely receive 1 terabyte per day,” Thiagarajan explained. “In 2013, we continued to make incremental progress. By 2014, we could receive up to 14 terabytes per day.”

Thiagarajan attributes this exponential increase to NCI’s efforts to add network streams and the Center for Information Technology’s initiative to upgrade the NIH-wide network, including the local firewalls in June 2014.

“Today, the average speed of the stream is obvious to our staff. The data is downloaded faster on each stream. Single stream speeds have improved so much we have cut back on the number of connections to CGHub, which in turn, has helped their global performance,” said Thiagarajan.

Although the data at CGHub will move from UC Santa Cruz to NCI’s Genomic Data Commons at the University of Chicago in 2016, the ability to transfer data across the country is an important advance.

“This upgrade was extremely crucial,” said Thiagarajan. “[Among] data providers and data consumers, there will always be competition for bandwidth, so we need to have a good working relationship with our technology teams so they can understand our work and mitigate issues. Knowing we have the capability to do 14 terabytes per day is incredibly useful. New projects and opportunities come up every day.”

Above: Researchers work at an NHGRI-supported large-scale sequencing center.
PHOTO: BROAD INSTITUTE OF MIT & HARVARD

Right: Mathangi Thiagarajan, CGHub project manager, says, “Today, the average speed of the stream is obvious to our staff. The data is downloaded faster on each stream. Single stream speeds have improved so much we have cut back on the number of connections to CGHub, which in turn, has helped their global performance.”