

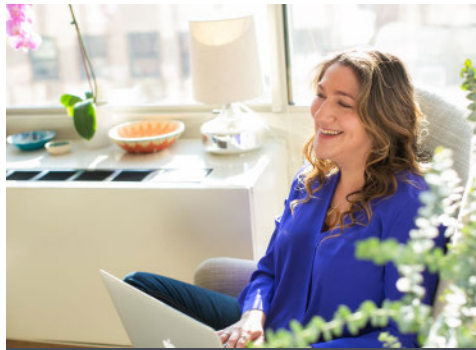
NIH Patient Shares Stories of ‘Invisible Illness’

BY DANA TALESNIK

Harper Spero spent the first 27 years of her life hiding her rare disease from family and friends. Determined to live a normal life, she spent years managing her symptoms while ignoring her doctor’s repeated pleas to seek help at NIH.

After going public with her story 7 years ago, Spero started looking for ways to help others. In July 2018, she launched a weekly podcast featuring people like her, who seem fine on the outside but live with the daily struggles of chronic “invisible illness.”

“I knew of NIH years earlier but didn’t want to be a specimen,” said Spero, a business



Harper Spero counters “invisible illness” via a podcast called *Made Visible*.

coach and consultant, on the first episode of her podcast series, *Made Visible*. A turning point came in 2012, when she had to decide whether to have life-threatening surgery. “At that time, I instinctively knew that going to NIH was exactly what I needed to do.”

A native New Yorker, Spero had started an exciting new PR job when she began to get easily winded. A visit to a

pulmonologist revealed a cyst the size of a golf ball in her lung. Now she needed another medical opinion. The required surgery would be especially risky given her immunodeficiency disease.

That diagnosis came when Spero was 10. She was born with hyper IgE, also known as Job’s syndrome, a rare disease that leaves patients prone to infection and affects many parts of the body.

“Growing up, I was so ashamed of my health condition,” she said. “I was used to being uncomfortable in my skin...Things continued to get worse.”

At age 27, Spero remembers feeling terrified riding in the car with her parents to Bethesda. Her fears were quickly allayed when she arrived at the Clinical Center.

“I’ve never felt such competence in the hands of doctors as when I met Dr. [Alexandra] Freeman and Dr. [Steven]

SEE SPERO, PAGE 6



“Coloured Tulip Genome” is on display in the CC.

‘TULIPMANIA’

Exhibit in CRC Reveals Flower Genome, Art of Science

BY CARLA GARNETT

The more no’s she heard, the more motivated artist Anna Fine Foer became. Her latest exhibit, which combines art, genomics, history and horticulture, was born essentially of dismissal. Nearly 2 years in the making, “Tulipmania and the Tulip

SEE TULIPMANIA, PAGE 8

Increasing Access to Mental Health Requires Action

Dr. Margarita Alegria envisions a country where everyone who needs mental health services gets them—a system that is available 24/7, where walk-ins are welcomed, clients have a menu of treatment options to choose from and where retention in care is paramount.

Furthermore, youth services are prioritized and providers are given enough time to connect with their clients and interested in them. Peer support and recovery coaches are connected from the start and disparities have



Dr. Margarita Alegria

SEE ACCESS, PAGE 4



Groundbreaking for new center at CC, p. 12.

ALSO THIS ISSUE

Briefs	2
Veterans Administration Model of Care Shows Potential, Gaudet Says	3
Two NIH Director’s Lectures Scheduled for February	5
Digest	7
Milestones	10
Volunteers	11
Ground Broken for New Center for Cellular Engineering	12

NIH to Host Rare Disease Day, Twitter Chat in February

Rare diseases affect an estimated 30 million Americans. On Thursday, Feb. 28, NIH will host an event to raise awareness about these diseases, the people they affect and current research collaborations.

Sponsored by the National Center for Advancing Translational Sciences and the Clinical Center, Rare Disease Day at NIH will take place from 8:30 a.m. to 4 p.m. in Kirschstein Auditorium, Bldg. 45.

The event will feature interactive panel discussions on collective research models for rare diseases, patient registries, rare cancer research initiatives and “no disease left behind, no patient left behind.”



New this year will be a presentation of the first-ever Zebbie award for the NCATS Rare Diseases Are Not Rare! Challenge. Other highlights include posters and exhibits by rare disease groups and researchers as well as artwork, videos, networking opportunities and tours of the CC. Admission is free and open to the public. In association with Global Genes, participants are encouraged to wear their favorite pair of jeans.

Learn more about Rare Disease Day at <https://ncats.nih.gov/rdd>. Visit https://events-support.com/events/Rare_Disease_Day to register and view the agenda. Follow the event on social media at #RDDNIH.

Prior to the event, NIH is hosting a Twitter chat on rare diseases on Friday, Feb. 22, from 1-2 p.m. The chat will feature NIH director Dr. Francis Collins, NCATS director Dr. Christopher Austin and CC CEO Dr. James Gilman as well as representatives from the rare diseases advocacy community. Join the conversation using #NIHchat and follow @ncats_nih_gov.

Sailing Association Open House, Mar. 6

The NIH Sailing Association invites everyone to its open house on Wednesday, Mar. 6 from 5 to 7:30 p.m. at FAES House at the corner of Old Georgetown Rd. and Cedar Ln. Explore your interest in learning to sail and discover opportunities for sailing with NIHSA. There will be information about 6-week basic training classes, the club's racing program and social activities offered by NIHSA. A fee of \$5 at the door includes pizza, drinks and snacks. Cash bar for beer and wine—\$2 each. Look for NIHSA posters and flyers around campus. For more information, visit www.nihsail.org/.



Musicians Entertain at Clinical Center Atrium

Clinical Center staff and patients enjoyed a spirited performance by violinist Kenneth Naito (l) and pianist Serhii Morozov in the hospital atrium on Jan. 8. Naito has been playing the violin since the age of 4. He has appeared in many venues throughout the world and is currently a freshman at The Juilliard School, majoring in violin performance. Ukrainian pianist Morozov has won many piano competitions and has extensive international experience.

PHOTO: DEBBIE ACCAME

FAPAC Issues Call for Award Nominations

The Federal Asian Pacific American Council (FAPAC) has issued a call for award nominations, with a deadline of Feb. 28.

The Dr. Howard K. Koh Award for Excellence in Leadership at HHS recognizes an individual who exemplifies outstanding leadership, service integrity and excellence and has significantly contributed to the mission of HHS. The nominee needs to be a member of the Asian American/Native Hawaiian/Pacific Islander (AANHPI) community and a current HHS employee.

The Dr. Francisco S. Sy Award for Excellence in Mentorship at HHS recognizes an employee who has provided exceptional mentorship to others from the AANHPI community, fostering their growth and development.

The recipients receive a 1-year FAPAC honorary membership, a \$300 honorarium and will be recognized during the Asian Pacific American Heritage Month Celebration in May.

The application package should include the nominee's curriculum vitae and a narrative of less than a page supporting the candidate's nomination.

Send nominations or questions to Dr. Xujing Wang, Xujing.wang@nih.gov, (301) 451-2862 and Dr. Jean Yuan, xin.yuan@nih.gov, (301) 827-7245.



NCI's Rosenberg Honored

Dr. Steve Rosenberg, chief of NCI's Surgery Branch, has received the American Medical Association's 2019 Dr. Nathan Davis Award for Outstanding Government Service and the American Association of Immunologists' 2019 Steinman Award for Human Immunology Research.

The Davis award recognizes individuals who promoted the art and science of medicine via government service and demonstrated outstanding leadership in his/her field.

The Steinman award recognizes an individual who has made significant contributions to the understanding of immune processes underlying human disease pathogenesis, prevention or therapy.

VA Model of Care Shows Potential, Gaudet Says

BY ELLEN O'DONNELL

In a recent NIH lecture, Dr. Tracy Gaudet, who leads an initiative in the Department of Veterans Affairs to deliver more “personalized, proactive and patient-driven care to our veterans,” discussed the foundation and progress of that initiative and the reasons it is bringing hope.

A board-certified obstetrician-gynecologist, Gaudet is the inaugural executive director of the VA's Office of Patient Centered Care and Cultural Transformation and a prominent speaker and writer on the transformation of health care. She gave NCCIH's Stephen E. Straus Distinguished Lecture in the Science of Complementary Therapies, which honors the center's founding director.

Her talk reflected three of NCCIH's research priorities: chronic pain, emotional well-being as a component of disease prevention and health promotion and pain research in military and veterans' populations—as through the NIH-Department of Defense-VA Pain Management Collaboratory, led by NCCIH.

Gaudet described current U.S. health care as “find-it/fix-it” and “reductionistic” in its approach, quoting a finding from a National Academy of Medicine report: “The disease-driven approach to care has resulted in spiraling costs as well as a fragmented health system that is reactive and episodic as well as inefficient and impersonal.” The opioid epidemic and the declines

in the past few years in U.S. life expectancy may be results, she suggested.

“This is crippling us,” Gaudet continued. “We're not even getting the health outcomes that we desire. Chronic conditions are our primary burden, largely affected by lifestyle choices. To tell somebody, ‘Exercise more, reduce your stress, see you in a year,’ isn't working.”

She places no blame on physicians and other health care providers—who are doing what they've been trained to do “with treatments we are blessed to have”—but rather on the system's limitations: “We have advanced science, clearly and in very big,



Dr. Tracy Gaudet of the VA wants to change the model of health care delivery.

PHOTOS: MARLEEN VAN DEN NESTE

bold ways, in recent years. But in general, health care has not shifted in the same way. Like all other industries, it's time to look at that.”

Among the major steps the VA has taken is its new Whole Health System, part of the Veterans Health Administration. As a first step, patients complete an innovative personal health inventory

• • •

“To tell somebody, ‘Exercise more, reduce your stress, see you in a year,’ isn't working.”

—DR. TRACY GAUDET

• • •

(available on the program website with other tools) that asks them what matters most to them and brings them the most happiness—i.e., what do they want their life, and better health, for? A personal health plan is created and a partnership launched that includes personal mission, self-empowerment and self-care.


“As I see it,” Gaudet noted, “self-care is the big determinant for the future of health care...The person and his or her mission is at the center—not the disease, not the chief complaint. We help people build the skills they need and have the support across time to make changes.”

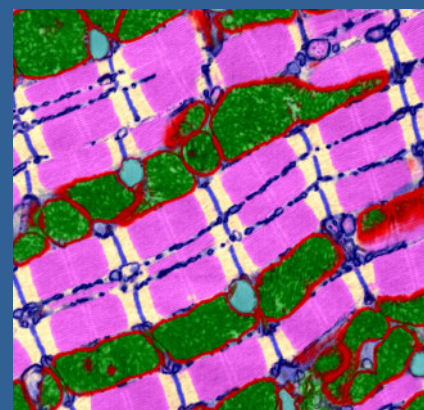
The model also includes conventional care; complementary care where needed, such as acupuncture and yoga; skills training; and more engagement with the “social determinants of health” such as family, peers who are veterans and activities outside the home.

The concepts in this approach are not new, nor were they invented by the VA, Gaudet emphasized. But they are being delivered in a system redesigned to optimize their impact in one of the nation's largest delivery systems. Other components include health services research, provider

training and employee wellness. The program was initially launched at 18 VA flagship facilities, with more on the way.

Feedback from patients and staff has been positive, Gaudet said. “Clinical outcomes are improving and utilization of mainstream health care is decreasing. But what strikes me most is hearing the theme of hope. Our veterans are reconnecting, discovering more reasons to live and having hope again. That's pretty amazing!” So is the potential she sees for the nation.

The full lecture is available at <https://videocast.nih.gov/Summary.asp?Live=28933&bhcp=1>. 



ON THE COVER: Focused ion beam scanning electron microscopic image shows the major structures within a single heart cell of a healthy adult mouse, highlighted in color via computer enhancement—mitochondrial membranes (red), mitochondrial interior (green), sarcoplasmic reticulum (dark blue), fat droplets (cyan/greenish blue) and the contractile apparatus (pink, yellow, lighter blue). February is American Heart Month.

IMAGE: BRIAN GLANCY, NHLBI

The NIH Record

Since 1949, the *NIH Record* has been published biweekly by the Editorial Operations Branch, Office of Communications and Public Liaison, National Institutes of Health, Department of Health and Human Services. For editorial policies, email editor or phone (301) 496-2125.

Editor: Rich McManus
Rich.McManus@nih.gov

Associate Editor: Carla Garnett
Carla.Garnett@nih.gov

Staff Writers:
Eric Bock • Eric.Bock@nih.gov
Dana Talesnik • Dana.Talesnik@nih.gov

Subscribe via email: listserv@list.nih.gov Follow: <http://nihrecord.nih.gov/>



The *NIH Record* is recyclable as mixed paper.



National Institutes of Health
Turning Discovery Into Health

Access

CONTINUED FROM PAGE 1

been eliminated. Patients trust their providers; services are brought to where people congregate, work or live; and employers facilitate their employees receiving services. Interventions are focused on communities to build social ties and social capital.

“We have a lot of knowledge of what we need to do and how to do it, but we’re missing the action,” said Alegría, chief of the disparities research unit at Massachusetts General Hospital and a professor in the departments of medicine and psychiatry at Harvard Medical School. She spoke at a recent NIMH Director’s Innovation Speaker Series lecture at the Neuroscience Center.

Those who need mental health services most aren’t getting the care they need, she said. The current system focuses solely on those who proactively seek treatment, rather than those needing care but not seeking it. The cost of finding effective, culturally congruent care and getting to and from a treatment location are barriers.

If everyone gets the service they need, the field will require a larger workforce for a nation that needs healing, Alegría said. In the U.S., there are immigrants with advanced health care degrees from other countries who do not have licenses to practice medicine. She proposed inviting immigrants who have medical, nursing, psychology and other health professional degrees to get accelerated training and supervision to obtain a license to practice in the U.S., without having to start all over again. Some patients, she noted, are more willing to work with professionals who speak the same language and come from the same culture they do, which is another reason for welcoming trained professionals from foreign lands.

Alegría also suggested establishing a millionaire’s tax to fund the necessary expansion and investment in mental health services, like California’s Proposition 68. Services funded by the tax succeeded in reducing homelessness, incarceration and hospitalization among people with mental illness and improved well-being of people served by the programs.

She also suggested that health care professionals develop a smartphone app like Uber—but for obtaining mental health care services. Uber is a ride-hailing app that

connects users with drivers on demand. The mental care app would connect the approximately 120,000 community health workers with people who need mental health services at any time of the day. Psychiatrists and psychologists would supervise the community health workers offering this care.

Telemedicine might also help to eliminate mental health disparities and get more services to rural communities. Alegría said people who go without mental health services often move out of the areas where

treat their patients and correct their treatment approaches, if necessary, said Alegría. When caregivers listen to their patients and practice shared decision-making, she said, trust increases between provider and patient, making it our best chance at personalized medicine.

Right now, said Alegría, many mental health professionals practice based on their own opinions and gut feelings, rather than paying attention to patients’ needs. She believes that sometimes providers treat

★ ★ ★

“We have a lot of knowledge of what we need to do and how to do it, but we’re missing the action.”

-DR. MARGARITA ALEGRÍA

★ ★ ★

they get treatment. Many times, a patient begins a treatment, moves, then stops treatment. Being tele-assisted by phone rather than coming to clinic allows patients to continue care when and where it’s convenient for them.

Providers “could get continuous coaching to improve clinical and interpersonal skills, update knowledge, practice shared decision-making, reduce bias, discrimination and stereotypes and empower the patient.” They need opportunities to reflect on how they

patients based on what they felt more comfortable doing, rather than working with the patient to develop personalized treatments.

After finishing treatment, she recommends that patients work with recovery coaches who understand that most mental illnesses are “chronic diseases, where you get better, but you also get worse.”

Alegría will soon publish results from her Boricua Youth Study, which seeks to understand the experiences of Puerto Ricans in Puerto Rico and in the rest of



If everyone gets the service they need, says Alegría, the field will need a larger workforce.

PHOTOS: CHIA-CHI CHARLIE CHANG

the U.S. The study examines the effects of acculturation and environment on mental health outcomes.

Going forward, Alegría believes experts must study the influence of neighborhoods on mental health. By studying the conditions where people live, work, study and socialize, researchers can learn how these variables affect people's mental health. Based on the results, policymakers and payors can allocate resources more efficiently.

"We've been focused too much on changing behavior of our patients and too little on changing behavior of our systems," Alegría concluded. **R**

Butz To Present NINR Director's Lecture

On Thursday, Mar. 7, Dr. Arlene Butz will present "Understanding Inner-City Pediatric Asthma: Environment Matters," from 1 to 2 p.m. She will discuss behavioral, home-based interventions for inner-city children with asthma. Her research has an emphasis on environmental exposures and medication adherence. The lecture will take place in Lipsett Amphitheater, Bldg. 10.

Butz is a professor of pediatrics at Johns Hopkins University School of Medicine, with a secondary appointment in the School of Nursing. For more than 15 years, her primary program of research has focused on inner-city children with asthma. Her current research targets interventions linking emergency care, home-based care and primary care with the goal of improving asthma morbidity in young children with recurrent emergency room visits.

Butz served on the research committee for the National Association of Pediatric Nurse Practitioners and as research department editor for the *Journal of Pediatric Health Care*. She works as a pediatric nurse practitioner in an urban primary care clinic and has served as a PNP on pediatric medical missions to Peru.

The event is free and open to the public. For more information and to register, visit <http://ow.ly/SBdO30nqkYr>.



Dr. Arlene Butz

Two NIH Director's Lectures Scheduled for February

The NIH Director's Wednesday Afternoon Lecture Series (WALS) will host two NIH Director's Lecturers in February.

Delivering the second of three annual NIH Director's Lectures, Dr. Judith Campisi will speak on the topic "Cancer and Aging: Rival Demons?" on Feb. 13 at 3 p.m. in Masur Auditorium, Bldg. 10.

Campisi is a professor at the Buck Institute for Research on Aging in Novato, Calif. She will discuss how one complex tumor suppressive mechanism termed cellular



Dr. Judith Campisi (l) and Dr. Sandra Wolin are slated for WALS talks this month.

senescence is thought to drive a surprising number of age-associated diseases and current strategies for maintaining tumor suppression while mitigating aging.

Dr. Sandra Wolin will deliver the third of three annual NIH Director's Lectures; her topic is "Autoantigens and Autoimmunity: A Bedside to Bench and Back Again Story," which will be held on Feb. 27 at 3 p.m., also in Masur Auditorium.

Wolin is chief of the RNA Biology Laboratory at the National Cancer Institute. Her lab studies how noncoding RNAs function, how cells recognize and degrade defective noncoding RNAs and how failure to degrade these RNAs affects cell function and contributes to human disease.

As part of NIH's Wednesday Afternoon Lecture Series, the Director's Lectures feature leading researchers from around the globe. Nominated by scientists and interest groups throughout NIH, the speakers are specifically approved by the NIH director. There are approximately three NIH Director's Lectures per year.

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

WALS CONTINUES



Spero with Dr. Alexandra Freeman, an NIH physician who, with Dr. Steven Holland, forms the team that takes care of Spero and many other Job's syndrome patients

Spero

CONTINUED FROM PAGE 1

Holland,” Spero said. “Nobody has taken care of me like this team. They care on a personal level...They were so dedicated to figuring things out.”

Freeman and her team confirmed Spero should have the surgery. In March 2012, a quarter of her right lung was removed and she took a 2-month medical leave to recover.

“When I decided to tell people, I suddenly felt like I was removing a mask I’d been wearing [my whole life],” said Spero, who has since celebrated each anniversary of her surgery with family and friends.

“It’s a reminder that the routine challenges associated with my invisible illness are still a huge part of my life, but there’s a lot to be thankful for,” she said.

Going public about her condition was liberating but also tough. There’s no manual for this, Spero noted. Friends and family, shocked by the news, were unsure how to react and support her needs.

“I learned you can go to a dark place and

come out on the other side,” said Spero. “Things get better even though they don’t become totally perfect.”

On her podcast, Spero interviews people coping with mental health conditions, Asperger’s syndrome, diabetes, cancer, multiple sclerosis, rare genetic disorders and hearing loss. She aims to make each episode compelling and educational.

“I created the podcast so that a person—whether living with or affected by invisible illness or the average person listening—is learning and becoming more compassionate and empathetic,” said Spero. “I’m not looking for people to be upset; I’m looking for people to be inspired when they learn more about these amazing people.”

Meet podcast guest Anthony, who has Asperger’s syndrome, clinical depression and anxiety. Doctors had told his mother he’d be nonverbal and nonfunctioning in society. Today, he’s an award-winning playwright who uses theater and the arts to challenge misconceptions about autism spectrum disorder and mental health issues.

“There is so much stigma attached to mental health and other chronic health issues,” said Spero. “Everyone relates to being misunderstood. I tell people you must advocate for yourself because no one else will do it for you.”

Made Visible also gives voice to caregivers of loved ones with chronic illness. In one recent episode, Jan Wiese describes the daily stress of caring for her 10-year-old daughter, Lucy, who shares the same diagnosis and NIH doctors as Spero. Lucy’s condition has greatly improved since a bone marrow transplant 2 years ago, a journey featured on the recent NIH-focused Discovery documentary *First in Human*. Still, Wiese must manage Lucy’s many chronic health issues.

“I’m so busy advocating for my daughter, but you also have to advocate for yourself,” Wiese tells Spero. “I’ve learned to give myself a lot of grace.” She hopes their story will point others who might need help for Job’s or other rare diseases to NIH.

Spero still communicates with her NIH doctors weekly and visits the CC annually as 1 of 175 Job’s syndrome patients they’ve been tracking and treating. Having a cohort of patients together enables the research team to see patterns and better understand the disease, said Freeman on the Dec. 18 episode of the podcast.

Many of Freeman’s patients are thriving in large part due to early diagnosis and intervention. “Now, when people [with Job’s] have children with the disease,” said Freeman, “we can diagnose those children within the first couple of weeks of life and [their] lives are dramatically different from their parents.”

Through her podcast, Spero highlights the difficult and brave journeys of regular people who struggle daily with chronic illness but don’t let it rule their lives. Uninhibited, they’re eager to share their stories.

Spero recounted that it wasn’t long ago when she was pretending to be fine, internalizing her emotions while feeling increasingly isolated.

“When we don’t hide,” said Spero, “we find people we can relate to and start a conversation about what it means to live with an illness and not be defined by one.”

Listen to the podcast series at www.madevisiblepodcast.com. **R**

Blood Test Shows Promise for Early Detection of Severe Lung-Transplant Rejection

Researchers have developed a simple blood test that can detect when a newly transplanted lung is being rejected by a patient, even when no outward signs of the rejection are evident. The test could make it possible for doctors to intervene faster to prevent or slow down so-called chronic rejection—which is severe, irreversible and often deadly—in those first critical months after lung transplantation. Researchers believe this same test might also be useful for monitoring rejection in other types of organ transplants. The work was funded by NHLBI; the study's findings were published Jan. 22 in *EBioMedicine*, a publication of *The Lancet*.

“This test solves a long-standing problem in lung transplants: detection of hidden signs of rejection,” said Dr. Hannah Valentine, co-leader of the study and lead investigator of NHLBI's Laboratory of Organ Transplant Genomics in the Cardiovascular Branch. “We're very excited about its potential to save lives, especially in the wake of a critical shortage of donor organs.”

The test relies on DNA sequencing, Valentine explained, and as such, represents a great example of personalized medicine, as it will allow doctors to tailor transplant treatments to those individuals who are at highest risk for rejection.

Lung transplant recipients have the shortest survival rates among patients who get solid organ transplantation of any kind—only about half live past 5 years. Lung transplant recipients face a high incidence of chronic rejection, which occurs when the body's immune system attacks the transplanted organ. Existing tools for detecting signs of rejection, such as biopsy, either require the removal of small amounts of lung tissue or are not sensitive enough to discern the severity of the rejection. The new test, called the donor-derived cell-free DNA test, appears to overcome those challenges.

Smoking Linked to Higher Risk of PAD in African Americans

African Americans who smoke appear to be at greater risk for peripheral artery disease, or PAD, new research has found. Additionally, the findings suggest that smoking intensity—how many cigarettes a day and for how many years—also affects the likelihood of getting the disease.

PAD affects 8 million to 12 million people in the United States and 202 million worldwide, especially those ages 50 and older. It develops when arteries



IMAGE: NIKKYTOK/ISTOCK

in the legs become clogged with plaque, fatty deposits that limit blood flow to the legs. Clogged arteries in the legs can cause symptoms such as claudication, pain due to too little blood flow, and increased risk for heart attack and stroke.

The impact of cigarette smoking on PAD has been understudied in African Americans, even though PAD is nearly three times more prevalent in African Americans than in whites. The current study looked at the relationship between smoking and PAD in participants in the Jackson Heart Study, the largest single site cohort study investigating cardiovascular disease in African Americans.

The new research, as well as the Jackson Heart Study, are funded by NHLBI and NIMHD. The new findings appear in the January issue of the *Journal of the American Heart Association*.

“These findings demonstrate that smoking is associated with PAD in a dose-dependent manner,” said lead researcher Dr. Donald Clark III, an assistant professor of medicine at the University of Mississippi Medical Center. “This is particularly important in the African-American community and supports the evaluation of smoking-cessation efforts to reduce the impact of PAD in this population.”

Temperature-Stable Experimental TB Vaccine Enters Clinical Testing

Vaccinations have begun in a phase 1 human clinical trial testing a freeze-dried, temperature-stable formulation of an experimental tuberculosis (TB) vaccine candidate. The trial is being conducted at the Saint Louis University School of Medicine Center for Vaccine Development and will enroll as many as 48 healthy adult volunteers ages 18 to 55. The experimental vaccine, called ID93, was developed by scientists at the Infectious Disease Research Institute in Seattle; NIAID is supporting the trial through a contract to IDRI.

ID93 is a recombinant vaccine candidate made from four proteins of *Mycobacterium tuberculosis* (the bacterium that causes TB). Many vaccines require a temperature-controlled system during transport, which can be costly and logistically challenging. Freeze-dried powder vaccines can be distributed at a cheaper cost to remote, low-resource settings. The powder formulations are mixed with sterile water for administering with a needle and syringe.

Investigators are examining if a powder formulation combining ID93 and the adjuvant GLA-SE (an immune response-stimulating protein) in a single vial, reconstituted with sterile water, is as effective at inducing an immune response in participants as the previously tested two-vial combination of powdered ID93 and liquid GLA-SE.

“Tuberculosis remains the leading infectious cause of death worldwide and a highly effective vaccine would be a crucial tool in ending this pandemic,” said NIAID director Dr. Anthony Fauci. “A vaccine

that did not require a cold chain could be much more easily distributed to communities in need.”

New Findings Reveal Surprising Role of the Cerebellum in Reward, Social Behaviors

A new study in rodents has shown that the brain's cerebellum—known to play a role in motor coordination—also helps control the brain's reward circuitry. Researchers found a direct neural

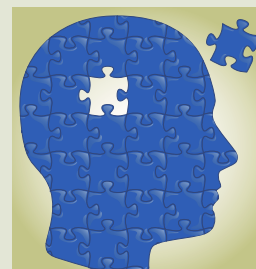


IMAGE: ISTOCK

connection from the cerebellum to the ventral tegmental area (VTA) of the brain, which is an area long known to be involved in reward processing and encoding. These findings, published in *Science*, demonstrate for the

first time that the brain's cerebellum plays a role in controlling reward and social preference behavior and sheds new light on the brain circuits critical to the affective and social dysfunction seen across multiple psychiatric disorders. The research was funded by NIMH.

“This type of research is fundamental to deepening our understanding of how brain circuit activity relates to mental illnesses,” said NIMH director Dr. Joshua Gordon. “Findings like the ones described in this paper help us learn more about how the brain works, a key first step on the path towards developing new treatments.”

The cerebellum plays a well-recognized role in the coordination and regulation of motor activity. However, research has also suggested that this brain area contributes to a host of non-motor functions. For example, abnormalities in the cerebellum have been linked to autism, schizophrenia and substance use disorders and brain activation in the cerebellum has been linked to motivation, social and emotional behaviors and reward learning, each of which can be disrupted in psychiatric disorders.

These earlier findings led Dr. Kamran Khodakhah of Albert Einstein College of Medicine and colleagues to wonder if there was a direct connection between the cerebellum and the VTA—a brain structure involved in controlling reward and motivational behaviors. To examine this, the researchers used a technique called optogenetics, in which the neurons of animals are genetically modified, so they can be controlled using pulses of light. The researchers used this technique in mice, activating neurons in the cerebellum that connected to the VTA. The researchers found that activating the cerebellar neurons led to increased activation in the VTA of mice, indicating a working connection between these two brain structures.



Artist Anna Fine Foer and NICHD's Dr. Henry Levin stand before Tulipmania, an exhibition installed until Mar. 1 in the Clinical Research Center's main lobby. The piece at left—"Boeket Tulpen," Dutch for bouquet of tulips—is a culmination of what the artist learned throughout the nearly 2 years it took to research and produce the exhibit.

Tulipmania

CONTINUED FROM PAGE 1

Genome" is now on display in the Clinical Research Center.

"I've been inspired by scientific concepts for awhile after watching episodes of *NOVA*, the [Public Broadcasting Service] show on TV or listening to [WNYC's] *Radiolab* or reading articles in the press," Foer said.

When she learned she'd won the opportunity to show work at NIH, she shared the news with long-time friend and NIH'er Dr. Henry Levin, senior investigator and head of the section on eukaryotic transposable elements in NICHD's cell regulation and development group.

"I knew immediately that I wanted to collaborate with him," she said.

Levin's lab studies "the biological impact of transposable elements using high-throughput DNA sequencing," he explained. "Recent projects include the finding that transposable elements in fission yeast are the major drivers of adaptation when cells are exposed to stress. We also study the role of transposable elements in human disease, including mental illness.

"I've known Anna for over 20 years and have been intrigued by her artistic interests," Levin continued. "In particular, I have been fascinated by her collages portraying social and scientific concepts. When the draft

sequence of the human genome was first published, I thought she might be inspired by the images in the special issue of *Nature* that described the breakthrough. I think that sparked her interest in DNA and the coding potential it had to portray all of biology."

Indeed, Foer was enthused by genomics, taking in all she could learn about the topic through books and lectures. At about the same time, she also was reading up on the 16th century Dutch tulip craze that had brought the flower into worldwide prominence. Foer determined to combine the two pursuits in her art.

"Over the years we have talked about her projects, including her passion for tulips," Levin recalls. "When Anna showed me the images of broken tulips, I immediately thought their sectored petals were the result of transposable elements. I've come to recognize the typical sharp lines of color variation they produce in plants when, during tissue growth, they damage pigment genes. The sharp lines of color in maize kernels were the clue that led [Nobel laureate] Barbara McClintock to discover transposable elements. In reading more about broken tulips, I discovered that mosaic virus, not transposable elements, was responsible for the stunning patterns of these highly prized plants."

"I decided to find the genome of tulips and use the code as the material for my collages," Foer explained. That's when she began meeting resistance. The tulip genome would be too big and too expensive to sequence, she was told repeatedly by scientists and experts of most every stripe. Foer kept searching for ways it could be done, however.

After a lecture on CRISPR/Cas gene editing, held in late 2017 at the National Academy of Sciences in D.C., Foer raised a question about genome sequencing to the speaker, whose response was, basically, "It's a science thing—you wouldn't understand it if you saw it." Foer replied, "I have to see it to understand it."

Foer was hurt and discouraged, but not deterred. "I really couldn't believe it," she said. "Artists can use a concept in their work without understanding it the way that scientists do."



"A Code for Tulips" (l) is now on display in the CC; a wall-size reproduction of it (r) was installed in May 2018 at the Oxford Nanopore Technologies Conference, "London Calling."

Then, serendipity stepped in.

“I was introduced to Nicholas Schurch, a computational biologist, at a SciArt conference in December [2017] in New York City,” Foer



recounted. “It was a result of my comments about being dismissed by the geneticist working with CRISPR at the NAS—that was the instigation.”

Schurch knew of someone who had sequenced the tulip—in Leiden, South Holland, no less, the proverbial home of the flower. Did the artist want to be put in touch?

Foer immediately contacted the sequencer, Dr. Christiaan Henkel, who was happy to share his group’s raw data, which amounted to 45 pages of black type on 8.5 x 11 paper. Someone familiar with genetic code told Foer she probably had not received the flower’s entire genome—just a relevant fraction.

“When I first saw the tulip code, I was excited because it looked like it could be tulips, turned on its side,” said Foer. For the next year, she developed a collection of 12 collages illustrating the tulip genome, which eventually would be framed, mounted and shown for the first time at NIH—home to scientists responsible in part for publishing the human genome sequence in the Feb. 15, 2001 issue of *Nature* that Levin gave Foer.

Her exhibit incorporates materials such as hand-dyed rice paper, watercolor and vellum as well as mirrored and metallic papers to give viewers a sense not only of the beauty and science of tulips, but also of the history of their popularity and importance economically to Holland specifically and Europe in general.

Beyond a typical viewer’s appreciation of aesthetic, Levin sees Foer’s work—and fine art in general—providing much more to researchers on any number of levels.

“My interest in Anna’s work comes from her keen ability to see patterns when others don’t,” Levin said. “I have always wanted her help in developing imaging software that would portray the complex patterns of repeats [that] transposable elements make across chromosomes. This is just one

◆ ◆ ◆
*“Artists can use a concept
 in their work without
 understanding it the way that
 scientists do.”*

—ANNA FINE FOER

◆ ◆ ◆

example of how the talents of a gifted artist can help scientists decipher the mysteries of natural patterns.”

“Once this information is made available, there’s no telling how it will be used,” Foer agreed, explaining her own aspirations for the work beyond the 8-week NIH show. She’s also uploaded the collection to her website.

The last piece—“Boeket Tulpen,” Dutch for bouquet of tulips—is a culmination of what the artist learned throughout the nearly 2 years it took to research and produce the exhibit. “It’s the only one that I knew what it was going to be when I started,” Foer said. “The tulip genome is part of the landscape. The vase was inspired by a 17th century cabinet of

curiosity. [Boeket Tulpen] puts the genome in historic context.

“I really want to emphasize three aspects that make this significant—especially now,” she concluded. “First, it’s the intersection of art and science. Also, it’s using and viewing the genome in an unintended way. And finally, the international aspects of scientific research—it’s the perfect example of why we need to keep people from all over the world coming here to the United States.”

Without cross-pollination of many different cultures from many different countries, the science of tulips, and Tulipmania, could not occur, she said.

The historic nature of her work is not lost on Foer either. “A hundred years from now people are going to look at the first images of the tulip genome,” she noted, “and I’m going to be a part of it.”

Financially supported in part by the Randall Frank Contemporary Artist Grant Program and the Giving Spirit Foundation Unicorn Barn Project, Tulipmania will be on display in the CRC main entry through Mar. 1.

See Foer’s work online at www.annafineart.com/art/. 

Charity Campaign Benefits Veterans

The NIH community recently demonstrated its support of the nation’s veterans, donating more than 306 new boots, shoes and other winter items (socks, scarfs, hats and gloves) during the “Walk in Their Footsteps” campaign, which ran from Nov. 2 through Jan. 4. Donations benefit homeless veterans and veterans transitioning to stable housing and their families in the Washington, D.C., area.

The NIH veterans recruitment and retention force (VRF) piloted the initiative with its counterpart at the U.S. Department of Housing and Urban Development. The new boots and other items were distributed to the Washington Veterans Affairs Medical Center during its annual Winterhaven stand-down event on Jan. 26.

This NIH pilot program was led by VRF member Toni Calzone of NIAAA and had the support of the Office of Human Resources, Client Services Division. VRF members who hosted a collection site included: Jill Bartholomew, NCI; Donna Dassen, CC; Heather Hanson, NIAID; Jayne Lura-Brown, NIDCR; and Cathy Troutman, NHLBI.



The number of veterans experiencing homelessness increased in 2018. On any given night, more than 40,000 veterans experience homelessness, staying in emergency shelters, transitional housing programs or living in places not meant for human habitation. Many are also in need of basic clothing items. A pair of new boots or shoes can make a difference in getting to a medical appointment, attending an employment interview or taking employment training. The campaign provided a way of positively affecting lives and giving comfort to those who’ve served the country.

For more information about the VRF, contact Mitzi.Kosciulek@nih.gov.



Gladys Sanders retired recently after 22 years in the Clinical Center.

HER DREAM JOB

Blood Bank's Sanders Ends 22-Year NIH Career

BY RICH MCMANUS

It's a good bet that the countless number of people who have given blood at the NIH Blood Bank over the last 22 years under the skillful hand of Gladys Sanders had no idea they were making a trip to the dentist.

There are a lot of things about Sanders, who retired on Jan. 3, that donors probably didn't know. What they did know, however, was more than enough; she exuded a warmth and professional competence, a friendliness and good cheer, that took the sting out of a procedure some folks are still leery about.

"The volunteer blood donor service is our face to the public and we have been fortunate to have had Gladys in that position for 22 years," said Dr. Harvey Klein, chief of the Clinical Center's department of transfusion medicine (DTM). "Gladys leaves as a member of our family and we will miss her smile as much as her remarkable work ethic. She deserves all the best in her retirement."

By the time Sanders reached NIH on Nov. 12, 1996, she had already had a number of careers. A native of the District of Columbia, she had graduated from McKinley Tech High School and gone on to Howard University, where she earned a B.S. in zoology. She then went to 4 years of dental school at Howard, where she got her D.D.S. (technically, she is Dr. Sanders).

"I had passed my boards, and I worked in a friend's [dental] office for a little while, but I just didn't like it," she said.

While in dental school, Sanders worked

part-time at the old Woodward & Lothrop department store, known locally as Woodies. When she decided dentistry was not for her, she began a 20-year retail career at Woodies' flagship site downtown.

When the store went out of business, Sanders decided to go back to school to train as a medical technologist. Tuition came out of a severance package negotiated between Woodies and the District government.

who was underage and therefore ineligible to donate. "We needed to get FDA permission, but we saved his life," Sanders said.

There was the "bad bleeder" in the operating room who needed massive amounts of blood. "It was over the holidays," said Sanders, "when not many people are around. All these people from the Clinical Center donated, even from the OR."

Then there was former NIH director Dr.

• • •

"Gladys leaves as a member of our family and we will miss her smile as much as her remarkable work ethic."

-DR. HARVEY KLEIN

Because Sanders already had both an undergraduate degree in science and a doctorate, she completed what normally is a 4-year program at the University of Maryland in just 2 years. She also began working part-time at NIH under the old stay-in-school program. She worked at DTM while she earned her certification in blood banking and hematology, then was hired full-time as a medical technologist at the Blood Bank.

A few moments in a long and satisfying career stood out for Sanders, who retired as a clinical laboratory scientist. There was the visit by former HHS Secretary Tommy Thompson, who gave blood at NIH. "I did the screening on him," she recalls.

There was the little boy with sickle cell disease whose body rejected every attempt at blood transfusion, except from his brother,

Elias Zerhouni, who she says was a regular at the Blood Bank.

"You never know who you're going to meet," said Sanders. "I've bled people from housekeepers to Dr. Zerhouni. He's the one who got us badges [temporary NIH ID cards] for the donors. Donors love it!"

"NIH was always my dream job," said Sanders. "It's nice in life to be able to go where you've always wanted to go. I've met some of the most wonderful people here."

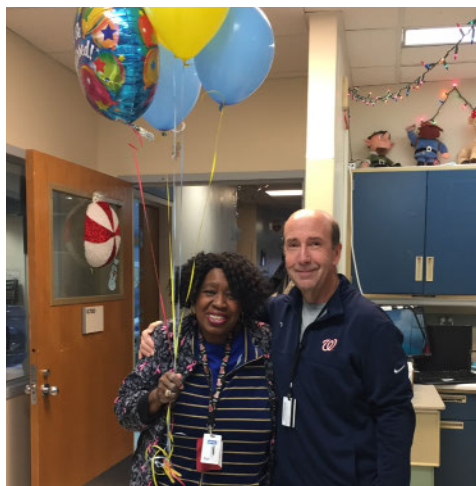
In retirement, Sanders plans to travel, pursue some volunteer activities and "work on my house." She also plans to add 2 more years to the 16 she has already spent working part-time—12 hours every Saturday—at Georgetown University Medical Center, where she works in a lab.

On the day after her Dec. 18 retirement party ("I had a great send-off!"), Sanders posed for a selfie with a long-time donor who had dropped in to say goodbye. Speaking for what must be a large cadre of such donors, another of Sanders' clients had this to say:

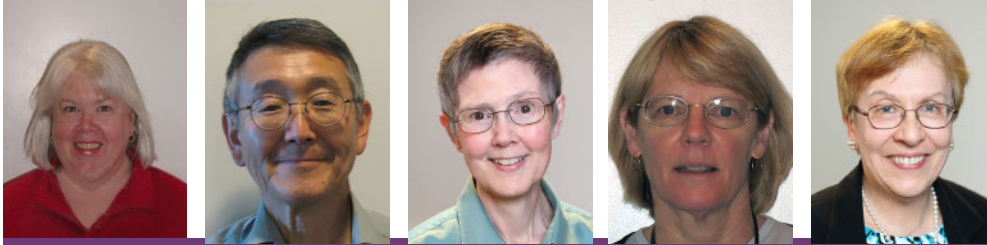
"I have been giving blood to NIH's hemochromatosis study for over 20 years and Gladys has been a part of my life at NIH for all of those years," said Rick Gannon, of Chevy Chase. "Every time I showed up to donate blood, she always had a smile on her face, was extremely professional and loved by those around her. Though I will continue giving blood, I will miss seeing her and wish her the best health, joy and happiness as she begins the next chapter in her life."

Sanders, of course, gets the last word.

"Come and donate blood!" she said, with her trademark smile.



Long-time donor Rick Gannon wishes Sanders well on her last day at NIH.



NIGMS staffers saying so long are (from l) Eileen Hyde, Dr. Richard Okita, Patricia Pillsbury, Dr. Janna Wehrle and Dr. Hinda Zlotnik.

NIGMS Bids Farewell to Long-Serving Staff

NIGMS recently bid fond farewells to a number of long-time employees. Combined, this group of retirees put in more than 117 years at the institute.

Among the retirees are scientific staff members Dr. Janna Wehrle, Dr. Hinda Zlotnik and Dr. Richard Okita.

Wehrle joined NIGMS 24 years ago as a program director in the Division of Cell Biology and Biophysics (CBB). Following NIGMS's reorganization in 2018, she moved to the Division of Biophysics, Biomedical Technology and Computational Biosciences, where she administered research grants in the areas of biophysical and biocomputational approaches to protein structure, protein folding and misfolding.

Zlotnik began her NIGMS career nearly 21 years ago, when she joined the Division of Minority


Opportunities in Research as a program director. She rose to the level of branch chief before moving to the newly created Division for Research Capacity Building in 2018. Zlotnik managed a variety of diversity and capacity-building programs over the years, most recently the Support of Competitive Research program and the Institutional Development Award's Centers of Biomedical Research Excellence.

Okita served for more than 17 years as a program director in the Division of Pharmacology, Physiology and Biological Chemistry (PPBC), handling research grants in the areas of drug metabolism and transport, drug-induced toxicology and drug delivery. In addition, he managed training grants and fellowships in related fields and the NIH Common Fund initiative Building Infrastructure Leading to Diversity.

The Division of Extramural Activities said goodbye to long-time staffers Eileen Hyde and Patricia Pillsbury. Hyde, a grants management specialist,

handled grants for CBB and later PPBC. She joined NIGMS more than 27 years ago. Pillsbury, a program specialist who moved her way up through four positions at the institute, is the longest-serving of the recent retirees. She is credited with more than 28 years of service.

What makes the institute such a special place to work that it leads to such longevity? Over and over, departing staff credited "the people" of NIGMS. Wehrle summed it up best: "What a pleasure it has been working with such great colleagues—consistently thoughtful, patient, dedicated and fun—throughout all parts of the institute and over all the years."

In retirement, the retirees plan to enjoy a range of activities including traveling, spending time with family and learning a new language.—Susan Athey 

VOLUNTEERS

VRC Needs Healthy Volunteers

Vaccine Research Center researchers seek healthy volunteers, 18-50 years old, for a study evaluating an investigational vaccine that targets HIV. Compensation is provided. There is no risk of infection. To learn how to participate, call 1-866-833-5433, email vaccines@nih.gov or visit <http://bit.ly/VRC-018>.

NHLBI Study Recruits Volunteers

NHLBI invites volunteers ages 18-80 of African descent with or without sickle cell trait and patients with sickle cell disease to participate in a one-time visit research study. Volunteers will provide blood samples that will be used to look for a link between the PKLR gene and pyruvate kinase protein. The PKLR gene is active in the liver and in red blood cells and helps to create protein called pyruvate kinase that is essential in normal functioning of red blood cells. Compensation is provided. For more information about study 18-H-0146, call 1-866-444-2214 (TTY 1-866-411-1010) or visit <https://go.usa.gov/xP8Hx>.

Healthy Volunteers Sought

Healthy volunteers at least 18 years old with no history of cardiovascular disease are needed to participate in a research study with NHLBI. Researchers are interested in understanding the effects of diets enriched with palmitoleic acid (omega-7) on decreasing cardiovascular risk and effects on metabolism. All study-related medications, tests or procedures are at no cost. Receive compensation for your participation at the end of the completed study. For more information, call the Office of Patient Recruitment, 1-800-411-1222 (TTY 1-866-411-1010) or visit <https://go.usa.gov/xQq2p>. Refer to study 18-H-0019.



At left, participating in National Drugs & Alcohol Chat Day are (from l) FDA Center for Tobacco Products director Dr. Mitch Zeller, NIAAA director Dr. George Koob, NIMH director Dr. Joshua Gordon and NIDA deputy director Dr. Wilson Compton. At right, NIDA's Josie Anderson holds an NDAFW sign as she braves the cold in New York City outside NBC's *The Today Show* studio.

NIH Educates on Drugs, Alcohol

National Drug & Alcohol Facts Week, an annual health observance about drug and alcohol use, took place Jan. 22-27. Launched in 2010 by NIDA, and in partnership with NIAAA since 2016, the event links students with scientists and other experts to shatter the myths about drugs and alcohol that teens get from the Internet, social media and movies.

This year, close to 2,000 events were held in all 50 states and in several international sites. On Jan. 24, NIDA also held its annual Drugs & Alcohol Chat Day, a web chat between hundreds of students in 44 schools across the nation and approximately 50 NIH scientists who answered a variety of drug, alcohol and mental health-related questions. Representatives from NIDA, NIAAA, NIMH and FDA were all in attendance. Nearly 4,500 questions were submitted. Visit <http://teens.drugabuse.gov/national-drug-facts-week> for more information about NDAFW and to read the transcript from Chat Day.



Taking part in the groundbreaking are (from l) NHLBI director Dr. Gary Gibbons, NIAID director Dr. Anthony Fauci, NIH deputy director for intramural research Dr. Michael Gottesman, construction project officer Hamideh Alehossein, ORF director Dan Wheeland, NIH director Dr. Francis Collins, HHS assistant secretary for health Adm. Brett Giroir, Clinical Center CEO Dr. James Gilman, DTM chief Dr. Harvey Klein and Dr. David Stroncek, chief, cell processing section.

PHOTOS: DANIEL SOÑE

Ground Broken for New Cell Processing Center

On Jan. 22, the Clinical Center celebrated the groundbreaking of a new cellular processing facility on the southeast patio of Bldg. 10 and establishment of the CC department of transfusion medicine's Center for Cellular Engineering (CCE). The facility marks the most recent expansion of DTM's growing capacity to support intramural cellular therapy protocols.

The CCE will operate under the guidance of DTM chief Dr. Harvey Klein and deputy chief Dr. Bill Ward. Dr. David Stroncek will direct daily CCE operations.

Attendees included NIH director Dr. Francis Collins, hospital CEO Dr. James Gilman and Adm. Brett Giroir, HHS assistant secretary for health.



Clinical Center CEO Gilman speaks at the event on Jan. 22.

They emphasized that the groundbreaking underscores the continued commitment at the Clinical Center to lead the science of precision medicine and develop new and more effective therapies for patients who come to the CC to find hope where none existed.

The expansion from DTM's Cell Processing Center into the Center for Cellular Engineering reflects the strategic plan of the NIH intramural research program for new and more effective cellular and precision treatments. It is NIH's response

to increased investigator demand from institutes such as NCI, NHLBI, NEI and NIAID with protocols across a wide range of cellular research including CAR-T immunotherapies for cancers and rare diseases, pluripotent stem cells for macular degeneration, gene therapies for epithelial cancer and CRISPR/Cas to edit DNA as a potentially safer, faster and more effective treatment for sickle cell and other diseases.

Thirty-four clinical trial protocols, such as those involving complex cell and gene therapy and hematopoietic stem cell transplants, rely on the CCE. By 2020, 12 more protocols are expected to be up and running.

In 2018, the cell processing section included 11 rooms for cellular engineering as well as laboratories to develop and characterize novel cellular products. By 2021, this is expected to double. To accommodate this expansion, additional space for the CCE is being renovated on the 12th floor of the CC's E-wing.



Collins greets Giroir at the Clinical Center. Giroir also gave the keynote talk at an NIH workshop on cell-based immunotherapy on the same day as the groundbreaking for the new NIH center.