

PARTNER IN HEALTH

Collins Shares His Experience with Prostate Cancer

BY DANA TALESNIK

A medical school professor once told Dr. Francis Collins: if you're going to get sick, at least try to be an interesting case. Collins inadvertently took that advice to heart earlier this year when he found himself not on the familiar physician-researcher side of NIH, but rather as a surgical patient.

Earlier this year, Collins was diagnosed with an aggressive form of prostate cancer. For five years, his doctor had been monitoring a modestly elevated PSA blood test associated with a rather unimpressive

prostate MRI lesion, something common in men his age. Collins wasn't worried. But then something changed, and the new diagnosis took him by surprise.

"I'm an outlier," said Collins. "Most of



Dr. Francis Collins discusses the NIH protocol that detected and treated his prostate cancer.
PHOTO: DIANE BAKER

the time when doctors do this kind of active surveillance with repeated testing, images and biopsies, men tend to stay in the same pattern for a long time. If you start out, as I did, as a Gleason-6 [on the prostate cancer grading scale], you often stay there for a decade or more. I broke the rules."

NIH Protocol

Five years ago, Collins's doctor informed him of a slightly elevated PSA—the blood test for prostate-specific antigen. This health change inspired Collins to enroll in an NIH clinical protocol to monitor and test ways to improve screening and managing cancer.

"I was glad to serve as another data point they could add to this long-term study," said Collins, who has dedicated his career to studying genetics and helping others—as former NIH director (2009-2021), former National Human Genome Research Institute

SEE **PROSTATE**, PAGE 6

Understanding Cognitive Load Theory Makes Teachers More Effective

BY ERIC BOCK



Dr. Jennifer Spicer

Medical school curriculums require students to learn complex information. To help students retain what they're taught, faculty and staff can use teaching principles based on cognitive load theory, said Dr.

Jennifer Spicer, during a recent Graduate Medical Education Grand Rounds.

"We have a lot of evidence about how we learn," said Spicer, assistant professor of medicine at Emory University School of Medicine. "We know a lot about the science

SEE **SPICER**, PAGE 4

Interns Gather for Poster Day

BY KRISTINE DURU AND MAHELATE SOLOMON

More than 800 lab interns from across NIH convened in August to display their research at Summer Poster



(From l) OITE's Dr. Natasha Lugo-Escobar, Deandre Gaither and Jackie Newell-Hunt

PHOTO: MARLEEN VAN DEN NESTE

Day, organized by the Office of Intramural Training & Education (OITE). The annual event took place in Bldg. 45's Natcher Conference Center.

Dr. Natasha Lugo-Escobar, director of the postbac and summer research programs at OITE, helped organize the two-day event.

"I'm here as a support system for the

SEE **POSTER**, PAGE 8



The NSO returns to the Clinical Center. See p. 12.

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Bhamla to Deliver Greenberg Lecture on Frugal Science**Oct. 7**

Dr. Saad Bhamla, an associate professor of chemical and biomolecular engineering at Georgia Institute of Technology in Atlanta, will present the



Dr. Saad Bhamla

Judith H. Greenberg Early Career Investigator Lecture on Monday, Oct. 7, at 1 p.m. ET.

The lecture—open to everyone in the scientific community—will take place in person at the Natcher Conference Center, Bldg. 45, balcony A, and virtually via Zoom.

During his talk, titled “Fast and Frugal: Cells That Move Without ATP

and Life-Saving Tools That Cost Pennies,” Bhamla will describe his research into the physics of living systems to uncover principles underlying ultrafast movements in biology and inform the design of bioinspired robotics. He’ll also discuss how his lab uses frugal science to build accessible and affordable tools for global health applications.

After the lecture, Bhamla will answer questions from in-person and remote participants about his research and career path.

This annual series highlights the achievements of early-career grantees of the National Institute of General Medical Sciences (NIGMS). It is designed to introduce students and other early-career scientists to cutting-edge research and to inspire them to pursue careers in the biomedical sciences.

For details and registration information, visit <https://go.nih.gov/greenberg2024>. Participants requiring sign language interpretation and/or other reasonable accommodation should submit a request at <https://go.nih.gov/8GRCl1m> at least 5 days prior to the event.

NIMHD Seminar to Focus on Health Effects of Residential Segregation**Oct. 3**

The next National Institute on Minority Health and Health Disparities (NIMHD) Director’s Seminar will feature Dr. Rudolph Rodriguez, a board-certified internist and nephrologist.

Rodriguez’s presentation, “Residential Segregation and Health Outcomes: The Impact on the Hispanic/Latino Population,” will take place Thursday, Oct. 3 from 2:00 to 3:30 p.m. ET via videocast. No registration is required.

Rodriguez is director of Hospital and Specialty Medicine at the VA Puget Sound Health Care System. He is also vice chair of the Department of Medicine at the University of Washington.

Virtual attendees are invited to submit questions and comments via NIMHDDSS@mail.nih.gov. The event is open to all NIH staff, trainees and external groups. For details, visit go.nih.gov/zu7RemM.

CHRONIC DISEASE DAY**NIAMS, NCATS, CDC Participate in Hill Briefing**

(From l) Good Days Chief Operating Officer Randie Odebralski, Clorinda Walley, Dr. Josh Fessel, Dr. Lindsey Criswell, Jess Myers, Dr. Karen Hacker and Good Days Vice President of Human Resources and Compliance Tricia Freels

In July, NIH participated in a congressional briefing on chronic disease management and prevention that took place in the Rayburn House Office Bldg.

The event honoring Chronic Disease Day featured remarks by Dr. Lindsey Criswell, director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); Dr. Karen Hacker, director of the CDC’s National Center for Chronic Disease Prevention and Health Promotion; Dr. Josh Fessel, director of the Office of Translational Medicine at the National Center for Advancing

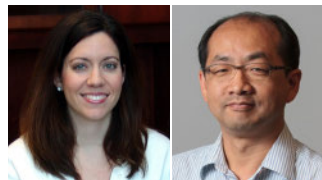
Translational Sciences (NCATS); and Jess Myers, communications and advocacy manager at the Hereditary Angioedema Association, an organization serving those living with the rare genetic condition, hereditary angioedema (HAE).

Some chronic diseases are common; many others are rare, a point Fessel highlighted in his remarks. Chronic diseases, which account for seven of the top ten causes of death in the U.S., can cause lifelong pain, disability or disfigurement.

Criswell, Hacker and Fessel presented several efforts related to chronic diseases from the NIH and CDC. Criswell discussed how many types of bone diseases, autoimmune diseases and skin conditions are chronic and affect people of all ages and racial and ethnic backgrounds. Myers, who lives with HAE, spoke on how the condition impacted her life.

Rep. James McGovern (D-MA) expressed his support for continued investment in biomedical research and acknowledged the critical role of NIH and CDC in improving the lives of those with chronic diseases.

Good Days, the nonprofit that hosted the event, presented McGovern with the Len Rodgers Spirit Award for his dedication to serving people in need. The award is named after Len Rodgers, who was diagnosed with multiple myeloma and dedicated his life to helping communities around the world. —Linda Yang

NCI Hosts Webinar on Pediatric Proton, Photon Therapy**Oct. 8**

Dr. Cari Kitahara (l) and Dr. Choonsik Lee

Join the National Cancer Institute’s (NCI) Childhood Cancer Data Initiative (CCDI) on Tuesday, Oct. 8, from 1 - 2 p.m. ET, for an informative

webinar on the NCI Pediatric Proton and Photon Therapy Comparison Cohort. Hear from Drs. Cari Kitahara and Choonsik Lee on this multicenter study and collaboration between the NCI’s Division of Cancer Epidemiology and Genetics, Massachusetts General Hospital and investigators from participating treatment centers.

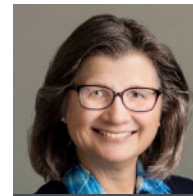
This webinar will focus on the study design, current enrollment status and state-of-the-art methods—developed specifically for this cohort—to determine the amount of radiation exposure to different body sites. A Q&A will follow.

This virtual event is open to the public. Registration is required to get the event link. To register, visit <https://events.cancer.gov/ccdi/webinar/registration>. If you need reasonable accommodations to participate in this event, please email CCDIevents@mail.nih.gov by Oct. 2.

Giger to Discuss Medical Imaging**Oct. 11**

NIH’s Office of Data Science Strategy hosts a seminar series to highlight exemplars of data sharing and reuse on the second Friday of each month. The next seminar will take place on Oct. 11 at noon.

Dr. Maryellen Giger, vice chair of radiology and the A.N. Pritzker Distinguished Service Professor of Radiology at the University of Chicago, will discuss



Dr. Maryellen Giger

the role of the Medical Imaging and Data Resource Center (MIDRC) in medical imaging artificial intelligence (AI), with a focus on curated real-world data, representative data, validation methods and sequestered data, understanding of potential biases and sustainability.

AI in medical imaging involves research in task-based discovery, predictive modeling, robust clinical translation and patient engagement. To enable the development of trustworthy AI, requires curated, diverse and reusable data. The open data and open resources of MIDRC will be described, eventually leading to their impact on clinical AI and patient care.

To register for this event, visit bit.ly/4emDc79.

NIEHS Launches Climate and Health Data Website

BY SUSAN COSIER

The National Institute of Environmental Health Sciences (NIEHS) launched a new website of data resources, tools and training materials that can aid researchers in studying the consequences of climate change on the health of communities nationwide. The site, Climate and Health Outcomes Research Data Systems (CHORDS), includes a catalog of environmental and health outcomes data from various government and nongovernmental agencies.

“This project is fundamentally a way for this institute and others to come together to empower the use of environmental determinants of health,” said Dr. Aubrey Miller, deputy director of scientific coordination at NIEHS. “We’re seeing climate change and health disasters around the country increasing in frequency and severity, so the need is greater than ever.”

The resource is one of several planned as part of a three-year project by the Patient-Centered Outcomes Research (PCOR) Trust Fund. NIEHS competed with other agencies for the funding to build up data systems that will improve patient or population health. The website, its publicly available datasets and the CHORDS project are part of the NIH Climate Change and Health Initiative (CCHI).



The CHORDS technical expert panel met in person for the first time at NIEHS in July.

PHOTO: STEVE MCCAWE / NIEHS

What’s available

The website provides data resources; tutorials and for downloading, integrating and visualizing health and environmental data; a listing of publications of note on wildfire and health research; and links to existing resources, such as the NIEHS climate change and health glossary and literature portal.

The catalog includes a listing of dozens of data resources provided by different federal and state environmental and health sources. Users can sort the listing based on environmental and health measures of interest — such as specific air pollutants or chemicals — from data providers including NASA and the U.S. Environmental Protection Agency with many more to come.

In addition, users can search the catalog by keyword, such as “PM2.5,” which is a measure of air pollution, and the population studied. They can then drill down into the information available and narrow their results to specific domains, such as environmental justice, climate change or electronic health records.

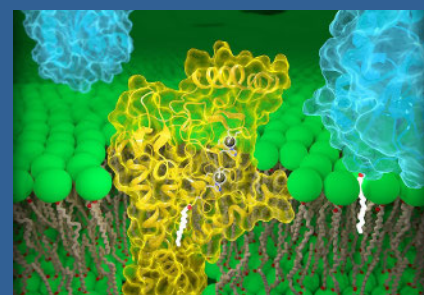
What’s next

The CHORDS team will add additional resources to its catalog and expand the content in the training toolkit. The team also is developing new software and climate analysis tools. The new software tools will also be used to generate standardized environmental datasets that health researchers can readily add to their own research projects.

“We’d like to make sure we’re doing the best we can, representing other resources, getting input on how to improve, and asking what we might be missing,” said Dr. Charles Schmitt, director of the NIEHS Office of Data Science. “We’d like to collaborate with people on additional resources and point people to where they can go to get additional information.”

To learn more about CHORDS, visit: go.nih.gov/jQqLJ1I.

For more on the CCHI, see: <https://climateandhealth.nih.gov>.



ON THE COVER: Molecular view of DhHC palmitoyltransferases. Human DhHC20 (yellow) is embedded in the Golgi membrane (green), a compartment located inside cells. DhHC20 attaches a fatty acid chain (white) to a target protein (blue, foreground), which anchors the protein to the Golgi membrane. NIH researchers have reported the first 3D structure of DhHC enzymes. The finding promises to improve drug design for common forms of cancer.

IMAGE: JEREMY SWAN, NICHD

The NIH Record

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National Institutes of Health
Turning Discovery Into Health

EDI To Host Unity in Diversity Forum

NIH’s Office of Equity, Diversity, and Inclusion (EDI) will host the inaugural EDI Forum, “Unity in Diversity: Building a Stronger NIH Community through DEIA,” on Tuesday, Oct. 8 from 8:00 a.m. to 5 p.m. ET and Wednesday, Oct. 9 from 7:30 a.m. to 4 p.m. ET at the Natcher Conference Center.

Equal employment opportunity and diversity, equity, inclusion, and accessibility (DEIA) are critical imperatives that allow NIH to achieve its goal of turning discovery into health. The forum will explore how embracing diversity enriches our work and drives innovation, resilience and collective progress.



This event is open to all NIH staff. NIH Director Dr. Monica Bertagnolli and HHS Assistant Secretary for Administration Cheryl Campbell will provide the forum’s welcoming remarks. The forum will offer presentations and trainings around key topics and focus areas divided into the following tracks: equal employment opportunity compliance, DEIA and program evaluation and policy.

To view the full agenda, visit: bit.ly/4enfqrU.

Individuals who require sign language interpretation or other reasonable accommodations should contact Céline Dazé at celine.daze@nih.gov. Requests must be received on or before Sept. 30.

Spicer

CONTINUED FROM PAGE 1

of how we learn and take in and retain information.”

Cognitive load refers to the amount of mental energy it takes to learn new information or perform a task. The theory proposes that people have a limited amount of energy available.

When a student is taught something new, that information goes into their working memory. Working memory can store only 5-7 pieces of information for 30 seconds. If a student focuses on a piece of information, it will move into long-term memory, where it's believed there's infinite storage.

“Working memory is the bottleneck for us being able to take in and understand information,” she said.

According to cognitive load theory, there are three components of working memory that affect how a student processes new information: intrinsic, extraneous and germane load. Intrinsic load refers to the information's complexity; extraneous load refers to outside distractions and germane load refers to effort it takes to organize information.

In many cases, teachers don't have much control over the difficulty of a course's content. “There are just some topics that are really complex,” she said. “We have to think really carefully about how to manage the intrinsic load.”

There are strategies teachers can use to help students with difficult material. First, they must consider what a student is capable of learning. A first-year medical student, for example, doesn't have the baseline knowledge that experts have.

Teachers can let students “preview” course material. This gives students a chance to familiarize themselves with unfamiliar terms so they can digest and understand them before class.

In the clinical setting, Spicer will give a 10-15 minute “chalk talk” before rounds. She structures these short talks around key concepts that students can build on later. Overwhelming students with too much too soon, she said, can interfere with their ability to learn.

She will also share relevant podcasts with her students in advance. To eliminate distractions, students turn their laptops and

papers off and put their phones away before class starts.

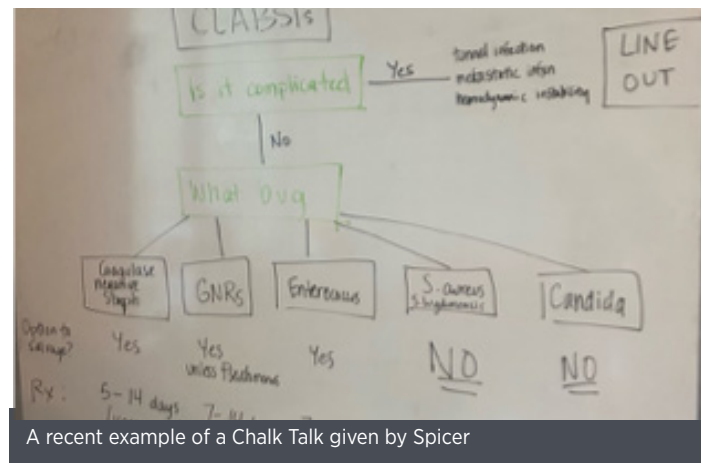
During multimedia presentations, Spicer limits the amount of text on slides so she can include complementary images, graphs and figures. She incorporates Mayer's Multimedia Principles into her slide design. These principles state that people learn best when words are paired with images rather than words alone.

She prefers to give lessons using a conversational style, instead of scripting her lessons. “A conversational tone is much easier for people to take in and understand compared to a formal script.” Non-experts will also review her course materials to make sure she isn't making assumptions about students' knowledge.

Retrieving information from memory is an important skill for doctors when they make clinical decisions. During rounds, Spicer asks her students questions as a learning tool. “We're forcing them to retrieve and apply information to patients in the future,” she said.

In the classroom, she gives students partial outlines of lectures. Data suggests that filling in partial outlines in their own words increases students' long-term retention. Flash cards featuring questions that are harder than what's on an exam also increases retention.

As students learn more, Spicer continues to challenge them. “We need to make things a little more difficult to really enhance



A recent example of a Chalk Talk given by Spicer

learning.” She thinks about where she can stretch each student's knowledge. For instance, a current student is learning how to deliver bad news to patients. She'll prep her student about how to speak to a patient, role play a scenario and then bring her student into a patient room.

Before the visit, she tells the student: “I know this is going to be uncomfortable, but let's try it. I'm here for support and you can turn to me if you get to the point where you can't move forward.” These experiences are much more effective learning experiences, she said.

“Learning isolated facts doesn't help unless we can apply them to situations,” she explained.

Finally, the best doctors are always working on something, even if they have long graduated medical school. Experts set goals for their learning and then practice and ask for regular feedback from colleagues. These high performers take the feedback and refine their approach over time.

Teachers must simplify and organize their content to help students learn, Spicer concluded. “We then want to engage in effortful, repeated practice on realistic and varied scenarios with targeted feedback.” **B**

CFC 2024 Begins

The 2024 NIH Combined Federal Campaign (CFC) officially started on Sept. 1 and ends on Jan. 15. The Clinical Center (CC) is this year's lead institute.

The CFC is the federal government's largest workplace giving campaign, and an opportunity to support your favorite causes easily and efficiently. The campaign will hold a virtual kickoff event on Oct. 9 from 11:00 a.m. to 11:30 p.m., via NIH videocast at <https://videocast.nih.gov/watch=55047>.

Also mark your calendars for these upcoming CFC events. The first is the Virtual Fall Charity Fair and Costume Contest on Oct. 31, from 11:00 a.m. – 1:00 p.m. at <https://videocast.nih.gov/watch=55048>.

Three charities will share about their missions and how your generous donations make a difference.

For the costume contest, costumes that include a CFC message will earn an extra point. The entry form can be found at <https://cfc.nih.gov>. All entry forms must be submitted by 4:00 p.m., Oct. 8.

The second event is the Directors Challenge Cornhole Tournament on Nov. 21 at 10:30 a.m. The in-person event will take place in the CC north atrium. Only IC Directors are invited to compete.

Every contribution makes a difference. This year's theme is “Give Happy.” CC CEO Dr. James Gilman said, “It's amazing to see how giving a little out of each paycheck or a few volunteer hours a month adds up to so much happiness.”

Donenberg Selected to Head NIH Office of AIDS Research

Dr. Geri R. Donenberg has been selected as NIH associate director for AIDS Research and director of the NIH Office of AIDS Research (OAR), part of the Division of Program Coordination, Planning, and Strategic Initiatives in NIH's Office of the



Dr. Geri Donenberg

Director (OD). She will work closely with the institutes and centers to lead the advancement and coordination of HIV/AIDS research at NIH.

Donenberg brings more than 25 years of HIV/AIDS research experience with a focus on understanding the underlying

mechanisms of risky sexual behavior and substance use among youth and designing specially targeted interventions to prevent HIV transmission. Her studies have addressed each stage of the HIV cascade and prioritized the inclusion of diverse HIV-affected populations. Donenberg's research has illuminated HIV-risk mechanisms, conducting prevention and treatment efficacy and effectiveness trials and testing implementation strategies in complex low-resource settings.

Over the past 10 years, Donenberg's research has elucidated the determinants, processes and strategies that will optimize intervention delivery and to conduct hybrid trials to improve implementation outcomes and clinical effectiveness.

A clinical psychologist, Donenberg joins NIH from the University of Illinois - Chicago (UIC) where she is a professor of medicine, psychology and epidemiology and biostatistics, and chair of scholarly activities in the Department of Medicine. She is the founding director of the Center for Dissemination and Implementation Science in Health Disparities, and director of the Healthy Youths Program at UIC.

She earned her bachelor's in psychology and political science from the University of Michigan, Ann Arbor, and her M.A. and Ph.D. in clinical psychology from the University of California, Los Angeles (UCLA). In 2007, she was selected as a Fulbright Scholar in Cape Town, South Africa.

Donenberg has been an active NIH grant reviewer and chair for NIH study sections and has authored more than 170 publications. She has led dozens of research projects, including NIH-supported studies. She was among the first to establish the role of mental health in adolescent HIV risk-taking and to design and implement HIV prevention interventions for youth with mental health distress. Donenberg has been a mentor for 24 NIH-funded career development awards, actively working with marginalized populations, including individuals living with HIV and racial/ethnic and sexual minorities. **R**

Keegan Shares Tips for Combating Anxiety

BY AMBER SNYDER

Everyday life is full of stressors—traffic, looming deadlines, conflicting family schedules. But how do you manage when anxiety creeps into your work life?

Jeanne Keegan, senior project officer in the division of design and construction management in the Office of Research Facilities knows what that's like. She lives with generalized anxiety disorder (GAD) and is open about sharing her experience and coping strategies. She has been an NIH employee for five years and was a contractor prior to that. Overall, she has been involved in NIH construction projects for 19 years.



Jeanne Keegan

"I picked up more work with more responsibilities as my career progressed," she recalled. "I hit breaking points where I would feel overwhelmed and want to quit."

In retrospect, she realized she was experiencing burnout, or a state of mental, emotional and often physical exhaustion brought on by prolonged or repeated stress. Thankfully, Keegan had access to a support system that included trusted mentors, doctors and counselors to help her discuss her reasons for wanting to quit.

"It usually wasn't the job that caused anxiety, but how I handled the things my job threw at me," she realized.

Over the years, she learned to cope with stress and anxiety. Counseling and medication are helpful for Keegan, as are

identifying and avoiding things that

trigger her anxiety. Strong scents such as certain perfumes and colognes can trigger migraines and so, as she explained, any strong scent can elicit anxiety because she doesn't know if it will cause a migraine.

Virtual meetings and hybrid work have been enormously helpful, she said. Having the space on-site to move to a quiet area and having the option to work remotely provide opportunities for people with anxiety disorders to avoid triggering situations. She also prioritizes sleep and exercise, and listens to music and audiobooks to distract from cyclic, anxious thoughts.

Keegan currently has 11 mentees and also has several of her own mentors. She sees mentoring as a productive outlet for her anxiety. "When you take time out of your day to assist someone else, you are taking yourself out of your mental environment to focus on someone else's needs, which can be both a relief and a morale booster," she said.

Finally, Keegan encourages an open and accepting environment with the team she manages.

"You need a supervisor who you're able to talk to," she found. In her own supervisory role, several team members and mentees have come to her and expressed how Keegan's vulnerability helped them feel less alone.

Creating that environment amongst colleagues can also benefit the entire team, Keegan concluded. "Sharing helps bring teams closer together." **R**

SHARING IS CARING

October is Work and Family Month

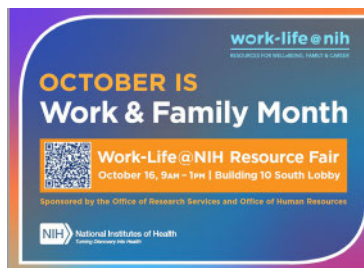
Throughout October, NIH's Office of Research Services will highlight the importance of creating a healthy relationship between work, family and life responsibilities. Whether you are a federal employee, trainee, fellow or a contractor, there are many services available to help support you.

Throughout the month, ORS will provide a robust

calendar of offerings highlighting the five areas of well-being: financial, career, social/family, mental/physical and community. Events include live and archived webinars, fitness classes, resource links and more.

Also, mark your calendar for the Work-Life@NIH Resource Fair on Oct. 16 from 9 a.m. to 1 p.m. in the south lobby of Bldg. 10, which will feature more than 25 exhibitors.

For registration information and access to resources, see: <https://go.nih.gov/Sniw2Qp>



Prostate

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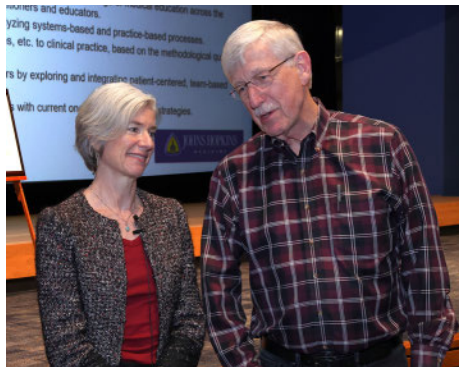
director, current NHGRI distinguished investigator and, most recently, a patient partner in research.

Collins knew he had a higher risk of developing prostate cancer. His father had been diagnosed with the disease 40 years ago and suffered significant side effects from treatment.

When Collins saw his PSA go outside the normal range, he said, “I did my own due diligence, checking out what other institutions do in that circumstance, reading the literature. And, I concluded that our own doctors at the NIH Clinical Center were on the leading edge of research and clinical care. I concluded they were the people I could most count on to take care of me and make sure that whatever happened could add to the body of knowledge about this disease.”

“Our prostate MRI scan saw his tumor,” said Dr. Peter Pinto, senior investigator and urologic surgeon in the National Cancer Institute’s (NCI) Urologic Oncology Branch, who heads the clinical protocol. “We biopsied it multiple times over the years and it remained low grade. Then something changed in the biology of his cancer.”

For a PSA test, less than 5 is considered normal. In March, Dr. Collins’s PSA jumped to 22. A targeted biopsy showed the tumor had become a Gleason-9, on a scale that only goes to 10. The aggressive cancer was pushing through the outer layer of the prostate, but a very sophisticated PET scan



Two weeks before his surgery, Collins chats with Nobel laureate Dr. Jennifer Doudna (l) after her lecture on gene editing. Six weeks after surgery, Collins performs with his band of NIH colleagues at a charity event on campus. PHOTOS: CHIA-CHI CHARLIE CHANG

with high sensitivity for prostate cancer cells found no sign of distant spread.

“The images showed my cancer had grown and spread itself around like a crescent and might have breached the capsule,” recounted Collins. “Then it was time to act.”

Surgery

On April 26, Collins underwent a radical prostatectomy, which removes the entire prostate gland and surrounding lymph nodes.

“Today, this surgery is less invasive with better imaging and there’s less blood loss,” said Pinto, who was the lead surgeon. “You can go back to work sooner. You recover faster.”

Pinto performed a robot-assisted laparoscopic surgery. In the operating room, Pinto used the prostate MRI to guide the surgery “to improve [the chances of] removing all the cancer in the areas where it appeared to

be breaking out,” he explained.

“When I remove the prostate, we go wide where we have to” with the goal of getting clean margins so no cancer is left behind. Using the MRI, he added, “enhances our ability to spare the muscles and nerves around the prostate to reduce the risk of side effects.”

Collins knew post-surgery incontinence was a possibility. “It’s a reality of what happens when you rearrange the plumbing down there,” he said. “That was my experience [initially], but it’s getting much better now.”

A few days after surgery, Collins was re-admitted to the Clinical Center with a gastrointestinal complication that was swiftly addressed by his care team. A few days later, Collins had another unpleasant surprise: he got shingles, despite being fully vaccinated. “There’s a pretty big stress to the body with



At left, an operating room in the Clinical Center. At right, Pinto peers through the console of the da Vinci robot, where he sees a high-definition, magnified version of the surgical area and uses controls to guide tiny robotic hands during surgery. PHOTOS: CC DEPARTMENT OF PERIOPERATIVE MEDICINE



(From l): Drs. Ismail Baris Turkbey, Brad Wood and Peter Pinto pose next to the high-tech, portable UroNav in the Clinical Center. PHOTO: DANA TALESNIK

major surgery. I guess the immune system was distracted and the sleeping chickenpox virus took advantage,” Collins said.

The surgery was a success. “Using surveillance—PSA testing, MRI and biopsies—we caught the cancer before it became metastatic,” said Pinto. And, on July 31, Collins received a happy lab result, when his PSA was undetectable, less than 0.1. He’ll need to have this checked every three months for the next couple of years, but the signs now are really good.

Pinto said, “It’s great to see Dr. Collins benefit from all the work he supported as director here for so many years.”

Precision

Prostate cancer screening and surgical techniques have come a long way over the past decade, thanks to imaging technology pioneered by NIH.

For many years, Pinto was frustrated by testing methods that frequently led to overtreatment or missed aggressive cancer entirely, a standard of care that confounded doctors and left patients leery of getting tested in the first place.

“As a urologist, the idea of a PSA screening test leading to a “blind” biopsy really disturbed me,” said Pinto. “I couldn’t think of any other solid cancer where a blood test led to a biopsy of the organ that was not directed to where the tumor was, instead just hoping to hit the cancer.” For decades, that was what doctors did. “I came to NIH to solve this problem.”

Pinto has worked at NIH for 21 years, collaborating with the same prostate imaging team—radiologists Dr. Peter Choyke, Dr. Ismail Baris Turkbey and Dr. Brad Wood, and pathologist Dr. Maria Merino—who together have changed the way prostate cancer is now detected.

Today, clinical guidelines advise a prostate MRI should accompany the PSA test if cancer is suspected. Now, if further testing is needed, there are new devices that offer a targeted biopsy. The biopsy device

combines prostate MRI with ultrasound to direct the biopsy needles into suspicious cancer areas and can be performed in a doctor’s office.

“Over the past 20+ years, our NIH prostate team, working with medical industry partners, has taken this new biopsy device, UroNav, from concept to commercialization,” Pinto said. “We built it from the ground up and now MRI-directed fusion

“It was incredibly reassuring to see the remarkable compassion and medical care I received...I feel really good about this personal insight into the kind of care the NIH Clinical Center gives to people who come here.”

-DR. FRANCIS COLLINS

biopsies to diagnose prostate cancer is pretty much standard of care.”

With this imaging fusion technology, Collins commented, “You can be confident, when you do it this way, that the biopsies really are reflecting what’s going on and you haven’t missed the most important part of the prostate.”

Now, the NIH team has begun developing artificial intelligence analysis to better detect and confirm tumor characteristics. Pinto also is working on decreasing the harms of current treatments through his NIH clinical protocols that destroy just the tumor(s) within the prostate, an emerging field called focal therapy.

Someday, these advances will help determine which patients with prostate cancer will never need treatment and which may progress over time. Active surveillance is key.



Dr. Peter Choyke (r) points at a scan, collaborating with Pinto.

PHOTO: RHODA BAER

Pinto said, “If you could ensure the cancer is low grade and will not over time change, so you will die with it not from it, then we can just [watch it] and leave you alone.”

Care

Collins is grateful to have received his care at NIH.

“It was incredibly reassuring to see the remarkable compassion and excellent science and medical care that I received at the Clinical Center,” Collins said. “I can’t say enough about how impressive their team was with every detail.”

From the surgery, imaging and pathology team to the urology fellows to the nurses, “Everyone involved in my care was unfailingly polite, courteous, reassuring and supportive,” he added. “So I feel really good about this personal insight into the kind of care the NIH Clinical Center gives to people from all over the world who come here.”

Hope

Prostate cancer is still the second leading cause of cancer death for men and the most common non-skin cancer in men. But NIH-led advances in screening, detection and management are offering new hope.

“As we see these new technologies and advances from our clinical protocols become adopted more widely, we expect death rates will drop,” said Pinto, “and there will be less pain and suffering.”

Collins continues to candidly discuss his prostate cancer journey to impart lifesaving information. “I’m trying to be as transparent as possible,” he said. “I hope my experience will benefit others.” **R**

Poster

CONTINUED FROM PAGE 1

trainees,” she said. “For many of them, it might be their first summer internship program and that can be overwhelming and intimidating.”

Lugo-Escobar has worked alongside a team for several months in advance of the event, developing website content, managing registration, coordinating with NIH institutes and centers, and initiating conversations with this year’s interns.

The Poster Day event provides students from different education levels—high school, undergraduate, graduate and professional schools—the ability to showcase their research, and an opportunity to practice public speaking. Three summer interns shared their experiences.

College junior neuroscience and dance double major Rachel Chen combined her passion for both subjects and conducted research incorporating physical activity to curb depression symptoms. She interned in the National Institute of Mental Health (NIMH) genetic epidemiology branch under Dr. Kathleen Merikangas.

Chen’s project investigated whether physical activity and sleep interventions for adolescents to reduce depression symptoms included both physical activity and sleep. She and her team found that, though previous literature connects sleep and physical activity, nothing connects the two when targeting an intervention for depression.

Intern Ava Lorenzetti also spent her summer at NIMH, in Bldg. 35. She kept busy, “always doing something, whether running behavior [tests] or analyzing results.” In

her assigned lab, Lorenzetti and her colleagues ran an experiment in which they inhibited neurogenesis in lab rats. They aimed to find out how neurogenesis affected their approach/avoidance behavior and decision-making in an open-field test.

The test box was cold in one corner. Eventually, food was put into the cold corner to try to lure the rats away from the warmer part of the chamber. Ultimately, they observed a difference between the rats with and without neurogenesis. The temperatures affected all the rats’ behavior. However, the food reward was less successful at drawing the rats that lacked neurogenesis to the cold corner. Those rats moved more, spent less time in the conflict zone and took longer to start eating than the neurogenesis-intact rats.

Elise Kinyanjui, a college senior, worked in the Stroke, Cognition And Neuroepidemiology (SCAN) lab at the National Institute of Neurological Disorders and Stroke (NINDS). Kinyanjui worked with the postdoctoral researcher Dr. Marco Egle and senior investigator Dr. Rebecca Gottesman to research how smoking and multiple chronic conditions, such as cancer and atrial fibrillation (AFib), in mid-life are associated with developing incident dementia later in life. The project used cluster analysis to test this connection.

The researchers ultimately found that people who smoked or had metabolic conditions, peripheral arterial disease, AFib or heart failure are all at higher risk of developing dementia. Kinyanjui also said



Above, interns pose with NHLBI staff. From l, Kristen Morgan, director, Office of Education; Grace Jiang, intern with her poster; Auriel Sanders, postbac fellow; Hyesik Kong, staff scientist; Adeola Michael, deputy director, Office of Education. Below, throngs explore scientific posters.

PHOTOS: MARLEEN VAN DEN NESTE



they found mortality to be a big factor in the association of dementia and chronic conditions. The intern explained that clusters with no significant association to dementia, like renal dysfunction, may lack association because some in the sample died before the average age when dementia develops.

For the OITE office, Summer Poster Day centers on ensuring that all students, whether it be their first internship, or as they transition into the workforce or next educational stage feel confident and prepared in presenting their research.

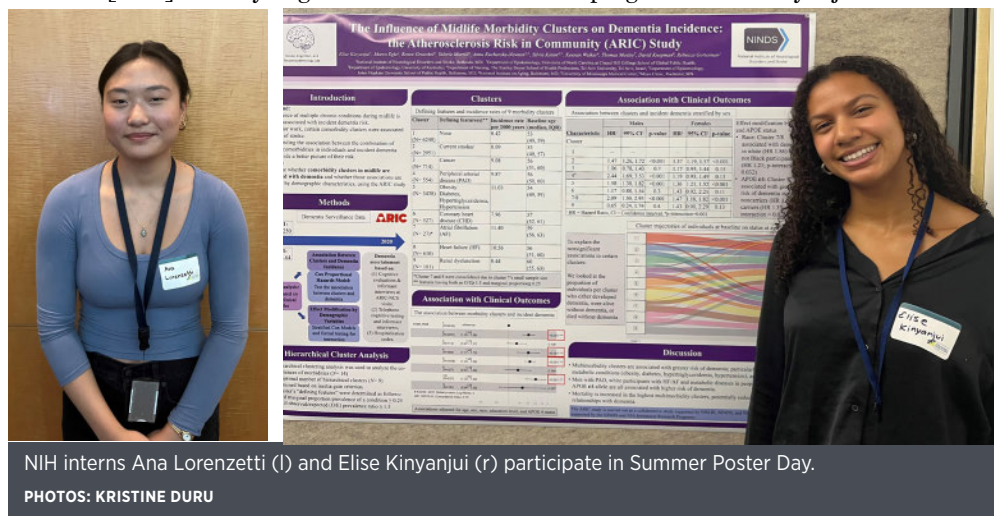
“Summer Poster Day celebrates the intern’s hard work and dedication throughout the summer. It provides them with a platform to share their research and accomplishments with their peers and the broader NIH community,” said Lugo-Escobar.

Each intern talked about what they are taking away from their time at NIH.

Chen described the warmth of the NIH community and expressed appreciation for NIH opportunities such as grad fairs, lectures and connecting with other interns. Additionally, her collaboration with NIH’ers and hearing other ideas taught her there is no set path to research. “It’s been interesting having experience working with people at all different levels,” Chen said.

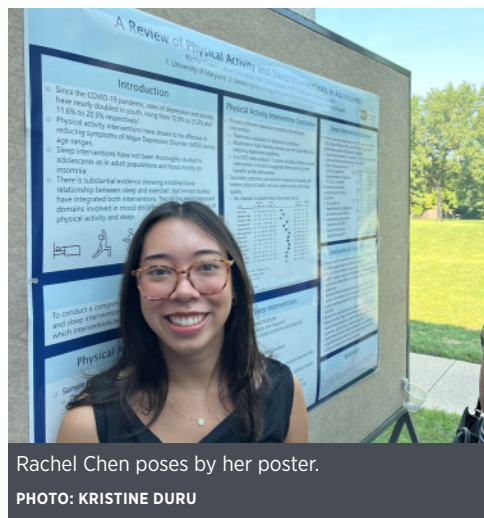
Kinyanjui said, “A summer internship at the NIH is different than an internship at a university. I think coming to NIH has made research feel less like an undergraduate, academic practice and more valuable, like you have a job to do.”

She learned new skills in discerning what data is most significant to the public. And



NIH interns Ana Lorenzetti (l) and Elise Kinyanjui (r) participate in Summer Poster Day.

PHOTOS: KRISTINE DURU



Rachel Chen poses by her poster.

PHOTO: KRISTINE DURU

she also learned more about the world of cluster analyses, how to apply them in real life and most importantly, the value of paying attention to your health to prevent diseases like dementia later in life.

Lorenzetti called her summer at NIH a comprehensive, enlightening experience. “Being here and seeing the specific subjects that people are working on, seeing other people’s posters—it’s opened my eyes to the work that NIH is doing, and it’s really cool,” she said.

“[Interns] need advice and support for their career and professional development,” said Lugo-Escobar. “They also need guidance to navigate research group dynamics and to prepare for these types of events.”

What’s next for these interns? Chen and Kinyanjui have resumed their studies at the University of Maryland and St. Mary’s College of Maryland, respectively. Chen is also working in a lab, conducting more psychology and neuroscience research. As for Lorenzetti, her college career is just beginning. She is a freshman at the University of Michigan and plans to major in neuroscience.

Beyond college, Kinyanjui and Chen hope to work with their NIH colleagues to turn the work they’ve done this summer into research papers. Kinyanjui hopes to return to NIH after her senior year as a postbac to continue building on her research. And after pursuing her master’s and doctoral degrees, she envisions herself employed at NIH long-term.

“I think NIH is a great facility,” Kinyanjui said. “They have great teaching programs and a lot of opportunities here. I’ve appreciated the time I’ve had here, and I hope I have the opportunity to come back.”

Foil the Flu: Staff Vaccinations Begin on Sep. 30

Foil the Flu, the annual seasonal influenza immunization program for all NIH workers, begins Monday, Sept. 30 and runs through Nov. 8. You need a valid NIH identification badge to receive your seasonal flu shot though Foil the Flu.

All federal employees, trainees and contractors are strongly encouraged to be immunized against the flu. All NIH staff who have contact with Clinical Center patients must participate in the annual Foil the Flu program. The NIH will not offer a Covid-19 vaccination campaign this fall.

Make an Appointment

The flu vaccine will be given by appointment only for all sites (including clinics in

Montana, North Carolina, Baltimore and Frederick, Md.), through an online registration system. To schedule your appointment, visit www.foiltheflu.nih.gov.

Please do not schedule an appointment at Harbor Hospital or Poolesville unless you work onsite at those locations. Simultaneous clinics will begin in satellite campuses across the country. Take care to select the correct site when registering to make an appointment.

Prepare for Your Appointment

Follow masking guidelines. Please do not arrive for your scheduled appointment time more than 10 minutes early. Wear clothing that allows easy access to the upper arm.

All staff with direct patient contact must be vaccinated against influenza

1 BUILDING 10 - MAIN CAMPUS SITE - 7TH FLOOR ATRIUM

Sept. 30 - Oct. 4	8:00-11:30am; 12:30-3:30pm
Oct. 10	6:00-11:30am; 12:30-7:00pm
Oct. 11	8:00-11:30am; 12:30-3:30pm
Oct. 15-16	8:00-11:30am; 12:30-3:30pm
Oct. 21-23	8:00-11:30am; 12:30-3:30pm
Oct. 30 - Nov. 1	8:00-11:30am; 12:30-3:30pm
Nov. 4-8	8:00-11:30am; 12:30-3:30pm

OFF CAMPUS SITES

Oct. 7-9	9am-3pm	2 Shady Grove
Oct. 17-18	9am-3pm	3 BRC
Oct. 21	9-11:30am	4 Poolesville
Oct. 24-25	9am-3pm	5 Fishers Lane
Oct. 25	1-2:30pm	6 Harbor Hospital
Oct. 28-29	9am-3pm	7 Rockledge

Schedule your appointment today!

NINDS Nonprofit Forum Encourages Patient Engagement, Empowerment

BY SHANNON E. GARNETT

The National Institute of Neurological Disorders and Stroke (NINDS) held its 18th nonprofit forum, “Progress through Partnership” in July. The forum convened representatives from patient advocacy groups, professional societies, industry, federal agencies and people with lived experience (PWLE) from around the country to discuss the importance of patient empowerment and to explore increased opportunities for patient engagement.

Organized in 2005, the annual forum provides a way for organizations to collaborate and share experiences and information with each other, and for NINDS to learn how to more effectively work with patient advocacy groups to address research needs and challenges.

“This is probably the best meeting of the year for NINDS. It’s fantastic for our staff to mingle with the people we are working for and with,” said NINDS Director Dr. Walter Koroshetz in welcoming remarks.

“It’s a good opportunity for us to talk to folks and learn. It also motivates our staff and, hopefully, generates collaborations that are productive for all our shared agendas.”

The day-and-a-half hybrid meeting, held at the Porter Neuroscience Center, began with a keynote presentation titled, “From Worrier to Warrior: How Community Engagement Gets Me Closer to a Cure,” by author and activist Mindy Uhrlaub. As an asymptomatic carrier of the C9orf72 gene— which causes the rare neurodegenerative diseases amyotrophic lateral sclerosis (ALS) and frontotemporal dementia (FTD)—she spoke about her journey with having a rare genetic disease. Both Uhrlaub’s grandfather and mother had ALS.

“When I received my positive test, I made it my mission to improve the conditions for people like my family members,” said Uhrlaub, who is a founding member of End the Legacy, a nonprofit organization dedicated to the needs of people with genetic ALS/FTD. “When it comes to people at risk of developing rare genetic diseases, collaboration is everything. There’s so much work,” she said.

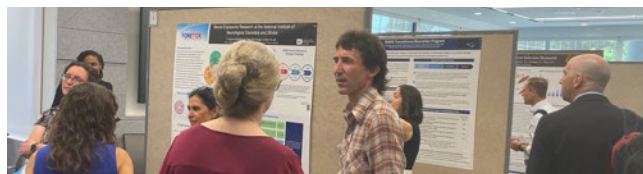
Following the keynote, Dr. Richard Benson, director of the NINDS Office of Global Health and Health Disparities, moderated a special panel focused on “Increasing Patient Participation and Engagement in Rural and Minoritized Populations.” Presenters in the session addressed the unique needs of engaging individuals that are not adequately included in the research process.

“Getting insight from community members can improve the science, influence the research questions and makes our research more relevant,” said panelist Dr. Rakale Quarells, professor

of Community Health and Preventative Medicine at Morehouse School of Medicine. She was joined on the panel by Dr. Suma Babu, a neurologist specializing in ALS research at Massachusetts General Hospital and Dr. Astrid Suchy-Dicey, principal investigator of the Brain Aging Study at Huntington Medical Research Institutes.

This year’s meeting included several panel discussions, and multiple occasions for attendees to connect with each other during networking and poster sessions and with NINDS during a “meet and greet” opportunity with program staff.

In “Engaging Participants as Partners in Research:



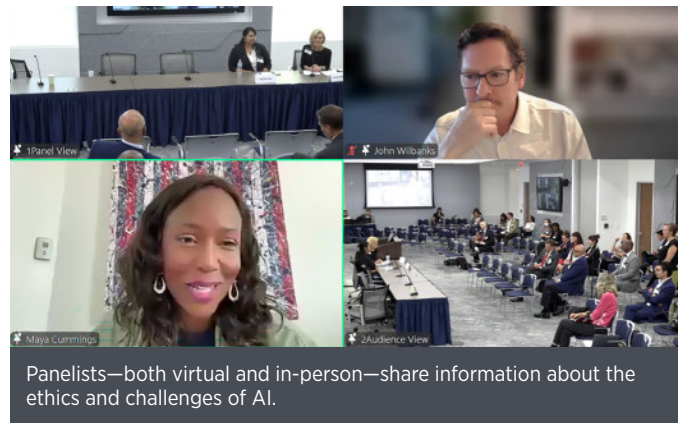
A poster session provides one of several networking opportunities.

PHOTO: REBEKAH CORLEW/NINDS

Data and Its Use,” panelists discussed the importance of involving patients and their advocates in the research process, particularly regarding how patient data is used.

“We recognize there isn’t a one-size-fits-all approach here and that engagement needs to be tailored to the needs and experiences of both people and communities themselves,” said moderator Dr. Adam Berger, director of the Division of Clinical and Healthcare Research Policy in NIH’s Office of Science Policy. “It’s critical we recognize that it truly is research participants who empower the research enterprise by entrusting us with their data and by holding us accountable to how that data is used.”

During the “Artificial Intelligence (AI): Opportunities and Challenges for Nonprofit Organizations and Patients” session, speakers from various backgrounds including researchers, academia and PWLE, shared timely information about the ethics and challenges of AI.



Panelists—both virtual and in-person—share information about the ethics and challenges of AI.

Panelist Laura Adams, a senior advisor at the National Academy of Medicine, mentioned four things that differentiate AI from other digital advances: Speed, scalability, ubiquity and democratization. “All of these things make it (AI) extremely difficult to govern and regulate. It is without question outpacing our capacity to govern it. We can’t even get ahead of it to understand it fast enough to regulate it,” said Adams.

On day two, NINDS Acting Deputy Director Dr. Amy Adams shared four key themes heard throughout the forum—accountability, inclusion, equity and trust. She emphasized NINDS’s renewed focus on building trust.

“Our mission is focused on improving the neurological health of all people. We have to find better ways to engage with all people throughout the research process,” Adams said. “I think collectively the direction is moving toward a more partnership-based research model. Thank you for engaging with us as partners as we move forward.”

A discussion on “Engaging Patients Throughout the Clinical Trial and Drug Development Process” led by Louise Vetter of the Lupus Foundation of America, explored the opportunities, hurdles and ethics of collecting, sharing and using patient data.

The meeting concluded with a forum favorite, “Success Stories: Co-Learning Amongst Nonprofits.” The panel, moderated by Jennifer French, executive director of Neurotech Network— featured several presentations on how advocacy ambassador programs help nonprofit organizations and PWLE learn about and understand research and the clinical trials process so they can become more engaged partners.

For more information on the NINDS Nonprofit Forum, including recordings of the 2024 meeting, visit <https://www.ninds.nih.gov/nonprofit-forum>.



Above, the panel “Increasing Patient Participation and Engagement in Rural and Minoritized Populations” highlighted the unique needs of engaging individuals who are not adequately included in the research process. Below, speakers at one panel discuss the importance of involving patients and their advocates in the research process, particularly regarding how patient data is used. PHOTOS: SHANNON GARNETT



Blood Test Predicts 30-Year Cardiovascular Disease Risks for Women

NIH-supported research has found that measuring two types of fat in the bloodstream along with C-reactive protein (CRP), a marker of inflammation, can predict a woman's risk for cardiovascular disease decades later. These findings were published in the *New England Journal of Medicine*.



PHOTO: ELNUR/SHUTTERSTOCK

Investigators collected blood samples and medical information from 27,939 women (median age 55 years), who were then followed for 30 years. During this period, 3,662 study participants experienced an adverse cardiovascular event. Researchers assessed how high-sensitivity CRP, along with low-density lipoprotein (LDL) cholesterol and lipoprotein(a), or Lp(a), a lipid partly made of LDL, singularly and collectively predicted these events.

Researchers found that women with the highest levels of LDL cholesterol had a 36% increased risk for heart disease compared to those with the lowest levels. Those with the highest levels of Lp(a) had a 33% increased risk, and those with the highest levels of CRP had a 70% increased risk.

When all three measures were assessed together, participants with the highest levels had more than a 1.5-times increased risk for stroke and more than a 3-times increased risk for coronary heart disease compared to women with the lowest levels.

The researchers note that while only women were assessed in this study, they would expect to find similar results in men.

Immune cells can sense excess cholesterol accumulation or activate in response to plaque build-up. This creates a hyperinflammatory environment—where plaque can form, become larger or even rupture—and cause cardiovascular events.

Primary prevention is the best way to support cardiovascular health. People with increased risks may use medication to lower cholesterol and/or reduce inflammation.

LDL cholesterol is routinely measured by healthcare providers and can be treated with widely available therapies, such as statins. However, standard Lp(a) and CRP screening recommendations can vary.

Cannabis and Hallucinogen Use among Adults Remained at Historic Highs in 2023

Past-year use of cannabis and hallucinogens stayed at historically high levels in 2023 among adults aged 19 to 30 and 35 to 50, according to the latest findings from the Monitoring the Future survey. In contrast, past-year cigarette usage remained historically low.



Drug and alcohol use update in young adults from the Monitoring the Future survey

PHOTO: PROSTOCK-STUDIO/SHUTTERSTOCK

Past-month and daily alcohol use continued a decade-long decline among those 19-30 years old, with binge drinking reaching all-time lows. However, among 35-50-year-olds, the prevalence of binge drinking in 2023 increased.

Reports of vaping nicotine or cannabis in

the past year among adults 19-30 rose over five years, and both trends remained at record highs in 2023. Among adults 35-50, the prevalence of nicotine and cannabis vaping stayed steady from the year before.

For the first time in 2023, 19-30-year-old female respondents reported a higher prevalence of past-year cannabis use than their male counterparts, reflecting a reversal of the gap between sexes. Conversely, male respondents 35-50 years old maintained a higher prevalence of past-year cannabis use than female respondents of the same age group, consistent with observations from the past decade.

Since 1975, the Monitoring the Future study has annually surveyed substance use behaviors and attitudes among a nationally representative sample of teens. Participants self-report their drug use behaviors across various time periods. Key 2023 survey findings include:

Cannabis use in the past year and past month remained at historically high levels for both adult age groups in 2023. Nicotine vaping among adults 19-30 maintained historic highs in 2023 and remained steady in adults 35-50.

Hallucinogen use in the past year continued a five-year steep incline for both adult groups, reaching 9% for adults 19-30 and 4% for adults 35-50 in 2023.

Alcohol remains the most used substance in the study. Past-year alcohol use among adults 19-30 has showed a slight upward trend over the last five years; however, past month, daily and binge drinking all remained at study lows in 2023. These numbers have decreased from 10 years ago.

Around 84% of adults 35-50 reported past-year alcohol use in 2023, not a significant change from the year before or the past five or 10 years.

Atypical Metabolite Levels at Birth May Be Linked to Increased SIDS Risk

Newborns who had an atypical pattern of metabolites were more than 14 times as likely to die of sudden infant death syndrome (SIDS) compared to infants who had more typical metabolic patterns, according to a study funded in part by NICHD.

Metabolites are molecules produced by the body's various chemical reactions. Researchers found that infants who died of SIDS had a specific pattern of metabolites compared to infants who lived to their first year. The researchers

believe that checking for this pattern could provide a way to identify infants at risk for SIDS. The study was conducted at the University of California San Francisco School of Medicine and appears in *JAMA Pediatrics*.

SIDS is the sudden death of an infant that remains unexplained after a complete investigation. From more than 2 million infants born in California, researchers compared newborn screening test results of 354 SIDS cases to those of 1,416 infants who survived to at least one year old.

The state screens all its newborns for many serious disorders. Test results include checking for metabolites that are markers for disorders and conditions.

The authors say that testing for metabolic patterns may provide a way to identify infants at risk for SIDS soon after birth, which could inform efforts to reduce SIDS risk. Similarly, research on the biochemical pathways that produce the metabolites linked to SIDS may yield insights into the causes of SIDS and ways to reduce its risk.



An NIH-funded study suggests checking for metabolite pattern at birth could reduce SIDS risk.

PIXEL-SHOT/SHUTTERSTOCK



Above (from l), piccolo trumpet soloists Michael Harper and William Gerlach; CC CEO Dr. James Gilman welcomes NSO; timpanist Jauvon Gilliam; conductor Steven Reineke **PHOTOS: MARLEEN VAN DEN NESTE**

‘OUR GIFT TO YOU’

Full NSO Returns to Enlighten Staff at the Clinical Center

The National Symphony Orchestra (NSO) serenaded NIH staff and patients with an array of classical pieces during its 12th annual NSO-NIH Sound Health concert on Sept. 4 in the NIH Clinical Center (CC) atrium.

The full, 60-piece orchestra performed music that spanned several centuries and continents, including works by Ludwig Van Beethoven, Antonio Vivaldi, Aaron Copland and Samuel Coleridge-Taylor, and contemporary composers Takashi Yoshimatsu and Carlos Simon.

The melodies were diverse, each evoking different tones and emotions: from dark, ominous and melancholy to light, bright and joyful.

“I love exploring the important, huge,

mysterious connection between music and mental and physical health,” said conductor Steven Reineke. In performing at NIH, “We get to give this gift to doctors, nurses, patients and staff,” he said. “Thank you for all the work you do here, day in and day out.”

Sound Health is an ongoing partnership between NIH and the Kennedy Center for the Performing Arts that studies how music affects mood, brain function and health.

“The Sound Health program explores the way music can reduce stress and promote wellness for all,” noted CC CEO Dr. James Gilman in opening remarks.

The performance was co-presented by the CC and the Foundation for Advanced Education in the Sciences.

Smaller groups of NSO musicians are slated to perform in the CC’s atrium in the coming months. These chamber concerts will take place at 12:30 p.m. on Dec. 12, Jan. 28 and May 15.



Above, violinist Mae Lin; below, double bass soloist Ira Gold



Above, the full 60-piece orchestra performs an array of classical pieces for hundreds assembled. At right, harpist Deb Braun