

October 11, 2024 Vol. LXXVI, No. 21

Event Honors NIH Partnership with Voices For Our Fathers Legacy Foundation BY ERIC BOCK

NIH recently debuted a plaque honoring the memory of the African American men unethically treated in the U.S. Public Health Service (USPHS) Untreated Syphilis Study and the 50th anniversary of the National Research Act at the National Library of Medicine (NLM) herb garden, across from Bldg. 38, on Sept. 19.

"This plaque shines a light on the injustices of the past, not letting us forget them so they are never repeated," said NIH Director Dr. Monica Bertagnolli during the dedication



In 1932, the study began in Alabama. Originally called the "United States Public Health Service Study of Untreated Syphilis

in the Negro Male at Tuskegee and Macon County, Alabama," the study enrolled 625 African American men. Researchers conducting the study did not obtain informed consent and did not offer treatment, even after it was widely available.

"Much is known about the inhumane, immoral, unethical treatment of these men," said Lillie Tyson Head, founding president of the Voices For Our Fathers Legacy Foundation, a nonprofit formed by the

National Institutes of Health



Members of the Voices For Our Fathers Legacy Foundation, who are descendants of men unethically treated in the Untreated Syphilis Study, and NIH leaders gather around the commemorative plaque in the National Library of Medicine herb garden. **PHOTO: CHIA-CHI CHARLIE CHANG**

SEE LEGACY, PAGE 6



NIDCR interns get a taste of science. See p. 10.

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STATUS REPORT NICHD-Led Meeting Tackles Gynecologic Pain BY AMBER SNYDER

Heart emojis

flooded the lower right corner of the Zoom screen as

Noa Fleischacker and Keena Batti

shared their stories. Their tales of years of undiagnosed

vulvovaginal pain-

similar despite the



Dr. Laura Payne of Harvard Medical School

two women living two thousand miles apart—resonated with many of the approximately 300 viewers of the Third Gynecologic Pain Research Virtual Meeting.

The *Eunice Kennedy Shriver* National Institute of Child Health and Human

TWO DECADES OF ENRICHMENT Training Center Offers Instruction at Every Level BY DANA TALESNIK



Barb LeClair (I) and Elena Juris PHOTO: DANA TALESNIK

You're ready. You're motivated. You want to hone an existing skill or learn a new one. Let's do this! But...where do you find the right course?

Training is valuable at every career level, yet a lot of NIH'ers don't know where to find growth opportunities. In many cases,

BRIEFS

Spirituality Interest Group Sets Oct. 15 Next Presentation

The NIH Religion, Spirituality and Health Scientific Interest Group (RSH-SIG) will present its next virtual presentation on Tuesday, Oct. 15, 2024 from ______ 2 - 3 p.m. ET.



Dr. Joseph Currier

Dr. Joseph Currier will present "Training Mental Health Professionals in Spiritual and Religious Competencies: Current Status and Future Horizons."

Currier is a licensed psychologist and Professor of Psychology at the University of

South Alabama. His research broadly focuses on understanding and addressing the multifaceted role of spirituality/religion in trauma, moral injury, and other mental health challenges in education, training and clinical practice.

This talk will be on Zoom (https://nih.zoomgov. com/j/1600810810?pwd=ghyJhmHX09mo5Qlx-068KUagkf41C21.1) and recorded. It is free and open to the public and no registration is required.

Individuals needing sign language interpretation should send a request to Joan Romaine at RSH-SIG@mail.nih.gov at least five business days in advance. For information on the RSH-SIG, visit: https://go.nih.gov/GAX7Dbx.

Diversity Seminar Will Delve Oct. 17 Into Data Science

The Office of the Chief Officer for Scientific Workforce Diversity (COSWD) will host its first Scientific Workforce Diversity seminar of the 2024–2025 season on Thursday, Oct. 17 from 1:30 – 3:00 p.m. ET.

The virtual seminar, "How Do Diverse Perspectives Enhance Data Science Outcomes?" kicks off with a conversation on the benefits of diverse perspectives in data science. Panelists will describe how diverse representation in data science enhances machine learning and artificial intelligence accuracy, particularly in the context of health sciences, such as in electronic health record data sets.

This event will include closed captioning. Sign language services and other reasonable accommodations are available upon request using the registration form. For more information, including the registration link, see: go.nih.gov/rizAalf.





(L to r): Monique Robinson, strategist, EDI; Shauni Jones, architect, Cleshette Brooks, lead project officer, ORF; Dr. Karen Parker, director, Sexual and Gender Minority Research Office; Colleen McGowan, director, ORS; Lisa Hoffman, space management specialist, ORS; Kevin Williams, director, Office of Equity, Diversity and Inclusion (EDI) **PHOTOS: CHIA-CHI CHARLIE CHANG**

First Gender-Inclusive Bathroom Opens on NIH Campus

The restrooms on the first floor of Bldg. 31B have re-opened as gender-inclusive bathrooms.

"This is the first gender-inclusive bathroom at NIH," said Office of Research Services Director Colleen McGowan during a recent ribbon-cutting ceremony. "It gives people a safe space and to celebrate who they are." The restrooms are located just outside the Division of Personnel Security and Access Control "badging office" next to the elevators. McGowan said one of the first things new hires see after they receive their badges is NIH's commitment to Diversity, Equity, Inclusion and Accessibility (DEIA).

Construction had begun in the fall of 2023.



At left, inside the new restroom. At right, Williams, McGowan, Brooks and Parker cut the ribbon.

Oct. 30

NEI to Host Annual 5K Walk/Run/Roll

On Wednesday, Oct. 30, the National Eye Institute (NEI) will host its 5th NEI 5K Walk/Run/Roll on the Bldg. 1 front lawn, rain or shine.

The course will exit campus, circumnavigate its perimeter and return through security (so remember to bring your ID badge).

For more details and to register as an individual or a team, visit nei.nih.gov/nei5k.

This event is sponsored by NEI in partnership with the Office of Research Services' Division of Amenities and Transportation Services and the NIH R&W Association. If you or someone you know requires ASL interpretation services to participate, reach out to the NIH interpreting office by emailing nih@ainterpreting.com.

Behavioral and Social Sciences Nov. 6-7 Research Festival Returns

Save the date for the annual NIH Behavioral and

Social Sciences Research (BSSR) Festival. This hybrid event will take place November 6 and 7 from noon – 4:00 p.m. ET. Attendees can participate in person at the Natcher Conference Center or watch on videocast: https://videocast.nih.gov/ watch=55231.

The festival—organized by the NIH Office of Behavioral and Social Sciences Research (OBSSR) will highlight a diverse range of outstanding research from across NIH, offering a comprehensive view of the latest NIH-funded BSSR projects and their impact in biomedical research.

This year's festival will include a keynote panel on artificial intelligence and BSSR; a fireside chat with NIH Director Dr. Monica M. Bertagnolli and OBSSR Director Dr. Jane Simoni; exhibits from offices across the Division of Program Coordination, Planning, and Strategic Initiatives (DCPCSI) and in-person networking opportunities each day.

For more details, see: obssr.od.nih.gov/ BSSRfestival.

Experts Convene at NIH to Discuss Long Covid

The National Institute of Allergy and Infectious Diseases (NIAID), in collaboration with the Foundation for the National Institutes of Health (FNIH), co-hosted a workshop titled, "RECOVER: Treating Long Covid (RECOVER-TLC)-Navigating the Pathway Forward." The three-day workshop took place in the John Edward Porter Neuroscience Research Center on NIH's campus in September.

There were 180 in-person and more than

Marrazzo and Dr. Lindsey Baden, vice president of clinical research at the Brigham and Women's Hospital and Harvard Medical School, co-chaired the workshop.

The workshop follows on a recent announcement by Bertagnolli describing the new RECOVER-TLC program, which is designed to develop



Dr. Lindsey Robert Baden (I), vice president of clinical research at Brigham and Women's Hospital, and NIAID Director Dr. Jeanne Marrazzo speak to participants about RECOVER.

PHOTOS: CHIA-CHI CHARLIE CHANG

1,200 virtual participants, including Long Covid researchers, healthcare providers, patients, advocacy organizations, industry partners, federal scientific agencies, and federal policymakers.

NIH Director Dr. Monica Bertagnolli, along with FNIH CEO Dr. Julie Gerberding gave welcoming remarks to open the meeting. NIAID Director Dr. Jeanne

therapeutic interventions for Long Covid and to provide these to health care providers and their patients as rapidly as possible.

Attendees discussed the current research landscape and helped plan the **BECOVEB-TLC** program including governance, agent prioritization, study design and outcome measures. This new

program builds on NIH's RECOVER ongoing observational cohort studies and clinical trials addressing Long Covid.

NIAID will lead the new program, leveraging its expertise in infectious and immunologic diseases and conditions and its experience in conducting Covid-19 clinical trials. This program will provide a clear path

> for ongoing scientific and community engagement to assess new ideas, identify potential therapeutics and biologics, and execute innovative study designs.

Importantly, RECOVER-TLC will provide additional clinical trial capacity, building on existing and new RECOVER clinical trial sites, to involve investigators and participants who are committed to Long Covid research and clinical care.



FNIH staff gather at an information table at the workshop.



neurodegenerative disease Niemann-Pick type C1.

IMAGE: I. WILLIAMS/NICHD

The NIH Record

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FNIH CEO Dr. Julie Gerberding (c) speaks on a panel as NIH Director Dr. Monica Bertagnolli (I), Marrazzo and Baden look on.

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National Institutes of Health

Turning Discovery Into Health



Training CONTINUED FROM PAGE 1

you need look no farther than your own backyard.

For 20 years, the NIH Training Center (NIHTC) has provided professional development courses to staff, with a range of offerings that have evolved based on the changing needs of NIH'ers.

"We've launched more leadership programs, more career development programs and we've expanded the types of course areas that we cover," said NIHTC Director Elena Juris. "We started from a really strong core. Now we offer more courses and more variety."

Types of training include leadership and supervisory coaching; individual development consulting; acquisitions, budget and data skills; computer classes; soft skills courses from time management to communication; and the consistently popular

pre-retirement planning. "We now have something for everyone, from Grade-5 all the way through to the

senior executive," said Kristen Dunn-Thomason, director, Workforce Support and Development Division, which oversees the Training Center in NIH's Office of Human Resources. "It's pretty unique in terms of having that range of availability."

In the early days, the NIHTC offered only a senior leadership program. Soon, executive

and mid-level leadership programs were added. For a time, NIH's parent agency, the Department of Health and Human Services (HHS) consolidated and centralized training under the hub of HHS University.

"But we made a last-ditch appeal that we had classes that needed to be done here because they were NIH-specific," recalled Dunn-Thomason. Eventually, HHS University stopped offering classes and the NIHTC began expanding into the areas that had been under the HHSU purview—soft skills, COR [contracting officer's representatives] and pre-retirement to name a few.

Learning Opportunities

- *Course catalog*: https://go.nih.gov/8mnvp2p
- *Leadership Programs*: https://go.nih.gov/GQjd0cZ
- Career Development Programs: https://go.nih.gov/CPWpjlU
- Coaching & other individualized services: https://go.nih.gov/cDvq420

An ongoing priority since the beginning is the focus on fellows and interns. The Management Intern and the Presidential Management Fellows programs—which predate NIHTC's founding—remain a big slice of their efforts.

Over the years, NIHTC staff have adapted training based on participant and leadership feedback. More recently, they've added civility, diversity and equity courses, the Emerging Talent Program for GS 5-11, and they continue to add specialized group trainings that support each institute and



Front row (from I): Moneca "Mo" Hill, Amber Avila, Shadae Cherenfant, Juris, LeClair, Razell Harris, Loseh Ishicheli, Briana James, Kristen Dunn-Thomason, Danielle Sullivan; Second row: Albert Sun, John Edmond Jr., Glenn Dempster, Onella Phillip-Gray, Nabilah Pape, Bob Michon **Photo: DANA TALESNIK**

center (IC). Flexibility is key.

"When the pandemic hit, there was no hesitation. We converted all our classes from in-person to virtual," recounted Barb LeClair, NIHTC deputy director.

"People had registered and paid for our classes. They needed them," added Juris. "We found a way to keep that running seamlessly until we could return on site."

During that difficult period, NIHTC played a vital role as a unifier.

"We bring people together to learn a particular topic and, in pandemic times, that was especially helpful for increasing team

morale while people were largely dispersed," noted LeClair.

Many courses remain virtual though some classes—which benefit from personal connections or hands-on training—have returned in person at the center's White Flint and campus locations.

The cost of NIHTC courses remains competitive with private companies.

"We provide training [often] at a lower cost while providing NIH-focused content with a network of NIH subject matter experts to help keep our [material] current," said Juris.

And that fee-for-service flexibility has made the NIHTC somewhat budget-proof over the years, noted Dunn-Thomason.

"We don't need to wait for a whole budget cycle to change or add programs," she said. "We never got cut because we make our own revenue." In fact, they often added classes during tighter budget periods. Of course, if a program is big enough to require additional staff, the new employee slots still must be approved.

"We are a service provider," said Juris, "but it's not about selling a service; it's about providing training for the good of the NIH community."

Center staff want NIH'ers to view training as an ongoing investment in learning.

"The Training Center looks at training as a journey," said LeClair. "That journey could involve attending future classes or seeking advice or coaching, in addition to our leadership programs."

"We're finding the more programs we offer, alumni communities that pay it forward," said Juris. Many program

graduates become mentors. Some find other ways to get involved, such as serving on panels.

But if the term "training" conjures up thoughts of "mandatory training," know that NIHTC's role is only to help make it easier.

"None of the 'mandatory training' is actually put out by us," Juris said. "We just help corral it and trim it down."

Some years ago, NIHTC staff evaluated mandatory training with NIH leaders and representatives across the ICs. As a result, some mandates were discontinued and others were consolidated. In surveys, staff found it easier to get through a bunch of training at once instead of taking a new training every month. From there, the IT security/privacy/records management/ emergency preparedness courses were combined into one.

"We grouped them and advised on the schedule," said Dunn-Thomason, so that it's an annual rather than a monthly requirement.

As for the class catalog, NIHTC staff monitor feedback from multiple sources to gauge demand.

"What we decide on offering is not based on one source of guidance or direction," said Juris. There's feedback from evaluations and data from enrollment figures. Sometimes senior leaders request a particular training. NIHTC also pilots different ideas and reassesses.

Each spring, staffers do a deep dive on what to offer in the fall. "We try to keep the good things running before we launch something else," Juris added.

"We're always trying to check the pulse on what's happening at NIH," said Danielle Sullivan. "What are people interested in? Did we exhaust that topic?"

Sullivan is one of the NIHTC's program managers, each of whom has one or more specialized areas. They not only run the courses, but they also audit them to make sure the topics and instructors are engaging.

In celebrating NIHTC's 20th anniversary, Juris reflected on its evolution.

"I think about our resilience because, looking back-having been here since 2007it doesn't matter what's thrown at us. We keep our doors open and we keep offering the service. Some training offices, when going through a difficult time, close up shop for a while, but we just keep it running." B

Filipino Nurses Help Shape the U.S. Healthcare System

BY ERWIN LEYVA. LEOREY SALIGAN AND BELA MISTRY GOSINE

For generations, nurses have been the backbone of the American healthcare system.



Deemed the unsung heroes during the Covid pandemic, the harsh realities nurses face were brought to light, and we were given a glimpse of the human behind the hero, including an

invisible hero - the Filipino nurse. In 2019, one out of 20 nurses was trained in the Philippines and, tragically, 24% of the nurses who died from Covid-19 complications were Filipino.

While Filipinos comprise only 1% of the U.S. population, they make up 4% of the nursing workforce. Their growth in this specialty dates back to the end of the 19th

century when, due to U.S. colonization of the Philippines, Filipinos were permitted to become U.S. nationals and train under the U.S. army as nurses. This loophole provided access to working abroad



Dr. Erwin Leyva (I) and Dr. Leorey Saligan

and returning to the Phillipines to establish westernized nursing schools, creating a path with little to no restriction for other Filipinos to practice nursing in the U.S.

During times of crisis, America called on Filipino nurses, who were familiar with the Americanized nursing system, to help fill gaps in staffing at hospitals and other healthcare facilities. As a result, there was an influx of Filipino nurses into the country over the next several decades. They embedded themselves as an integral part of the American healthcare system.

This opportunity, however, did not come without a price. Knowing many Filipino nurses were drawn to the U.S. for economic gain, they were often placed in understaffed hospitals and tough-working environments. Despite inequities in pay and treatment,

Filipino nurses continue to lend their expertise and experience to support the American healthcare system.

Filipino nurses continue to advance science at NIH, including at the National Institute of Nursing Research (NINR). NINR applies nursing's knowledge and perspectives to solve pressing health challenges and advance health equity.

During Filipino American Heritage Month, we honor the many Filipinos who have contributed to the science and research infrastructure at NIH. As various public health issues continue to affect the health of Americans and the world, Filipinos will continue to contribute to science toward improving health and social outcomes.

At NIH. Filipino scholars have contributed to health discoveries for decades.

Spotlight on Current NINR Filipino Scientists

Dr. Leorey Saligan, an NINR senior tenured investigator, aims to better understand how physical and cognitive decline impact cancer treatments. His innovative approach aims to identify factors that can improve function for cancer

> survivors and those living with chronic illness.

By studying the effects of social determinants and climate change, postdoctoral fellows at NINR Dr. Carielle Jov Rio and Dr. Erwin Leyva aim to understand how health outcomes can vary for the most vulnerable populations.

Two Former Filipino Scientists

Dr. Eduardo Padlan, a structural biologist, joined the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in the 1970s. He expanded his work in antibody structure and 'humanization' of antibodies paving the way for theraputic management of multiple conditions, including cancer.

Dr. Manuel Datiles III, a retired senior investigator with the National Eye Institute (NEI) was a world-renowned expert in cataract pathogenesis, prevention and treatment. He was instrumental in establishing the NIH operating room for eye surgery, investigating the role of aldose reductase inhibitor in preventing cataracts, and the development of a special clinical device that could aid in the discovery of non-surgical cataract treatments.

Legacy CONTINUED FROM PAGE 1

descendants of the men who were treated unethically in the study. "But little is known about their humanity."

As Tyson Head noted, most of the participants were poor sharecroppers who had little time or money for doctor visits. During the growing season, they spent their time working in vegetable gardens, tending to farm animals and preparing fields for corn, beans and cotton. They had few opportunities to learn to read and write.

These men were sons, husbands, fathers and brothers. "The most important things to them were caring and providing for their families," she said.

federal rules to protect human research

undone," said Tyson Head. "We can con-

care. By working together, we can make

participants. The law was a direct response

to the men who were mistreated in the study.

"We understand that history cannot be

struct bridges to trustworthiness and health

health equity a reality, dismantle racial and

The study ended in 1972, after a reporter

exposed it and a federal committee, which met at NIH among other locations, recommended the study be shut down. After a public outcry, the National Research Act was signed into law, creating

The assembled guests applaud. At right, Tyson Head, whose father Freddie was in the study, speaks at the dedication as (from I) NLM Director Dr. Stephen Sherry, Bertagnolli, Jorgenson and Berger look on.

Lyric Jorgenson, NIH's associate director for science policy. NIH worked with the foundation to locate and preserve documents from the study.

"We are incredibly pleased that we could work with these leaders and help shed some additional light on this unjust effort so that we may never again repeat our past," said



Jorgenson.

Documents from the study are now publicly available on NLM's website, said acting NLM Director Dr. Steven Sherry. Working closely with Fisk University, NLM digitized more than 3,000 records from the

> study. Examples of records include correspondence, meeting minutes, reports and scientific articles. Previously, these documents were only available in physical form.

"NLM's stewardship of this collection supports our mission to enable biomedical research and support health care and public health through free online access to scholarly biomedical literature," he said. "Our goal for this significant collection is to

reach a broad audience and serve as a beacon of transparency with the biomedical and health care community."

The National Research Act acknowledges the government's past failures and commits health officials to a future where ethical principles are paramount to the conduct of



Above left, Tyson Head (r) with her brother Leotis Tyson and sister-in-law Shirley Tyson, pose with Bertagnolli. At center, descendants Tyson Head, her sister Joyce Tyson Christian, who is secretary of VFOFLF, and brother-in-law Will Tyson Christian, Jr. share a reflective moment by the plaque. At right, Rueben Warren, director, Tuskegee University National Center for Bioethics in Research and Health Care, and Hilary Polk of the CDC, pose together.





Above, NIH Director Dr. Monica Bertagnolli (I) and VFOFLF Founding President Lillie Tyson Head, reveal the commemorative plaque and stone, shown closer up at right. PHOTOS: CHIA-CHI CHARLIE CHANG

social injustices and advance biomedical research."

Recently, the foundation met with NIH leadership to discuss how NIH could assist in uncovering the truths held within records that might be yet undiscovered, said Dr.

research, said Department of Health and Human Services Assistant Secretary for Health ADM Rachel Levine in recorded remarks.

"We can construct bridges to trustworthiness and health care."

~LILLIE TYSON HEAD

"The National Research Act is the U.S. government's commitment to the American people that the pursuit of knowledge must not come at the cost of human dignity and human rights," Levine concluded. She thanked everyone in attendance for partnering to ensure transparency and high ethical standards in research to create a healthier future for all who live in the U.S.

View the full collection of documents from the study at go.nih.gov/PCjiOXk.

VOLUNTEERS

CC Seeks Volunteers for Thyroid Tumor Detection Study

Did you know your thyroid gland produces hormones that regulate body temperature, heart rate and metabolism? Physicians want to explore a better method to detect thyroid tumors by using a compound called 68Gallium-DOTATATE. This compound may bind to a tumor and make it visible during a PET/CT scan. This information will help guide future research and treatment. Contact the NIH Clinical Center Office of Patient Recruitment at 866-444-2214 (TTY users dial 7-1-1) or ccopr@nih.gov. Refer to study #000079-DK https://go.nih.gov/wzd8jOq.

NHLBI Recruiting for CADASIL Study

NHLBI researchers are looking for study participants with CADASIL as well as healthy volunteers for an observational research study to examine genetic and physical characteristics of the small vessel disease called CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarct and leukoencephalopathy). To inquire about this study, contact the NIH Clinical Center Office of Patient Recruitment at 866-444-2214 (TTY users dial 7-1-1) or ccopr@ nih.gov. Refer to study #000413-H. Online, visit: https://go.usa.gov/xtB6E.

NIH Awards \$27M to Establish New Genomics Network

NIH is awarding \$5.4 million in first-year funding to establish a new program that supports the integration of genomics into learning health systems.

Present in many hospitals across the country, learning health systems are a type of clinical practice that bridges research and

patient care. These systems use a variety of methods to continually analyze patient data. Clinicians then use the results to refine practices and improve future care.

The new genomics-enabled Learning Health

System (gLHS) Network aims to identify and advance approaches for integrating genomic information into existing learning health systems. As genomic testing becomes increasingly common, more and more genomic data are available in clinical settings, and learning health systems present an opportunity to translate this evidence quickly and directly into improvements in medical care.

The network consists of six clinical study sites and a coordinating center, all of which have an operating learning health system. Each clinical site will propose a project that uses patient data to develop and refine some aspect of genomic medicine. These could include implementing testing for hereditary diseases or using genomic information to select which medications a patient is given.

The network also includes a coordinating center, which will select a set of projects

NIH Federal Credit Union Extends Hours

The NIH Federal Credit Union (NIHFCU) has resumed operating at full pre-pandemic hours in its Bldg. 31 and Clinical Center branches on the main campus.

Stacie Stickland, NIHFCU's vice president of retail delivery, said, "We are excited to be able to



that both seem feasible in the program's five-year duration and have the potential to be shared throughout the network.

A major aim of the gLHS Network is to create generalizable knowledge and genomic medicine practices so that data collected at each clinical site can improve

patient care more broadly. Beyond exchanging information within the network, the coordinating center will orchestrate sharing the network's tools and resources with the greater clinical and scientific communities.

Such sharing practices have the potential to reach patients outside of hospitals with learning health systems. This includes many under-resourced settings, such as rural hospitals or other clinical settings in low-income areas.

The awards are jointly funded by the National Human Genome Research Institute (NHGRI) and the National Cancer Institute (NCI) and total \$27 million, which will be distributed over the program's five years, pending the availability of funds.

The coordinating center is Vanderbilt University Medical Center in Nashville, Tenn. The clinical sites are: Vanderbilt; Boston Veterans Administration Research Institute; Geisinger Health System in Danville PA; Indiana University School of Medicine; Northwestern Feinberg School of Medicine in Chicago; University of Utah Health.

bring more banking convenience back to the NIH workforce. We invite NIH employees, contractors, fellows and all others to stop by for a great range of banking solutions, especially as we inch closer to our 85th anniversary in January."

NIHFCU's new campus hours:

Branch Hours: Mon. - Fri., 9 a.m. - 4 p.m.

Live video tellers: Choose to see, talk or text chat in real-time with an NIHFCU representative. Monday – Thursday, 9 a.m. – 4 p.m.; Friday, 9 a.m. – 6 p.m.; Saturday, 9 a.m. – 1 p.m.

Learn more about the credit union at www.nihfcu. org, by calling 800-877-6440 or stopping into any of their local branch locations.

Pain CONTINUED FROM PAGE 1

Development (NICHD) aims to better understand and treat gynecologic pain. A now yearly series that first convened in 2022, the Gynecologic Pain Research Virtual Meetings serve as workshops that bring together established and new investigators to share ideas and discuss emerging trends in gynecologic pain research.

NICHD's Gynecologic Health and Diseases Branch (GHDB)—the home of gynecologic pain research at NICHD—organizes and supports these meetings. GHDB aims to improve women's reproductive health by guiding and supporting gynecologic research and career development programs.

"Gynecologic pain is understudied and underfunded compared to other types of pain, and the pool of scientists studying gynecologic pain is still very small," said Dr. Helena Ahn, program officer for GHDB and

the organizer of the Gynecologic Pain Research Virtual Meeting. "More vigorous research and funding support are needed in the area of gyne-

cologic pain, particularly considering the urgent need for effective and safe non-opioid options for pain management."

"Gynecologic pain is often ignored or



Clockwise from top I: NICHD Deputy Director Dr. Alison Cernich, Dr. Helena Ahn, program officer for GHDB, Dr. Candace Tingen, GHDB chief and Dr. Jae-Wook Jeong, professor, the University of Missouri





gaslit or overlooked, so we are really happy to be able to put a spotlight on this," added Dr. Candace Tingen, chief of the GHDB, who opened the meeting.

NICHD Deputy Director Dr. Alison Cernich also weighed in. "We normalize gynecologic pain so much and it's critical for us to understand that it does not have to be normal," she said.

On the Agenda

Meeting attendees discussed three major categories of gynecologic pain: menstrual pain, endometriosis and vulvodynia.

"Gynecologic pain is understudied and underfunded compared to other types of pain, and the pool of scientists studying gynecologic pain is still very small."

~DR. HELENA AHN

Researchers shared their findings in these areas, and attendees also had the opportunity to hear directly from patients with gynecologic pain. The final session of the

> day was dedicated to small business innovators who showcased devices intended for relieving gynecologic pain. Two speakers from the U.S. Food and Drug Administration (FDA) also provided an overview of the FDA review of gynecological devices and investigational new drug (IND) processes.

One common theme amongst the conditions discussed was the lengthy wait time for a diagnosis. Patients with endometriosis typically wait between 8 and 10 years for a diagnosis, despite the disease affecting more than one in 10 reproductive-aged women in the U. S. Vulvodynia patients also struggle with finding a diagnosis, with many seeing three or more doctors before being properly diagnosed.



Above, from I, Keena Batti and Noa Fleischacker, representatives from Tight Lipped, share their experiences with chronic vulvovaginal pain; Dr. Andrew Goldstein, director of the Centers for Vulvovaginal Disorders

"Gynecologic pain affects an estimated 26 percent of people worldwide but is often ignored despite having significant impacts on quality of life," said Cernich.

Menstrual Pain

Menstrual pain affects 90 percent of reproductive-age girls and women, with as many as a quarter of them experiencing severe and disabling symptoms, said Dr. Laura Payne, an assistant professor of

> psychology at Harvard Medical School. Worryingly, menstrual pain is also a risk factor for developing chronic pain later in life.

Payne's research has suggested that young women with primary

dysmenorrhea (a cramping pain associated with menstruation that is not caused by another condition such as endometriosis or uterine fibroids) have a lower pain tolerance when compared with a control group. She also found that multisensory sensitivity heightened sensitivity to multiple sensory stimuli—is a good predictor of susceptibility to chronic pain in the future.

Payne has learned that time is the biggest limiting factor for conducting these sorts of studies, which she thinks may help explain why there aren't many of them.

"We need more longitudinal studies of menstrual pain," she said.

Endometriosis Update

Endometriosis is an estrogen-dependent disease in which tissue similar to the lining of the uterus (the endometrium) grows outside the uterus. Women with endometriosis experience pain outside of their period, with about 80 percent reporting moderate to severe pain. Estrogen-suppressing therapies are often used to treat the condition, but almost 60 percent of women still experience persistent pain after treatment stops.

"Why do our current treatments not work well?" asked Dr. Emily Bartley, a researcher at the



Dr. Emily Bartley

University of Florida College of Dentistry who is studying pain modulation and nociceptive processing in patients with acute and chronic pain.

Dr. Jae-Wook Jeong of the University of Missouri is currently developing an anti-inflammatory nanodrug to target a signaling pathway involved in endometriosis pain. The drug, tofacitinib, is effective at reducing the size of endometriosis lesions when delivered as a nanoparticle (in its original form, it exhibited off-target toxicity and caused infertility in a mouse model).

Currently the only way to diagnosis endometriosis is via laparoscopic surgery. Jeong also believes nanoparticles could be useful for imaging endometriosis lesions. "The cancer world has done this very well," he said. "We could learn from them."

Vulvodynia Status Report

Vulvodynia—chronic pain or discomfort of the vulva—is a lesser-known gynecologic pain condition that nonetheless affects an estimated 10-26 percent of women in the U.S. alone. Despite its prevalence, little is known about what causes the condition or how to treat it.

"Treatment for vulvodynia should be per-

sonalized and not one-sizefits-all," said Dr. Andrew Goldstein, director of the Centers for Vulvovaginal Disorders. "But efforts to develop new therapies haven't moved forward in any



KRAKEN IMAGES/SHUTTERSTOCK

Aspiring Scientists Spend Summer at NIAMS

BY SARA ROSARIO WILSON

Over the summer, the National Institute of Arthritis and Musculoskeletal & Skin Diseases (NIAMS) gave 19 students at different stages in their learning journey the experience of a lifetime as part of the NIH scientific internship program. The 2024 cohort of summer interns worked sideby-side with NIAMS intramural scientists in their labs and received individualized mentorship.

During the eight-week program, students were immersed in biomedical research and interacted with top NIH researchers and current trainees, which helped them shape their career goals. They also spent time in NIAMS' state-of-the-art lab facilities and participated in journal clubs, trainings and networking events sponsored by NIAMS and NIH's Office of Intramural Training and Education.

The interns expressed enthusiasm as this summer's program drew to a close. One returning student noted she was thrilled to be spending another summer learning from peers and mentors at NIH. She learned new laboratory techniques and applied concepts from class to a hands-on research experience.

Another student said he enjoyed exploring the intersections between health and science at NIH and planned to pursue medicine after graduation.

Each year, the NIH Summer Internship Program provides outstanding training opportunities for high school, undergraduate, graduate and medical students. To learn more about the program and how students can apply, visit https://www.training.nih. gov/programs/sip.



NIAMS Director Dr. Lindsey Criswell (front row, fifth from r) and Dr. Janelle Hauserman, training director, Career Development and Outreach Branch, NIAMS, with 2024 summer interns

significant way in the last twenty years."

Goldstein attended a recent vulvodynia therapeutics research summit sponsored by several stakeholder groups and patient advocacy organizations that discussed some novel therapies in the research pipeline and identified the most promising candidates, which could be presented in a white paper to potential funding organizations. Tingen likened the summit to a *"Shark Tank* for therapeutics."

Representatives from the patient advocacy group Tight Lipped—Fleishacker and Batti—described the consequences of living with a condition that has few approved treatments.

"It is terrifying to be a patient with access and privilege, working with doctors who are the best in their field, and still be told 'we just don't know enough' at every turn," said Batti.

More to Do

Between the menstrual pain, endometriosis and vulvodynia discussions, the unifying theme from each was that more work must be done to address the pain women experience. Goldstein called for more "well-designed clinical trials to account for as many variables as possible."

Bartley agreed. "There's still a lack of awareness about these types of conditions," she said. "Ultimately, we need to keep the conversation going."

A recording of the meeting can be viewed at https://videocast.nih.gov/watch=54812.

Summer Students Soar at NIDCR

BY TIFFANY CHEN AND VANESSA MCMAINS

Each summer, the National Institute of Dental and Craniofacial Research (NIDCR) sponsors high school, college and dental students to work in research labs on campus to get a taste of what it's like to embark on a career in science. This year's group of students investigated salivary gland disorders, early face and skull development, pain and more. On July 31, they presented their work at an NIDCR-hosted poster session.

Restoring Saliva Flow

Several students investigated the origins of salivary gland dysfunction, which results in dry mouth that can increase the risk of tooth infection or decay. For example, local Poolesville High School student Iris Duan worked in the laboratory of Lasker Scholar Dr. Jacqueline Mays. Duan studied how the immune

system sometimes erroneously attacks the salivary glands after a stem cell transplant in a condition known as graft-versus-host disease.

In the laboratory of Stadtman Investigator Dr. Blake Warner, Howard University dental student Thomas Savage studied an autoimmune condition marked by dry mouth and eyes called Sjögren's

disease. Working with salivary gland tissue samples collected from patients, he focused on untangling the molecular processes that underlie the disease, in which immune cells attack the salivary glands.

Cracking the Code to Early Development

Other students focused on how stem cells form the face, including the bones, nerves and cartilage, during early embryo development. Bioengineering major Alaya Chubb worked in Dr. Laura Kerosuo's lab. Her work focused on DiGeorge syndrome, a disorder that results from a large DNA deletion and causes problems with face and skull development, among other issues.

Chubb created miniaturized organoids from patients and healthy volunteers that replicated living embryos. Once she graduates from the University of Maryland at College Park (UMCP), Chubb plans to attend dental school, where she hopes to merge her passion for regenerative medicine research with dentistry.

Jacob Svoysky, also an undergraduate at UMCP, spent his third summer in the laboratory of senior investigator Dr.

Achim Werner. His project investigated mutations in the enzyme that causes LINKED syndrome, a disorder that affects development of the face and other organs.

Mishaps in face and skull development can also happen as a result of errors in cell division. Phyllicia Hemphill studied a gene mutation that damages tiny, cylinder-shaped structures called centrioles, which ensure cells divide properly. In Dr. Shaun Abrams' lab, Hemphill helped develop and characterize mouse models of disorders driven by



"This internship deepened my understanding of my current field in dentistry and enhanced my problem-solving skills," said Hemphill, a

Howard University dental student. "Most importantly, it gave me the necessary tools for my future education and career goals."

Mapping the Brain

Jasmine Gray, a dental student at Howard University, joined the lab of senior investigator Dr. Mark Hoon to help identify groups of neurons in the brain involved in modifying pain perception under different circumstances.

Meanwhile, Remi Brebion, a dental student at the Medical University of South Carolina, investigated a group of neurons in the brain that may be linked to sleep apnea, a disorder in which breathing



Students from the NIH Summer Internship Program and the NIDCR Summer Dental Student Award program with their mentors **PHOTOS: NIDCR**



Aishwarya Rao, a predental student at Barnard College, explains her project investigating why some cancer therapies lead the body to attack the salivary glands.

repeatedly stops and starts during sleep. Under the guidance of Stadtman Investigator Dr. Yuanyuan Liu, Brebion traced the neural circuitry that connects the brainstem to spinal neurons that control the diaphragm, the main muscle responsible for breathing.

"Research serves as the foundation of our treatment and opinions as clinicians, so performing research has allowed me to appreciate each step of the process and critically evaluate and interpret my work," Brebion said.

Sugary Molecules

In many organisms, including humans and bacteria, bulky chains of sugar molecules decorate proteins and cells and influence key biological processes, including the formation of our faces and the immune system's ability to distinguish "self" from foe.

Howard University dental student Baron Edmonson spent his summer in the lab of NIDCR associate scientific director Dr. Kelly Ten Hagen. Edmonson studied large sugary molecules found on cells that are important for developing nasal septum cartilage, which physically supports the structure of the nose and face.

Certain bacteria normally found in the mouth and throat, if they get into the bloodstream, can cause serious infections in babies and young children. The bacteria wear cloaks of sugars that mask them from the body's immune system. Pablo Cardirola, currently a freshman at Duke University, spent his summer in the lab of Stadtman Investigator Dr. Nadine Samara, figuring out the structure of the enzyme that assembles the bacteria's sugar cloaks.

Cancer and Regenerative Medicine

After finishing community college, Caden Diaz spent time in Dr. Kenneth Yamada's lab investigating why cancer cells become more active, change shape and migrate faster in viscous growth conditions that more closely mimic the human body than cells growing in a dish.

In Dr. Pamela Robey's lab, Bisrat Demissie, a dental student at the University of Pennsylvania. investigated a protein that may be crucial for bone growth and tissue repair.

"It was exciting to see results from my work and know it could help improve health care," said Demissie. "This experience really motivated me to continue with research."

NIH Releases Mpox Research Agenda

As part of the U.S. government response to the current mpox outbreak, NIAID released an update on its priorities for mpox research. This agenda focuses on four key objectives: increasing knowledge about the biology of all clades-also known as strains—of the virus that causes mpox, including how the virus is transmitted and how people's immune systems respond to it; evaluating dosing regimens of



micrograph of mpox virus particles (blue) cultivated and purified from cell culture.

IMAGE: NIAID

current vaccines to stretch the vaccine supply and developing novel vaccine concepts; advancing existing and novel treatments, including antivirals and monoclonal antibodies; and supporting strategies for detecting the virus to facilitate clinical care and epidemiological surveillance.

The first human case of mpox was recorded in 1970 in the Democratic Republic of the Congo. The disease is endemic in central and western Africa. Two types of the virus that causes mpox have been identified: Clade I is endemic in Central Africa and can cause severe illness. Clade II, endemic in West Africa, tends to result in milder illness and caused the global mpox outbreak in 2022. People with compromised immune systems, children and people who are pregnant are especially vulnerable to severe mpox regardless of the virus clade.

NIAID continues to collaborate closely with U.S. and international partners to reduce the impact of the current mpox outbreak and safeguard public health globally.

Use of Metformin in Adults with Diabetes Linked to Lower Risk of Long Covid

Adults who use the prescription drug metformin to treat their type 2 diabetes have a lower risk of developing Long Covid or dying after a Covid-19 infection than people with diabetes who take other anti-diabetes medications, according to a large NIH-supported study.



BORYANA-MANZUROVA/SHUTTERSTOCK

The findings, published in Diabetes Care, were based on health data from millions of U.S. patients and could have broader implications for use of metformin in Long Covid prevention generally. The study is part of the NIHfunded Researching Covid to Enhance Recovery (NIH RECOVER) initiative.

An earlier NIH-supported clinical trial in 2023 showed that treatment with metformin, commonly used to

help control blood sugar, reduced the risk of long Covid by as much as 40% in nearly 1,300 U.S. adults with overweight or obesity, most of whom did not have diabetes. To see if the drug had a similar effect in people with diabetes, researchers examined electronic health record data for nearly 38 million Americans from two large U.S. databases.

The researchers compared health records from 75,996 adults taking metformin for their type 2 diabetes to 13,336 records from patients who were taking other types of diabetes medicines. Researchers were specifically looking at how many patients either died or were diagnosed with Long Covid within six months after infection. They found that patients taking metformin had a 13% to 21% lower incidence of Long Covid or death than those in the non-metformin group.

Scientists are not clear how metformin may prevent Long Covid, but they speculate there may be several mechanisms that reduce inflammation. decrease viral levels and suppress the formation of disease-related proteins.

Metformin can have side effects and should be used with caution in some conditions. For these and other reasons, people should not take the drug unless prescribed by a doctor.

Long COVID is marked by a wide range of symptoms-including chronic fatigue, brain fog, and chest pain, that vary from person to person and can last for weeks, months or years after infection from SARS-CoV-2, the virus that causes Covid-19. While rates of new cases have decreased since early in the Covid-19 pandemic, millions of people are still living with it.

Bone Marrow Cancer Drug Shows Success in Treating Rare Blood Disorder



A clinical trial supported by NIH was stopped early after researchers found sufficient evidence that a drug used to treat bone marrow cancer and Kaposi sarcoma is safe and effective in treating hereditary hemorrhagic telangiectasia (HHT), a rare bleeding disorder that affects 1 in 5,000 people worldwide.

The trial results, which are published in the New England Journal of Medicine, detail how patients with HHT given the drug, called pomalidomide, experienced a significant reduction in the severity of nosebleeds and needed fewer of the blood

transfusions and iron infusions that HHT often demands.

"Finding a therapeutic agent that works in a rare disorder is highly uncommon, so this is a real success story," said Dr. Andrei Kindzelski of NHLBI. "Before our trial, there was no reliable therapeutic to treat people with HHT. This discovery will give people who suffer with this disease a positive outlook and better quality of life."

HHT, also known as Osler-Weber-Rendu Syndrome, is characterized by serious defects in the way the body's blood vessels form. Instead of growing linearly, they become unusually tangled and twisted. The disordered blood vessels are fragile and prone to leaking, which causes excessive nosebleeds or bleeding along the gastrointestinal tract and other mucosal surfaces. These bleeding episodes, which worsen with age, can result in anemia and reduced quality of life. In severe cases, they can be life-threatening.

Researchers speculated that pomalidomide worked by blocking the growth of abnormal blood vessels. It may cause the blood vessels to have a more normal structure or thicker walls so they are less fragile.

Researchers enrolled 144 adults with HHT at 11 U.S. medical centers between 2019 and 2023. All participants had moderate to severe nosebleeds requiring iron infusions or blood transfusions. Researchers gave 95 of the participants pomalidomide daily. The remaining 49 patients received a daily sugar pill in addition to their usual care.

In June 2023, 43 months into the scheduled four-year trial, an interim analysis found pomalidomide had met a prespecified threshold for efficacy. and the trial was closed to further enrollment.

"These findings have broader implications for people with more severe forms of HHT," said Kindzelski. "In those cases, malformed blood vessels can develop in organs such as the lung, liver and brain, which can lead to hemorrhagic stroke, bleeding in the lungs, or heart failure. A treatment like this could be lifesaving for such patients."



Congressional Staff Tour Labs, Meet with Bertagnolli BY DANA TALESNIK

A group of staffers from the House Democratic Caucus visited NIH in September to learn more about NIH research.

First, the Hill staffers toured three labs: one in the National Institute of Biomedical Imaging and Bioengineering (NIBIB) to learn about how biomaterials can restore damaged tissues, and two in the National Institute of Mental Health one working on treatments for pediatric mood and anxiety disorders, and another studying a noninvasive therapy for treatment-resistant depression.

The delegation then joined NIH Director Dr. Monica Bertagnolli for a roundtable working lunch in a classroom in the Clinical Center. Each staffer shared their congressional office's scientific interests and priorities—from biotech to neurology—and engaged in a robust dialogue on NIH's research and current challenges.

Bertagnolli began the conversation by outlining her priorities. She discussed NIH's Covid-19

response to help illustrate how long-term investments in research pay off and the importance of inclusion. Decades of NIH research into mRNA vaccines enabled effective Covid-19 vaccines to get produced in record time, she noted. She also alluded to progress in NIH's RECOVER initiative that studies Long Covid.

"This illustrates brilliantly how some diseases happen differently in every different person," she said. RECOVER is showing that some populations are disproportionately affected, such as pregnant women, who have a higher risk of long-term symptoms after recovering from acute Covid-19 infection.

"It shines a spotlight on what NIH is all about. We fund science to understand biology so we can spur into action and make this research relevant to people."

And the fact that people respond differently to treatments highlights the importance of inclusion.

"We have to make sure research involves everybody," Bertagnolli said. "Our goal in scientific discovery is to improve care and delivery. We have to own the process, from finding the nature of disease to helping everyone." Toward that objective, NIH institutes and centers (ICs) work collaboratively on projects big and small. Bertagnolli described such larger NIH efforts as the *All of Us* Research Program and UNITE. She also described CARE for Health™, a project NIH is piloting to assess and address health needs in rural, tribal and other communities where people have been left out.

Data has been another hot topic. "We're on a tear with AI [artificial intelligence] to have inclusive, diverse data," she said.

Another area she emphasized is rare disease research. By studying how to bolster the immune system to fight infection, this not only helps fight rare diseases but also many other conditions, from cancer to diabetes to dementia.

"We can always do better," and we can do a lot more to benefit everybody, Bertagnolli said. Sustained funding is critical for so many reasons, including to retain the best researchers.

"We're hitting the tip of the iceberg" in so many research areas, she added. It's an exciting time as we watch discoveries unfold. "Science transforms the world."





From I, front row: Becca Flikier, Daniela Puente, Sarah Skirmont, Jamie Truax, Jackie Weinrich; standing: Alison Cohen, Quentin Dupouy, Ben Kane, Victoria Bautista, Ata Khan, Bertagnolli, Kerry Mackenzie, Kellie O'Brien, Malka Berro, Justin Oh, Grace Scott and NIH Legislative Assistant Lauren Citron **Photos: CHIA-CHI CHARLIE CHANG**

Above, NIH Director Dr. Monica Bertagnolli (r) and, to her right, Kate Klimczak, NIH associate director for legislative policy and analysis, engage in a lively discussion with staffers. Below, the delegation visits an NIMH lab where a volunteer (seated) demonstrates Transcranial Magnetic Stimulation (TMS), a noninvasive therapy for treatmentresistant depression. NIMH's Dr. Sarah Lisanby (below, I) describes this technique.

