

## NIH Investigators Discuss Ethics of Ancestry Testing

BY DANA TALESNIK

Perhaps an old family photo first sparked an interest, or a story passed down through generations. Some wonder about the stories they never heard. Many begin the inquiry for health reasons, searching for clues to an illness that seems to run in the family.

Whatever the impetus, millions of people are inquiring about their roots, trying to get a glimpse into their lineages from at-home ancestry tests. These DNA kits can provide useful information but also have drawbacks. One looming question is their level of accuracy, a concern that's also prevalent when considering ancestry in clinical research.



Dr. Sara Chandros Hull and Dr. Adebowale Adeyemo spoke on ethics of ancestry testing.

At the outset, it's important to distinguish among ancestry, race and ethnicity, which should not be used interchangeably, advised Dr. Adebowale Adeyemo, deputy director, Center for Research on Genomics and Global Health, NHGRI.

When including ancestry data in research, proper use of these terms is essential to the study's validity, agreed Dr. Sara Chandros Hull, director of NHGRI's bioethics core and faculty member in the Clinical Center's department of bioethics who, along with Adeyemo, spoke at an Oct. 1 NCI ENRICH Forum.

Hull emphasized the need to carefully consider how ancestry is used in both clinical study design and when disclosing and disseminating results.

Were study populations recruited fairly? How should investigators manage expectations in the consent process? Should they return results selectively or at all? Did they explain the value of partnering with the diverse study communities, who are part of, and supposed to benefit from, the research?

"It's more than just saying good ethics precedes good science," Hull said. "It's really

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## Hiring People with Disabilities Is a Win-Win

BY ERIC BOCK



Dr. Kathy Mann Koepke

Employers benefit when they hire people with disabilities, said Dr. Kathy Mann Koepke at the Office of Equity, Diversity and Inclusion's first-ever "Cultivating Inclusion: Honoring NIH

Champions and Allies of Disability" awards ceremony. She gave the keynote address in Bldg. 45 on Oct. 24.

"We may have limits in parts of our sensory system, motor system, or our mental health processes, but that doesn't mean

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## WORK-LIFE FIT Supervisors Support Employee Well-Being at Work

BY DANA TALESNIK

Life is demanding: family commitments, errands, chores... With so much going on, it's tough to find time to take care of ourselves. Trying to juggle our busy personal lives while tackling work duties is a balancing act that can seem overwhelming. Luckily, NIH has programs and resources to help us maneuver through the circus of life.

Research shows that work-life



Tim Tosten of ORS

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Inn family enjoys NIDCR dinner; see p. 5.

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## Federal Benefits Open Season Underway Until Dec. 9

The Benefits Open Season, which began on Nov. 11, runs through Dec. 9. If you plan to make an Open Season election, now is the time to do it. Unless you experience a Qualifying Life Event during the year, the annual Open Season is your only opportunity to enroll, cancel your enrollment or make a change to your enrollment for the participating programs.

For detailed information, visit <https://hr.nih.gov/benefits/change-open-season/benefits-open-season>.

The three participating programs are:

- **Federal Employees Health Benefits (FEHB) Program**—To enroll, cancel or change your FEHB enrollment, you must use myPay (unless you are retiring between now and Jan. 4) at <https://mypay.dfas.mil/mypay.aspx>. Open Season elections will be effective on Jan. 5, 2020. Your current enrollment will automatically continue into next year, if you do not take any action.
- **Federal Employees Dental and Vision Insurance Program (FEDVIP)**—To enroll, cancel or change your FEDVIP enrollment, you must use the BENEFEDS Portal at [www.benefeds.com](http://www.benefeds.com) or call 1-877-888-3337 (TTY 1-877-889-5680). Open Season elections will be effective on Jan. 1, 2020. Your current enrollment will automatically continue into next year, if you do not take any action.
- **Flexible Spending Accounts (FSAFEDS) Program**—To enroll in an FSA for 2020, you must use the FSAFEDS website at [www.fsafeds.com](http://www.fsafeds.com) or call 1-877-372-3337 (TTY 1-866-353-8058). Note that your current enrollment will not automatically continue into next year. If you want an account in 2020, you must enroll during the Open Season. Open Season elections will be effective on Jan. 1, 2020.

Direct all questions to [AskBenefits@nih.gov](mailto:AskBenefits@nih.gov) or your benefits contact. To locate your contact, visit <https://hr.nih.gov/contacts/benefits>.

## Open Enrollment for NIH Leave Bank

Fall open enrollment for the NIH Leave Bank runs until Dec. 9. The membership period will begin on Jan. 5, 2020.

The Leave Bank is a pooled bank of donated annual and restored leave available to eligible members. It acts like a safeguard for your paycheck and amounts to paid leave for members who have exhausted all of their own sick and annual leave and are affected by a personal or family medical condition.

The Leave Bank differs from the Voluntary Leave Transfer Program (VLTP) in that the Leave Bank is a depository of leave; leave is distributed to members who are approved to be leave recipients. The VLTP, on the other hand, requires a direct donation from donor to recipient. An advantage of the Leave Bank is that eligible members may receive leave to cover

time out of the office without awaiting donations from coworkers.

To become a Leave Bank member, access the Integrated Time and Attendance System during open enrollment and select “Leave Bank Membership” to enroll. If you are a 2019 Leave Bank member, your membership will automatically continue into 2020, unless you opt out. The yearly membership contribution is one pay period’s worth of annual leave accrual. The membership contribution will automatically be waived if you lack sufficient leave.

For more information, visit <http://hr.nih.gov/leavebank> or contact (301) 443-8393 or send email to [LeaveBank@od.nih.gov](mailto:LeaveBank@od.nih.gov).

## Credit Union Offers Enhancements

The NIH Federal Credit Union (NIHFCU) is upgrading many of its NIH-based ATMs with new, interactive technology. Members can soon opt to see, talk or private chat with a Rockville-based NIHFCU video teller in real time at the ATM for teller transactions including: cashing checks, making NIHFCU loan payments and transfers, depositing cash and checks and receiving cash.

Video tellers will be available weekdays from 8 a.m. to 5 p.m. (an extension of 2 hours beyond normal branch hours) for added convenience. Four NIHFCU ATMs will be converted in 2019: Clinical Center (adjacent to the branch and B1 cafeteria), Bldg. 31 (outside A-wing entrance) and Fishers Lane (branch entrance). Additional ATMs will be converted in 2020.

A temporary disruption may be experienced as the ATMs are upgraded. Traditional ATM functionality and in-branch tellers will continue as usual. Non-members can continue to use NIHFCU ATMs for their cash withdrawals. Questions? Stop by any NIHFCU branch or call 800-877-6440.

Also, this winter, NIHFCU will be opening a new branch in Silver Spring. Located at the main entrance to the Blairs Shopping Center and directly across from the Silver Spring Metro station, the branch will bring an added level of convenience to the NIH workforce, and their families, who live nearby. Visit [www.nihfcu.org/SilverSpring](http://www.nihfcu.org/SilverSpring) for details on the branch opening.

## NCI Teleworkers Meet During California Wildfires

Acting on a staff accountability request from HHS, NCI’s emergency preparedness manager sent an email on Oct. 28 to NCI staff either living in or on official travel to an area near San Francisco under threat of wildfires. They were asked to confirm by email if they were safe and if they were being affected in any way by the fires.

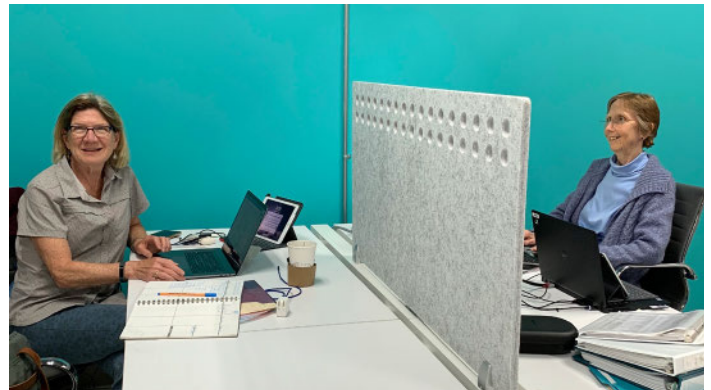
Dawn Walker, technical laboratory manager at NCI’s Laboratory of Molecular Biology West, replied to all that she was in Sonoma County, had power and, so far, had not had to evacuate.

Sherrí de Coronado of NCI’s Center for Biomedical Informatics and Information Technology also replied to all that she, too, was in Sonoma County, did not have power, but did not have to evacuate.

Walker reached out to de Coronado, whom she found was working from a coffee shop across the street from the shared workspace Walker was using. She invited de Coronado to cross the street and work in the shared workspace as her guest.

De Coronado took her up on the offer and was able to make use of desk space, high-speed internet and free beverages on two afternoons. Neither teleworker knew that there were other NCI staff in Santa Rosa before the fire. They discovered other things in common, such as a love of music and non-traditional career paths.

“New friends!” said Walker.



NCI teleworkers Sherrí de Coronado (l) and Dawn Walker found each other by accident on the West Coast.

## Smolke Describes Promise of RNA Sensors, Controllers

Her introducer, NIH director Dr. Francis Collins, described Dr. Christina Smolke's DeWitt Stetten Jr. Lecture on Oct. 23 as "a romp" through a kind of industrial-scale distillation of RNA sensors and controllers via various means.

But there were a lot of "aptamer hammerhead bulges" to be negotiated along the course of the Stanford chemical engineering professor's hour-long talk.

It was a tongue-in-cheek characterization of basic, preclinical science involving gene-expression control systems that have what Smolke called inherent programmability.

She outlined two scalable platforms for generating RNA switches, a class of genetic switches that are ribozyme-based; they modulate mRNA degradation, meaning they offer hope of turning targeted genes off and on.

Smolke envisions at least four opportunities that are ripe for exploitation if precise off/on control of genes unfolds as hoped:

- Proliferation control for T-cell therapy
- Control over the cell cycle
- Viral infectivity control
- Inducible, or conditional, control over genome editing.

She described the architecture of the switch and ways for applying higher throughput methods based on next-generation sequencing technologies, which can tease out which switches are the most robust.

Two technologies—RNASeq and FACS-Seq—offer the horsepower to assay thousands of candidate sequences in parallel.

Each has advantages, but the former takes only 8 days to the latter's 40, and RNASeq yields



Stanford's Dr. Christina Smolke describes RNA sensors and controllers at Stetten Lecture.

PHOTOS: LESLIE KOSSOFF

data with less noise and is a better predictor of activity of switches inside cells,

• • •

*The big question for biology is whether these switches work in vivo—that is Smolke's team's next step.*

• • •

Smolke said.

In the workflow she described, there is also a validation step that evaluates the

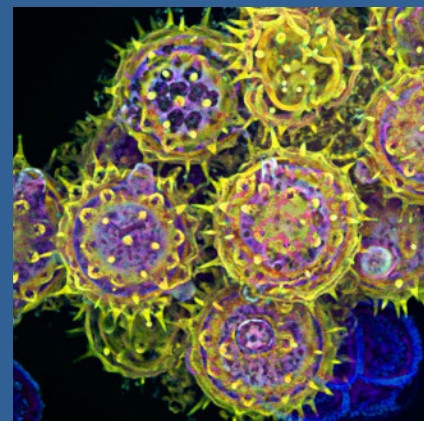


functionality of any individual switch.

Because this work is so data-intensive, machine-learning is now being applied to scan huge data sets, Smolke noted.

The big question for biology is whether these switches work *in vivo*—that is Smolke's team's next step.

During a brief Q&A session, she noted that optimizing sensors for a particular cell type will be necessary for any eventual therapy in humans.—Rich McManus **R**



ON THE COVER: Pollen grains: male germ cells in plants and a cause of seasonal allergies. People who get sneezy and itchy-eyed every spring or fall may have pollen grains, like those shown here, to blame. Pollen grains are released to fertilize the corresponding female plant parts. When they are instead inhaled into human nasal passages, they can trigger allergies.

IMAGE: EDNA, GIL AND AMIT CUKIERMAN, FOX CHASE CANCER CENTER, PHILADELPHIA

### The NIH Record

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Turning Discovery Into Health

## Ancestry

CONTINUED FROM PAGE 1

thinking about choosing questions that are important to address that use precise scientific tools correctly before we dive into a lot of the challenging ethical questions that tend to come up around genetics research.”

The terms race, ethnicity and ancestry each capture different but overlapping aspects of identity, said Adeyemo. Race assumes people are homogeneous, but they're not.

“There are no discrete biological groups or genetic groups of people different from everyone else,” he said. “Human variation exists along a continuum.”

Ethnicity, however, is not a geographic label; it comprises cultural factors such



Hull urges thoughtful use of ancestry data.

as customs and language. To log race and ethnicity in research studies, clinical staff generally rely on self-reporting. Sometimes they assign a label based on physical appearance, which often correlates poorly with underlying ancestry, Adeyemo said.

Ancestry refers to broad geographic regions or local populations from whence your ancestors came. Someone may be 70 percent European, 20 percent African and 10 percent split among other groups. But people tend to be forced into a single category, which can skew results.

“If you just have people check boxes [for race and ethnicity], then you force them to choose something,” Adeyemo said, “and what they've identified [may not be] representative. But if you allow them to choose 3 or 4 [options], you'll find you have dozens of terms that correlate to any single ancestry.”

Ancestry testing uses genetic markers to infer or estimate lineage. An ancestry panel has limits, said Adeyemo. It often partitions data between races and subgroups under study. It also often targets specific ancestries, e.g., African American vs. European American, or American vs. Native American, he said.

“Sometimes [race and ethnicity] can be inappropriately used as a surrogate for genetic ancestry or as proxies for socio-economic factors,” said Adeyemo. “There are stereotypes based on observations that something is more common in a group. However, this could be due to genetic factors, environmental factors, lifestyle, culture or a combination of these factors. So we get these reductionist explanations that pertain to a racial category.”

An ancestry panel also raises the risk of misclassification.

“If someone is studying a minority population and wants a comparable cell line but is getting something that's 99 percent something else, then it's wrong because that was not the intention of the researchers,” Adeyemo said. Such a study may incorrectly fail to confirm findings from other lines of research in that ancestral population.

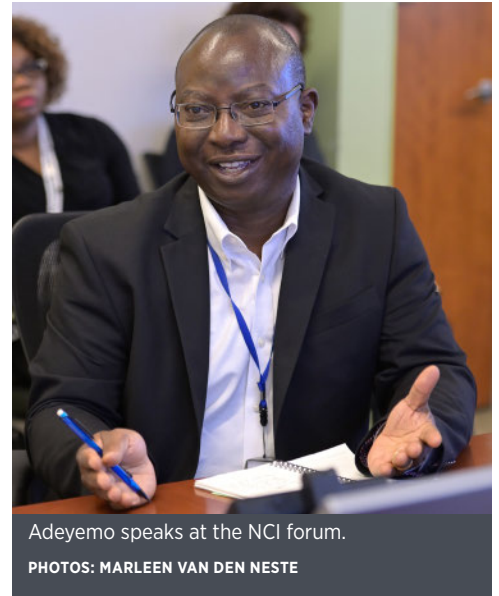
If an investigator sets out to enroll 100 African Americans and 100 Native Americans in a study, for example, and some of each group are misclassified as European Americans, this omission can have scientific consequences. “The misclassification would basically stymie our efforts to try to reflect the diversity that we so desperately need,” said Adeyemo.

The most useful testing is a genome-wide SNP array, he added, which isn't limited to pre-selected ancestries and therefore allows for inferring races and ethnicities across the globe. “It also has enough markers that we can come back later to reanalyze the data in light of new evidence or better techniques.”

In many cases, clinicians are overlooking a proportion of the world's genetic variation, which can exacerbate existing health disparities.

“There's a persistent lack of representation across non-European populations,” said Hull, which “fails to ensure that our investment in research will be as relevant as it should be to populations that also experience a disproportionate burden of disease.”

Yet some populations remain reluctant to



Adeyemo speaks at the NCI forum.

PHOTOS: MARLEEN VAN DEN NESTE

participate in genomic research due to past stigma, discrimination or lack of informed consent, issues that keep resurfacing in Hull's work with tribal communities.

“Any time we start talking with tribal communities about genetics research, the question of commercial ancestry testing comes up, how those companies are commodifying and selling genetic ancestry, indigenous ancestry, to the general public,” Hull said. These communities have asked, “Is the science legitimate? Is the science at NIH going to be used in these ways?”

“It's part of the context that research participants are bringing to the table when they sign up for our studies,” she said. “It affects our ability to partner meaningfully with tribal communities because it's a stated concern.”

Hull urges clinical researchers to be careful not to conflate issues of race, ancestry and biology. Too often she sees definitions of race that are incomplete and fail to account for important political and social determinants.

For example, she said, “naming disease types based on an entire continent on which they were discovered [such as African Kaposi sarcoma] uses ancestry as a disease label that has the potential to be stigmatizing.”

Adeyemo recommended that studies try to capture as many aspects of identity—self-identified race, ethnicity, ancestry and socio-economic variables—as possible. Hull concurred: Aim for precision, good communication and transparency. **R**

## Dental Team Works Together, Volunteers Together

BY ANNA MARIA GILLIS

In October, colleagues from NIH's Dental Clinic headed over to the Children's Inn at NIH after work to make dinner. "We wanted a different way to serve our patients," says Dr. Marie Kao-Hsieh, NIDCR's chief of dental clinic operations.

By day, Kao-Hsieh and her dental and nursing colleagues from NIDCR and the Clinical Center help patients with a wide array of problems that arise as a result of their dental and medical conditions. That care is not limited to patients who are enrolled in NIDCR research protocols. About 60 percent of the patients who are treated at the Dental Clinic are referred by intramural investigators from other institutes.

"Some of the patients we see in clinic are referred for research purposes, and some are referred for dental issues. Many are so medically compromised that dentists in their communities won't see them," says Dr. Pamela Gardner, chief of NIDCR's Dental Consult Service and chief salad maker for the clinic's volunteer team.



Gardner, chief of the Dental Consult Service, prepares salad for families at the inn.

The idea to serve hatched during one of the clinic's own potlucks, where "we discovered we had culinary talents," Kao-Hsieh says. For their first dinner at the inn, the NIDCR team—including dentists, dental hygien-

ists and technicians, a research program coordinator and the clinic's charge nurse—combined food they made with donations from Chipotle and the NIDCR leadership.

"It was great to come in and see how the inn is run," says Gardner, who, for many years had walked past the inn on her way to work, but like many NIH staffers, had never been in the building.

The Children's Inn, which is located



NIDCR's dinnertime volunteers stand with the Tavasoly family at the Children's Inn on Oct. 3. In front are (from l) Carrol Sterling, Sharon Mitchell, Rojan Vakili, Darian Tavasoly, Amir Tavasoly, Mercedes Garcia and Anitra Fitzgerald-Monroe. At rear are (from l) Dr. Marie Kao-Hsieh, Laurie Brenchley, Dr. Pamela Gardner and Jill Jacobs.

PHOTOS: CHIA-CHI CHARLIE CHANG

across from the Clinical Center, is a non-profit that provides free lodging and support services to families of children and young adults participating in NIH studies. It relies heavily on volunteers from within and outside the NIH community to help with meal preparation, tutoring and many other activities, including the making of "Thoughtful Treasures." The children rush down in the morning to see what is in their mailbox and often take their treasures with them to their appointments, says Sonja Luecke, communications manager for the inn.

Parents also look forward to caring gestures that come from staff and volunteers. "We're just grateful for all the support we're getting at one of the most stressful times in our lives," says Rojan Vakili, mother of 2-year-old Darian Tavasoly. Darian recently received gene therapy for GM1 gangliosidosis, a rare neurodegenerative disease. He and his parents will return to NIH in December and periodically over the next 5 years.

"When you have a special needs child, your own needs get put aside," says Vakili.

"Having food provided for us means we don't have to think about food. It is one less thing I have to worry about."

The Dental Clinic staff was "delighted that many of the Children's Inn residents recognized us," says Kao-Hsieh. She and



The Tavasoly family dines at the Children's Inn.

her colleagues plan to make volunteering a regular activity. They will next serve dinner to the children and their families in January.

For any individual or group interested in volunteering at the inn, contact Meghan Arbegast at [meghan.arbegast@nih.gov](mailto:meghan.arbegast@nih.gov) or (301) 827-6064 **R**



Offering perspectives on work-life balance are panelists (from l) Dr. Judie Walters; Melissa Bronez; OHR Director Julie Berko, who said, “Don’t get too busy making a living that you forget to make a life”; and Corey Adams of the Office of Personnel Management.

## Work-Life

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programs—such as flexible schedules, child and elder care programs, worksite fitness and other wellness and community programs, all of which NIH offers—help employees to be less stressed and more productive. In October, as part of National Work and Family Month, four NIH supervisors and an Office of Personnel Management employment specialist shared their experiences and philosophies for promoting work-life balance at a panel discussion in Lipsett Amphitheater.

“I really believe that if employees are supported by their supervisors and the organization as a whole in meeting both personal and professional obligations, the organization will benefit in terms of retaining good employees and meeting organizational objectives,” said Tim Tosten, associate director for program and employee services, ORS.

The ability to telework regularly helps Tosten achieve his fitness and other personal goals and spend extra time with his dog Jackson, rather than spending that time battling traffic on his commute.

Julie Berko, director of the Office of Human Resources, said she appreciates having time to participate in activities close to home when she teleworks, such as a mid-day break to help serve lunch at her son’s school, while remaining productive and engaged in her work.

“My philosophy is that employees should not feel they need to create a balance,” said Berko, “which is why I prefer the term work-life fit.”

Dr. Judie Walters and Melissa Bronez, both recent recipients of the NIH Work-Life and Well-Being Champion Director’s Award,

## Other Work-Life Events, Resources

During National Work and Family Month, NIH hosted several other events showcasing resources to assist the NIH community in fulfilling work and family responsibilities. These included meet-and-greet sessions with NIH stakeholders on Work-Life Wednesdays and webinars such as Work-Life@NIH: A Workforce Guide to Workplace Well-Being. A new website, “Work & Family Month@NIH” (<https://www.workfamilymonth.ors.nih.gov>), highlighted events and resources.

For the culmination of October’s events, the NIH Blueprint for Neuroscience Research, the Office of Research Services and the Office of Human Resources co-sponsored the Work-Life@NIH Information Fair, featuring more than 40 information tables with career and family resources for newly hired, mid-career and

preparing-for-retirement employees, as well as those navigating through caring for child, adult and elderly dependents.

Be on the lookout for next year’s Work & Family Month@NIH Campaign in October 2020.



Linda Owen (far l) of the Division of Amenities and Transportation Services engages an NIH employee in the bustling south lobby of Bldg. 10 at the Work-Life@NIH Information Fair.

PHOTO: DR. KRISTIN DUPRE



Panelists entertain audience questions as Chris Gaines (r), fitness and well-being program manager at ORS, listens in.

PHOTOS: LESLIE KOSSOFF

reflected on the early years of their careers. When they started their families, both initially returned to work part-time to make work and life fit.

“We’re all here because we love doing science,” said Walters, a neurophysiologist with NINDS who has worked at NIH for more than 40 years. “That’s a bond, something to encourage, and yet the pleasures of doing science and research are less satisfying if they don’t co-exist well with our other life challenges.”

Bronez, associate director for research operations and planning at NCI’s Center for Cancer Research, credited her executive officer for supporting Bronez’s change to a part-time schedule after starting a family, and two inspirational supervisors who supported her work-life balance, enabling her to do meaningful work and flourish. Eventually, she returned to management full time after her children were grown.

So much has improved over the years, said Walters, in the ways NIH supports and promotes child care and wellness programs and other work-life opportunities. Her employees with young children told her they especially have appreciated NIH’s child care centers, parenting coach, lactation rooms and flex schedules.

“My goal has been to try to nudge the culture,” she said, “to help the people I work with in the lab take advantage of available resources.”

Corey Adams, an OPM employee engagement and work-life specialist, said results from the 2017 Federal Work-Life Survey showed that NIH exceeded government-wide benchmarks for participation

in, and reported benefit from, work-life programs, particularly in family care and health and wellness programs.

Adams wasn’t surprised. “As we look across government,” he said, “NIH has a robust, strategically targeted family and

dependent care program that truly meets employee needs.”

Across all federal agencies, the survey also revealed that most employees who teleworked and/or participated in health and wellness programs performed their jobs better and were much more likely to remain at their agencies.

Still, some employees fear asking their supervisors for telework or other schedule flexibilities. Berko advised asking hesitant managers to try the program as a pilot, then check in periodically to evaluate the arrangement.

“Make the business case for why it will help the organization, not just what’s in it for you,” Berko said.

When an employee asks for flexibility, said Tosten, “Don’t say no; say let’s try.”

Supervisors shouldn’t wait for their employees to ask, said Bronez. “Reach out; ask how are things going? How can I help you be more productive?”

Communication is key. If supervisors and employees discuss expectations, and if there’s ongoing trust and transparency, staff tend to be highly productive, she added.

“Taking care of yourself physically, having a strong social support network and reducing stress improve your overall health,” said Tosten. “We can’t have the best, most effective work population doing incredibly important work for our country and the world unless we support them holistically.”

To learn about the many work-life programs at NIH, visit <https://hr.nih.gov/working-nih/work-life>. To watch a videocast of this event, see <https://videocast.nih.gov/summary.asp?Live=34856&bhcp=1>. **R**

## ‘NCATS Day’ Explores Responsible Data-Sharing, Dec. 17

Each year during NCATS Day, the National Center for Advancing Translational Sciences shines a spotlight on an important aspect of translational science and provides a forum to share and address patient and research community needs. NCATS Day 2019 presents “Conversations on Responsible Sharing of Data.”

The event will take place from 8:30 a.m. to 4:30 p.m. on Tuesday, Dec. 17 in Natcher Conference Center.

This year’s discussion will examine data-sharing from the perspectives of the research participant, community, scientist, federal funder and industry. Central to data-sharing is the recognized need for broad availability while ensuring the confidentiality and autonomy of research participants. The event will feature an interview with NCATS director Dr. Christopher Austin and a panel discussion of case studies that introduce issues such as where data is shared, how it’s accessed and by whom, what it’s used for and how it’s returned to research participants. Meeting participants will have an opportunity to delve more deeply into the varied perspectives on data-sharing and usage through breakout discussions.

To register and learn more, visit <https://ncats.nih.gov/events>.

## Webinar To Address Stigma, Dec. 11

The Office of Disease Prevention will present a Methods: Mind the Gap webinar with Dr. Valerie Earnshaw on Wednesday, Dec. 11 at 11 a.m.

Earnshaw, an assistant professor of human development and family studies at the University of Delaware, will offer a conceptual overview of stigma, identify targets for stigma measurement, recommend methodological approaches for stigma research and review an intervention toolkit to address stigma. She draws on examples from her own and others’ research, with a focus on two highly stigmatized disease contexts—HIV and substance use.

Register for the webinar at <https://prevention.nih.gov/education-training/methods-mind-gap/methods-understanding-and-addressing-stigma-prevent-common-risk-factors-disease>. The talk will be recorded and available on the ODP website within about a week.



Dr. Valerie Earnshaw

## Inclusion

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we can't be successful and meaningfully contribute," said Mann Koepke, the 2019 recipient of the Yvonne Thompson Maddox Award for Equity, Diversity and Inclusion and a program director in NICHD's Division of Extramural Research. "Look at what we do, not what we look like."

Hiring people with disabilities is a win-win result for everyone, she noted. They are creative problem-solvers, loyal employees and passionate about what they do. They bring the perspective of a large cohort of the American population to your workplace and product.

Employing them shows that organizations care about diversity and inclusivity, said Mann Koepke. "When we're in a workplace, colleagues know that our employers value what employees produce and not what we look like, not what color our skin is, what religion we're part of or what sexual orientation we are."

Unfortunately, many hiring officials are unaware of the talents of the disability community. According to Mann Koepke, perception and communication are two of the biggest challenges the community faces. "There are biases, prejudices and myths

about what people with disabilities can and cannot do," she said.

Supervisors who want to be allies of the disability community must strive to create a barrier-free workplace so "all employees have the opportunity to effectively contribute." They must, for instance, give employees the ability to safely, voluntarily self-disclose any disability and ask for reasonable accommodation that allows them to excel at their job.

what our job is—plays an important role in including everyone at NIH," Mann Koepke concluded. "Inclusion has to start with I."

After the keynote, EDI honored several employees from the disability community and their advocates for significant contributions to science and their work toward disability inclusion to help advance NIH's mission.

Winners of the Disability Ally Award are:

- NCI's Dr. Kent Hunter, for providing



*"Each and every one of us—no matter where we are in the pecking order, no matter what our job is—plays an important role in including everyone at NIH. Inclusion has to start with I."*

—DR. KATHY MANN KOEPKE



Mann Koepke noted that there are members of the disability community who don't realize there are opportunities in government. Actively reaching out to candidates at all levels who may not know about job opportunities is important, she said.

"Each and every one of us—no matter where we are in the pecking order, no matter

post-baccalaureate and post-doctorate opportunities to deaf and hard-of-hearing trainees.

- NIAMS's Yanira Ruiz-Perdomo, for advocating on behalf of patients enrolled in rheumatology clinical trials.

Winners of the Disability Champion Award are:

- NIEHS's Stella Sieber, for advocating on behalf of the limb loss/limb difference community.

- NICHD's Dr. Caroline Signore, for strengthening research on the reproductive health care needs of women with disabilities.

- NIDDK's Dr. Anne Sumner, for advancing the disability community in research and making NIH a more welcoming environment for those with disabilities.

- NIDCD's Kelli Van Zee, for promoting and advocating for disability awareness at NIH.

Joseph Cox, Sean Cullinane, Louise Davis, Nicole Huntington and Michelle Mejia received the Disability Ally Group Award, for their work to address parking and transportation needs of the disability community. The recipients work in the Division of Amenities and Transportation Services' Transportation Services Branch, ORS.

To read more about the awardees, visit <https://www.edi.nih.gov/people/sep/pwd/disability-awareness-2019/awards>. **R**



Awardees and members of NIH's Office of EDI include (seated, from l) Dr. Caroline Signore, Stella Sieber, Mann Koepke, Kelli Van Zee and Debra Chew, EDI director. Standing are (from l) David Rice of EDI, Sean Cullinane, Nicole Huntington, Louise Davis, Michelle Mejia, Joseph Cox, Dr. Anne Sumner, Dr. Kent Hunter and Yani Ruiz-Perdomo.

PHOTOS: MARLEEN VAN DEN NESTE



## Marijuana and Alcohol During Early Pregnancy May Disrupt Fetal Development

New preclinical research reported in animal models shows that exposure to compounds found in marijuana called cannabinoids (CBs), which includes cannabidiol (CBD) and tetrahydrocannabinol (THC), during early pregnancy can cause malformations in the developing embryo. The research also demonstrated that co-exposure to CBs and alcohol increased the likelihood of birth defects involving the face and brain. The study, funded by NIAAA, was published in *Scientific Reports*.

“Prenatal alcohol exposure is a leading preventable cause of birth defects and neurodevelopmental abnormalities in the United States,” said NIAAA director Dr. George Koob. “Since marijuana and alcohol are frequently used simultaneously, the combined effects of cannabinoids and alcohol are worrisome as well as the dangers of either substance alone.”



IMAGE: NATALIADERIBINA/ISTOCK

The detrimental effects of prenatal alcohol exposure on human development are well known and include an array of lifelong physical,

cognitive and behavioral problems collectively called fetal alcohol spectrum disorders. Alcohol can disrupt fetal development at any stage during pregnancy, even the earliest stages before a woman knows she is pregnant. The effects of marijuana exposure during pregnancy and the combined effect of alcohol and marijuana are less known.

In the study, scientists administered a variety of CBs alone and in combination with alcohol in varying amounts to mice on day 8 of pregnancy, which is similar to the third and fourth weeks of pregnancy in humans. The CBD amounts administered were within what is considered a therapeutic range for several medical conditions in humans. The THC

concentration administered was similar to levels reached by a person smoking marijuana.

The researchers found that one-time exposure to CBD and THC caused eye, brain and facial malformations similar to those caused by prenatal alcohol exposure alone. The researchers also found that when mice were given both CBs and alcohol, the likelihood of these birth defects more than doubled. They confirmed this finding in a zebrafish model.

## Vaccine Protects Monkeys Against Four Types of Hemorrhagic Fever Viruses

Scientists funded by NIH have developed an investigational vaccine that protected cynomolgus macaques against four types of hemorrhagic fever viruses endemic to overlapping regions in Africa. The University of Texas Medical Branch in Galveston and Profectus BioSciences of New York are developing and testing the candidate quadrivalent VesiculoVax vaccine, with support from NIAID and Redeemer's University in Nigeria.

The newly published study in the *Journal of Clinical Investigation* describes how the vaccine was created using a live-attenuated (weakened) vesicular stomatitis virus to deliver proteins that elicit protective immune responses.

The proteins are from Ebola virus (Kikwit strain), Sudan virus (Boniface strain, which also causes Ebola virus disease), Marburg virus (Angola strain) and Lassa virus (Josiah strain). There are no licensed vaccines to provide protection from any of those viruses—all of which can cause severe disease and death—although the European Medicines Agency has recommended licensing a VSV-Ebola vaccine.

Importantly, the monkeys infected in the study were exposed to different strains of Sudan virus (Gulu) and Lassa virus (0043/LV/14) than those in the candidate vaccine to help the researchers determine whether the vaccine would be cross-protective. Lassa 0043/LV/14 is circulating in an outbreak in Nigeria that began in 2018. Previous studies indicate that the investigational Ebola virus (Kikwit) vaccine will protect against other strains of Ebola virus.

## Unique Case of Disease Resistance Reveals Possible AD Treatment

Defying the odds, an individual at high risk for early-onset Alzheimer's disease remained dementia-free for many years beyond what was anticipated. A study funded in part by NIA led researchers to suggest that a gene variant may be the key, perhaps providing a new direction toward developing a treatment.

The research focused on the case of a woman who carried a gene mutation known to cause early-onset



IMAGE: JACOBBLUND/ISTOCK

Alzheimer's. However, she did not develop signs of the disease until her 70s, nearly three decades after her expected age of onset. The researchers suspect that she may have

been protected because in addition to the gene mutation causing early-onset Alzheimer's in her family, she also had two copies of the *APOE3* Christchurch (*APOE3ch*) gene variant. Findings of this case study as published in *Nature Medicine* suggest that two copies of the *APOE3ch* variant, named after Christchurch, New Zealand, where it was first identified, may protect against Alzheimer's.

“Sometimes close analysis of a single case can lead to a discovery that could have broad implications for the field,” said NIA director Dr. Richard Hodes. “We are encouraged that as part of our wide array of studies, this research in the unique genetic makeup of an exceptional individual can reveal helpful information.”

Early-onset Alzheimer's disease is rare, representing less than 10 percent of all people who have Alzheimer's. It typically occurs between a person's 30s to mid-60s. Risk for both early- and late-onset Alzheimer's disease is affected by genetic factors.



IMAGE: JACOBBLUND/ISTOCK

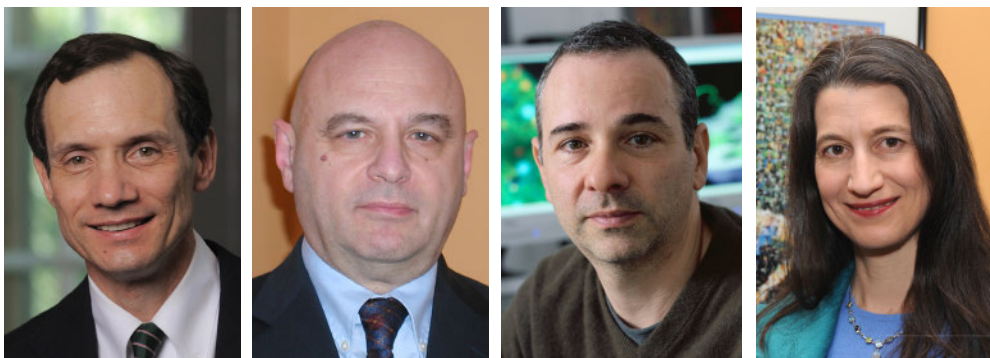
## Study Says Teens Prefer Mint, Mango Vaping Flavors

A new analysis suggests that teens prefer mint and mango as their vaping flavors of choice for e-cigarettes. Previous research showed that teens were attracted to nicotine vaping by the candy and fruit-flavored products offered by manufacturers. Products and trends are quickly evolving and estimates of the specific e-cigarette flavors teens use are lacking; therefore, scientists wanted to find out which flavors are now preferred by teens. The report, published in *JAMA*, was supported by NIDA, NCI and the FDA's Center for Tobacco Products.

The study focused on JUUL products, the most widely used brand, which are available in multiple flavors. Data were from the 2019 Monitoring the Future (MTF) study, which annually surveys 8th, 10th and 12th grade students in U.S. schools. A randomly selected third of MTF respondents were asked, “Which JUUL flavor do you use most often?”

The 2019 data suggests that among both 12th and 10th graders, mint and mango ranked first and second (at about 47 percent and 24 percent for seniors; 44 percent and 27 percent for 10th graders). Among 8th graders, mango was most popular at 34 percent, followed by mint at 29 percent. In all grades, fruit flavoring was ranked third, followed by “Other.” Menthol was among the least popular (less than 2.3 percent for 8th graders; less than 3 percent for 10th graders and less than 6 percent for seniors).

The overall 2019 MTF vaping data released in October showed a significant increase in past-month vaping of nicotine in each of the three grade levels since last year. Additional findings from the 2019 Monitoring the Future Survey, documenting the use of and attitudes about marijuana, alcohol and other drugs, will be released Dec. 18.



New NAM electees are (from l) Dr. Michael Lenardo, Dr. Luigi D. Notarangelo, Dr. Andre Nussenzweig and Dr. Julie A. Segre.

SEGRE PHOTO: MAGGIE BARTLETT

## Four NIH's Elected to National Academy of Medicine

Four NIH scientists are among the 100 newly elected members of the National Academy of Medicine, which announced the honor during its annual meeting. Election to the academy is considered one of the highest honors in the fields of health and medicine and recognizes individuals who have demonstrated outstanding professional achievement and commitment to service.

The honorees from NIH, and their citations, are:

Dr. Michael Lenardo, chief, molecular development of the immune system section, Laboratory of Immune System Biology, and director, Clinical Genomics Program, National Institute of Allergy and Infectious Diseases, "For the discoveries of molecular mechanisms of immunological tolerance, seminal work on programmed cell death, defining new inherited genetic diseases of immunity, and developing targeted therapies that have saved the lives of children suffering from certain of these devastating diseases."

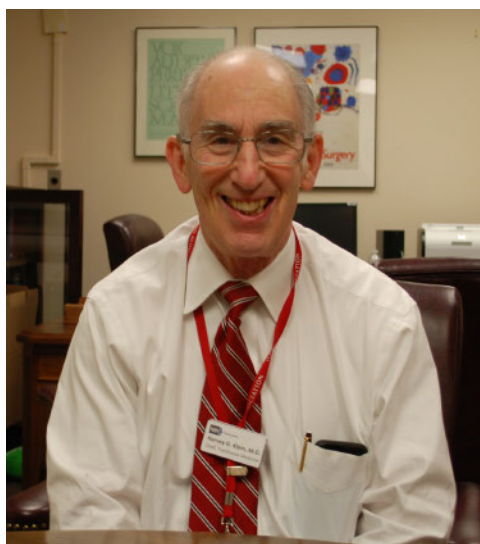
Dr. Luigi D. Notarangelo, chief, Laboratory of Clinical Immunology and Microbiology, NIAID, "For making seminal discoveries in the characterization of the molecular and cellular bases of several forms of primary immune deficiencies, and for his leadership role in the creation of networks of centers that care for patients with these disorders, aiming to improve diagnosis and treatment."

Dr. Andre Nussenzweig, chief, Laboratory of Genome Integrity, National Cancer Institute, "For making seminal discoveries that speak to how cells maintain their own genome stability, allow chromosome fragility, and license leukemogenesis at the hands of aberrant DNA repair."

Dr. Julie A. Segre, senior investigator, microbial genomics section, National Human Genome Research Institute, "For pioneering whole-genome sequencing to track the transmission of fully antibiotic resistant Gram-negative bacterium in the midst of a deadly hospital outbreak."

Established originally as the Institute of Medicine in 1970 by the National Academy of Sciences,

the National Academy of Medicine addresses critical issues in health, science, medicine and related policy and inspires positive actions across sectors. With their election, NAM members make a commitment to volunteer their service in National Academies activities.



Dr. Harvey Klein

PHOTO: RICH MCMANUS

## Klein, Titan of Blood Bank, Retires After Long NIH Career

BY RICH MCMANUS

Dr. Harvey Klein, chief of the Clinical Center's department of transfusion medicine (DTM) for the past 36 years and a stalwart of hematology research at NIH for 46 years, retired on Sept. 30. He has accepted scientist emeritus status and plans to mentor young recruits in retirement.

"I think you know when it's time," he said, "and it's time."

Klein arrived at what was then the National Heart and Lung Institute in 1973 as a "Yellow Beret," or individual who opted for "obligated service" as a member of the PHS Commissioned Corps rather than serve in the military during the Vietnam War.

A native of Boston, he was a graduate of Harvard College and got his M.D. at Johns Hopkins University, where he was involved in the first dozen bone marrow transplantations undertaken at its hospital.

Assigned to the heart institute's newly formed Blood Division, he came to what was then the NIH Blood Bank for a year to work with scientists there and ended up staying for 9 years as its deputy chief. In 1983, he was named DTM chief, taking over an operation that "increased logarithmically over the years" from 27 employees in 1975 to more than 200 today.

"There was no apheresis [separation of one component of blood, then return of the remainder to circulation] at all back then, neither for blood components or therapeutics," Klein recalls. "There was no HLA [blood-typing] lab in the Clinical Center or the blood bank. There was no such thing as cell processing of any kind back then. We were the first group in the country to collect platelets by apheresis entirely. Now, virtually all blood banks in the country use apheresis."

Most prominently, DTM now runs the Center for Cellular Engineering, a burgeoning enterprise that hosts the department's former special services laboratory (designed in the mid-1980s to process bone marrow for eventual transplantation; the lab later evolved into the cell processing section, which put the first genes into cells for the world's first cellular gene therapy) in a new building currently going up on the Clinical Center's east side, in addition to lab space on two wings of the hospital.

"The center has more than 30 protocols for making different kinds of cells," said Klein. "Retinal pigment epithelial cells, for NEI, CAR T-cells for NCI, stem cells, for bone marrow transplantation. We are doing very exciting kinds of things in cancer, immune deficiency diseases, chronic granulomatous disease and gene therapy, where we insert vectors into hematopoietic cells. The center has grown by leaps and bounds."

"[Engineered cells] is one of the most exciting developments in transfusion medicine today," Klein continued. "I am going to miss the excitement, and the people for sure. It's been wonderful. It has been not only a pleasure, but also an honor to be part of the NIH Intramural Research Program over the years."

Klein, DTM's fourth and longest-serving chief, also credits a long roster of CC directors, "all of whom have been just enormously supportive of this department."

Dr. John Gallin, director of the Clinical Center from 1994 to 2016, said, "Dr. Klein was not only a fabulous chief of transfusion medicine but also was a special advisor on all issues related to hospital function and the clinical research environment. He was a great colleague and friend and we will miss him greatly. But we are happy he will remain as an advisor in emeritus status."

Klein almost left NIH in 1998, when he retired after

25 years from the Commissioned Corps. “I had planned to leave for academia, and I had an offer from Harvard,” his alma mater, in his home town. “It’s unusual to go from the corps to [federal civilian employment]. And it was a tough offer to turn down—my mom would have turned over in her grave. But I never looked back, and I never regretted it. NIH is a great place to do clinical research.”

Klein presided over a number of other significant firsts, including DTM’s founding membership in the National Donor Marrow Program, which enrolled some 20,000 HLA-matched donors; he served on NMDP’s standards committee and board. Klein is also a founding member of the American Society for Apheresis, which was established in fall 1979.

Taking seriously the evidence for the benefits of exercise, he was among the four founding members of the NIH jogging club.

“Allen Lewis, Rick Davey and I from the Blood Bank, and Dave Young from NCI founded the NIH jogging club as Health’s Angels in 1976,” said Klein. “Linda Brown of Medical Arts designed the logo, a rabbit with a halo—I have one of the original T-shirts.”

A veteran of the Boston Marathon (best time, 3:12), Klein, once a fixture along Cedar Lane and the Rock Creek bike path, where he took 8- to 10-mile runs in the mornings before work, quit running “only in the past 3 years. I just cleared out my locker here. I miss it. I miss it a lot.”

Still committed to physical fitness, he now pursues elliptical training, rowing and walks on the C&O Canal, which abuts his home in Potomac, just south of Pennyfield Lock.

“My blood pressure goes down 10 points as soon as I turn in my driveway,” he said.

A search for DTM chief is now underway. Serving as acting chief is Dr. Cathy Cantilena, a long-time Clinical Center veteran whom Klein says is deeply familiar with every aspect of the department’s activities.

## NINR Welcomes New Advisory Council Members

NINR recently announced the appointment of four new members to its National Advisory Council for Nursing Research.

Dr. Eun-Ok Im is associate dean for research development and regulatory affairs and Mary T. Champagne professor at Duke University School of Nursing. She is a methodologist, researcher and theorist in international, cross-cultural women’s health.

Dr. Peter A. Lewin is R.B. Beard distinguished university professor of electrical and computer engineering in the School of Biomedical Engineering, Science and Health Systems at Drexel University. His current interests are primarily in the field of biomedical ultrasonics.

Dr. John Lowe is the current and founding director of the Center for Indigenous Nursing Research for Health Equity and the endowed McKenzie professor for health disparities research at Florida State University College of Nursing. He develops and studies interventions for the prevention and reduction of substance use and other risk behaviors among Native American and indigenous youth and young adults.

Dr. Joanne Wolfe is chief of the division of pediatric palliative care in the department of psychosocial oncology and palliative care at the Dana-Farber Cancer Institute, director of palliative care at Boston Children’s Hospital and professor of pediatrics at Harvard Medical School. She also directs a research program focusing on easing suffering and promoting well-being in children with serious illness and their families. **R**



Former NINR acting director Dr. Ann Cashion (third from l) and NINR acting deputy director Dr. Tara Schwetz (fourth from l) welcome new council members (from l) Dr. John Lowe, Dr. Joanne Wolfe, Dr. Eun-Ok Im and Dr. Peter A. Lewin.

## Study Needs Infants, Children

The Clinical Center seeks infants 3-12 months and young children 1-5 years of age who are developing typically. The study aims to learn more about the motor skill and brain development of young children who are at high risk for or diagnosed with cerebral palsy (CP) and autism spectrum disorder (ASD) compared to young children with typical development. The results of this study may assist with better methods for early diagnosis as well as improved treatment for children with CP and ASD. This is an outpatient visit and all minor participants require parents’ permission to participate. To learn more, contact the Clinical Center Office of Patient Recruitment at 1-800-411-1222 or [prpl@cc.nih.gov](mailto:prpl@cc.nih.gov). Refer to study 18-CC-0052. Read more at <https://go.usa.gov/xpBJD>.

## Healthy Volunteers Needed

NIAID researchers seek healthy volunteers, 18-50 years old, for the study of an investigational product targeting malaria. Financial compensation is provided. To learn how to participate, call 1-866-833-5433 or email [vaccines@nih.gov](mailto:vaccines@nih.gov).

## Has Your Brain Tumor Returned?

Are you faced with glioblastoma (GBM) that has returned despite standard treatments? Partner with NINDS researchers in a study designed to look at the effects of two research drugs on the brain’s immune system in people who have had a return of GBM brain tumor. We will also look at the effects of these drugs on the brain tumor. All research-related care and experimental treatment is provided at no cost. The team at the Clinical Center Office of Patient Recruitment is standing by to help you: 1-800-411-1222 or [prpl@cc.nih.gov](mailto:prpl@cc.nih.gov). Refer to study 18-N-0077. Read more at <https://go.usa.gov/xEANh>.

## Patients with ALS Needed

Amyotrophic lateral sclerosis (ALS) research at NINDS is testing the effects of a combination of 4 drugs on the HERV-K levels in patients with elevated blood levels, and to see if this affects their ALS symptoms. Learn more by calling information specialists at the Clinical Center Office of Patient Recruitment, 1-866-444-2214 (800-877-8339 TTY/ASCII) or [prpl@cc.nih.gov](mailto:prpl@cc.nih.gov). Refer to study 15-N-0126. Read more at <https://go.usa.gov/xpWSn>.



Then-NINR acting director Dr. Ann Cashion (l) and Dr. Jean McSweeney

## HEART ATTACK IN WOMEN

### Listening to Women Guides McSweeney's Research

BY JO-ANN KRIEBEL

Dr. Jean McSweeney did not set out to conduct revolutionary studies that identify the ways in which women's heart disease differs from that of men.

Rather, in her early research, McSweeney's goal was to identify the factors that helped patients change their health behaviors over the long term after myocardial infarction (heart attack). However, during the course of this line of research, she discovered that the heart attack symptoms reported by women in her studies greatly differed from those generally considered "standard."

Following this realization, McSweeney shifted her focus to better understand women's reports of their own heart attack experiences. Not only did she identify the most common symptoms reported by women before and during a heart attack, but also McSweeney built upon this finding to become an internationally recognized expert on women's heart disease over the course of her research career.

McSweeney noted that women were generally excluded from clinical trials until 1993, when Congress mandated adequate inclusion of women in NIH-sponsored clinical trials. Thus, the instruments developed to identify coronary heart disease (CHD) had


been based almost entirely on symptoms reported by men. McSweeney discovered that these instruments did not capture the symptoms women reported most frequently before a heart attack (fatigue, sleep disorder, anxiety, shortness of breath and indigestion).

Additionally, many of women's acute symptoms of heart attack (shortness of breath, weakness, fatigue and dizziness) did not align with the chest pain typically reported by men. To correct this omission, she developed an instrument—the McSweeney Acute and Prodromal Myocardial Infarction Symptom Survey—to predict CHD events in women.

McSweeney hopes future research can address the higher CHD mortality rates

experienced by minority and younger women. She cited progress in white women's awareness of CHD as women's number-one cause of death, while minority women's rate of awareness has risen only to that held by white women more than 20 years ago.

She closed by noting that "listening to women guided this research," and encouraged researchers to seek out women's experiences as they design and evaluate CHD interventions.

McSweeney is a professor and associate dean for research at the University of Arkansas for Medical Sciences in Little Rock. Her lecture is available at <https://www.youtube.com/watch?v=ih812hzWLPk>. 



NIAMS summer interns are shown with Rick Phillips (front, second from l), NIAMS acting executive officer, and Dr. Robert Carter (seated, c) NIAMS acting director. At rear (l) is Dr. Robert Walker, chief, Career Development and Outreach Branch, NIAMS.

### Young Scientists Expand Their Ambitions

This past summer, the NIAMS Scientific Summer Student Program welcomed the next generation of budding scientists and physicians to the NIH campus. The program provided a training experience that both motivated and challenged the young students for their future careers. Many of the interns concluded their summer with a new outlook on the possibilities that are available to them in their journey in biomedical research.

"At the NIH, you quickly realize that the opportunities are boundless, the knowledge is seemingly infinite and the widespread commitment to improving health is outright inspiring," said Tyler Kellenberger, a returning intern from the University of Florida.

The students also received individualized guidance and mentorship from top NIH scientists to help them shape their career goals.

"I had very encouraging mentors who advised, challenged and helped me excel as a young scientist," said Rutha Adhanom, an undergraduate from the University of Maryland. "This

invaluable research experience has been extremely beneficial for my future preparation and has taken my passion in biomedical research to the next level."

This year's diverse group of interns came from different regions of the United States. They were selected to participate in the competitive program based on their schooling and their proposed future contributions to areas of biomedical research keyed to NIAMS mission areas.

The students spent their summer immersed in innovative biomedical research and participated in career development seminars, journal clubs, clinical shadowing and seminars with NIAMS scientific and clinical directors, among many other enriching activities.

The NIH Summer Internship Program provides outstanding training opportunities for high school, undergraduate, graduate and medical students. Students can apply online at <https://www.training.nih.gov/programs/sip>. The application for summer 2020 is now available.