ERADICATING AN EPIDEMIC
In Push to End HIV/AIDS, Community Is Vital
BY CARLA GARNETT

In nearly four decades, biomedical research and prevention strategies have moved HIV/AIDS from being a 100 percent fatal diagnosis to a chronic but treatable disorder, with a vaccine and/or cure perhaps in sight. But as near on the horizon as ending the deadly epidemic may seem, the goal can only be reached via the continued engagement and empowerment of a particular sector—the community.

NIH’s Office of AIDS Research recently held “Community and NIH in Partnership to End the HIV Epidemic,” an event aimed at acknowledging and fortifying science’s collaboration with citizen groups.

“Research discoveries set the framework for public health and public policies to end the HIV epidemic,” noted OAR director Dr. Maureen Goodenow, opening the half-day forum. “Robust community engagement is critical, and since the earliest days of the pandemic, community voices were raised and continue today as significant partners...Although HIV demographics have evolved in complexity and diversity, something in common across the timespans and population is the persistent dedication, creativity and resiliency of the communities.”

Since 1981, 700,000 Americans—32 million people worldwide—have died due to HIV/AIDS. Globally, 38 million are infected with the virus. About 1.1 million people in the U.S. are HIV-positive, with 150,000 unaware of their status. About 250,000 know they are infected but are not getting treatment.

“What was a death sentence in 1990 is no longer associated with such a hopeless outcome,” said NIH director Dr. Francis Collins. “For those who can access antiretroviral therapy, HIV is now..."
Webinar on Research Methods for Rheumatoid Arthritis, Jan. 16

The Office of Disease Prevention will hold a Methods: Mind the Gap webinar with Dr. Jeffrey A. Sparks on Thursday, Jan. 16 at 11 a.m. The presentation will illustrate how epidemiologic and patient-oriented research studies can further the understanding of etiology and outcomes of rheumatoid arthritis (RA), a common chronic disease.

Sparks is an assistant professor of medicine and associate physician at Brigham and Women’s Hospital and Harvard Medical School. He performs studies to evaluate genetic, environmental, serologic and familial risk factors for RA, clinical trials for RA prevention and RA outcomes research focusing on the respiratory, metabolic, cardiovascular and mortality burden of RA.


PHS Officers Provide Opioid Overdose Response Training

Prompted by Surgeon General Jerome Adams’ 2018 advisory urging Americans to carry naloxone—an opioid antagonist—to reverse the effects of an overdose, PHS officers at NIH began offering opioid overdose response training.

So far, 75 sessions have been held. As of December 2019, 1,375 NIH staff have completed the training. Recently, the Maryland department of health reported an 11 percent decline in opioid-related deaths compared to the first half of 2018.

Opioid overdose response training classes are available in 2020 for anyone interested in attending the 1-hour session that includes a lecture on the opioid crisis, signs to recognize for an overdose and how naloxone works.

After the lecture, there is a hands-on training with scenarios and test kits to administer naloxone. The weekly trainings are in the FAES classrooms in Bldg. 10; NIH intramural staff are encouraged to attend. To sign up, visit https://www.signupgenius.com/go/30e0c4ada72ba2f1-hands.

For more information, contact Cdr. Leo Angelo Gumapas, leaoangelo.gumapas@nih.gov, (301) 832-4320. Individuals who need reasonable accommodation to participate should contact Gumapas and/or the Federal Relay (1-800-877-8339).

More Manchester Quartet in the New Year

The Manchester String Quartet continues its tradition of free performances at NIH in 2020 with a concert on Monday, Jan. 13 at 12:30 p.m. in Lipsett Amphitheater, Bldg. 10. The group will perform Brahms’ Viola Quintet in G Major, Opus 111, featuring guest artist Tsuna Sakamoto, viola.

Future performances in the new year will be on Mondays at 12:30 p.m. in the quartet’s normal concert space, Masur Auditorium. These include:

Feb. 10—Ravel’s Introduction and Allegro, with guest artists Adriana Horne (harp), Leah Arsenault Barrick (flute) and Paul Cigan (clarinet).

Mar. 2—Schubert’s Quartet in A Minor, Opus 29 #1.

Apr. 20—Tchaikovsky’s Souvenir de Florence, Opus 70, with guest artists Eric de Waardt (viola) and Eugena Chang (cello).

May 18—Brahms’ Piano Quartet in G Minor, Opus 25, with guest artist Lisa Emeneheiser, piano.

The series is supported by the Foundation for Advanced Education in the Sciences. For accommodation, contact Sharon Greenwell at (301) 496-1776 or sg115f@nih.gov.

Santa Visits Inn on a Harley

On Dec. 11, Santa Claus, escorted by 30 Montgomery County Police Department motorcycle officers, rode through parts of the county from Gaithersburg to Bethesda to support the Children’s Inn at NIH.

The 10-stop ride aboard thundering Harley-Davidsons culminated in a visit to the inn, where the motorcycle elves had fun with the kids.

Events included photos taken with Santa and Mrs. Claus, face-painting and ornament-making with the officers and shopping for donated gifts—Shop with a Cop—at the inn’s “Gingerbread Shop.”

PHOTOS: JEN FORESTER
NCI Welcomes Second Cohort of iCURE Scholars

“I have made life-long friendships, received excellent mentorship and have grown as a scientist. None of this would have been possible without the experience of being an iCURE scholar,” says Anaisa Quintanilla-Arteaga.

Nine more scholars now have the same opportunity to discover what is possible by participating in NCI’s intramural Continuing Umbrella of Research Experiences (iCURE) program, which provides students and scientists with mentored research experiences and encourages the participation of underrepresented individuals.

NCI’s Center to Reduce Cancer Health Disparities introduced the second cohort of iCURE scholars in a welcome ceremony recently at the John Edward Porter Neuroscience Research Center. The 7 post-baccalaureate individuals, 1 graduate student and 1 postdoctoral scholar who constitute the second cohort are now working in labs and programs across NCI’s campuses in Bethesda, Rockville and Frederick. They are conducting research in areas such as structural biophysics, cancer inflammation, health behaviors research, cell biology and protein dynamics and signaling, among others.

The 9 new scholars join the 15 continuing first-cohort iCURE scholars for a total of 24 iCURE scholars in 2019.

“Just like our inaugural class, this is an impressive group of new iCURE scholars,” said Center for Cancer Research director Dr. Tom Misteli. “They will change our science and our culture.”

Throughout the ceremony, iCURE

“I have made life-long friendships, received excellent mentorship and have grown as a scientist. None of this would have been possible without the experience of being an iCURE scholar.”

- ANAISA QUINTANILLA-ARTEAGA

Scholars who introduced their mentors included anecdotes about the support they have received from them, demonstrating the bonds that have formed and grown in the program’s first year.

Scholars described their mentors as their “greatest role model” and as someone who is “there for you mentally and emotionally.”

“For me, it’s already making a huge difference in my career,” remarked scholar Kimberly Meza. “I feel that this experience has really been like no other.”

iCURE is accepting applications until Jan. 17 for research experiences that will begin on Sept. 1.

Visit cancer.gov/about-nci/organization/crchd/diversity-training/icure for more information. Direct any questions to iCURE@nih.gov.

ON THE COVER: Radiology and imaging sciences technologist Rob Evers talks to a patient before a scan in the fully integrated whole-body simultaneous PET/MRI device. The Clinical Center acquired one of the first of these machines, which will contribute to the study of traumatic brain injury and related post-traumatic stress disorder.

IMAGE: CLINICAL CENTER

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is recyclable as mixed paper.
that “you can’t measure aging with lifespan—they are two different processes...Lifespan does not measure the rate of aging.”

In a well-received hour-long presentation to the proteostasis scientific interest group held recently, Giniger, as lively and enthusiastic an investigator as NIH’s intramural research program has to offer, outlined painstaking investigations of the mechanisms of neurodegeneration, and, in particular, its connection to aging.

Using gene-expression profiling in RNA extracted from the heads of fruit flies, Giniger and his colleagues have shown that about 70 percent of the changes in gene expression that occur in aging flies “have nothing to do with the aging program itself.”

Instead, they reflect “their response to the microbial environment, [which] evolves over the lifecycle,” Giniger said.

A quick note on flies: they—like dogs, fish and other critters—share genomic analogs to cellular function, maturation and degeneration with humans, minus the awkward poetry and country songs. Especially useful to scientific investigation is their lifespan: it’s all over, baby blue, in about 40 days, so it doesn’t take long to reach—conclusions.

So intimate have their studies been that Giniger and his team can read fly behavior, from the unpredictability of adolescence to the indolence of late age, which is useful for tracking age-related changes and tying them to gene expression.

The passage of time is not the only metric of interest in studies of aging, according to Giniger and his colleagues. They have also examined the role of the microbiome in prompting the progressive decline of organismal fitness that ends in death. It turns out that “axenic” flies—those raised in a sterile environment—leap, at the age of about 10 days, to a kind of metabolic middle age (30 days or so) and remain there until the end, which is itself delayed by about 20 percent compared to siblings raised under normal, non-sterile conditions.

His team has discovered that only about one-third of the changes that the fly genome experiences over time relate to the age measured by the calendar. The group has also applied similar ideas to tease out the non-aging components of neurodegeneration and to examine the role of innate immunity in cellular degradation.

Crediting a college professor who made him memorize metabolic pathways, Giniger and colleagues can trace many of the metabolic pathways associated with aging and see how they are connected to one another.

The result of their investigations—involving KEGG (Kyoto Encyclopedia of Genes and Genomes) pathways and ANOVA (analysis of variance), among other tools—is that aging is less a Thelma and Louise plunge off a cliff and “more like the Princess Bride fire swamp, where there are a dozen ways to die,” said Giniger.

“Lifespan is not a single entity,” he concluded, “but the net effect of several independent processes...a series of insults that accumulate at various rates.” Or to put it in the vernacular, we are killed by degrees, not simply by the neutral passage of time.

During a brief Q&A session after his talk, Giniger theorized that “a decrease in microbial assault in modern Western culture may be associated with both earlier puberty and later longevity. But I have no evidence.”

Asked whether people might live longer in sterile environments, with less exposure to various microbiomes, he suggested this may already be happening, to an extent:

“It may be why 70 is the new 60,” he said. 

NIGMS Hosts B-CC High School Students

On Dec. 5, eight students from Bethesda-Chevy Chase High School visited NIH as part of the school’s career day. The students were engaged from the beginning and partook in multiple tours. They were particularly interested in hearing from NIGMS staff and the PRAT fellows—including Philip Adam, above—about their careers, experiences working in labs as both students and professionals and the pros and cons of working in larger labs at bigger universities vs. smaller labs at private/liberal arts schools. As part of the event, the National Library of Medicine’s Tara Mowery and Dr. Stephen Greenberg (below, showing youngsters the Nobel Prize medal earned by NIH’s Dr. Marshall Nirenberg) led the students on a tour of NLM, providing overviews of NIH, the library and its History of Medicine Division.

PHOTOS: JYOTI SINGH

PHOTOS: MARLEEN VAN DEN NESTE
Science Day Inspires Next Generation of Researchers

The sixth annual Science Day hosted recently by NIH aimed to engage students from disadvantaged communities by giving them an opportunity to interact with researchers and mentors here and to explore the world of biomedical sciences. Nearly 500 middle and high school students—many of them African American, Hispanic/Latino and Asian—participated in the event at Natcher Conference Center.

They listened to presentations about career options in biomedical research, participated in hands-on activities and lunched with a scientist. The presentations and activities helped students gain useful experiences and interact with STEM professionals about their personal journeys in science.

Dr. Courtney Aklin of the National Institute on Minority Health and Health Disparities said, “I am humbled to participate, along with my colleagues, in developing the minds of our future health care providers, researchers and scientists.”

Dr. Lynn Holden, co-founder and president of Mentoring in Medicine, Inc., said, “With this partnership, we are providing exposure, inspiration, education and empowerment for students to pursue biomedical careers. Through this immersion experience in science, we incorporated exploration with hands-on activities, networking with scientists and providing educational resources to plant the seeds to achieve a future career in health and science.”

During the opening panel titled “My Journey to a Career in the Biomedical Field,” many of the NIH scientists and biomedical professionals provided candid and encouraging stories of their careers. Their personal accounts of failure and success were directed toward empowering and encouraging the next generation to be innovators and believers in endless opportunities in STEM fields.

During the lunch sessions, small groups of students gathered around individual scientists to share academic, social and peer-related issues they’re encountering. The scientists listened to the students’ concerns and shared their own views about navigating the complexities of young adulthood. In many ways, Science Day wasn’t just about getting students interested in STEM fields. It was also about coaching the youngsters from minority communities about how to keep up in the fast-paced academic world.

Dr. Richard Benson of the National Institute of Neurological Disorders and Stroke noted, “You are what you are becoming.” He was there to inspire, encourage and support the next generation of underrepresented students.

NHLBI’s Dr. Melissa Green Parker said, “My heart is full given the inspiration I received after speaking with our next generation of STEM scholars. They are going to make us proud!”

Throughout the day, students received plenty of encouragement to not be deterred by their socioeconomic standing. Many of the NIH scientists expressed their gratitude for being able to give their opinions and feedback to the next generation and felt confident that the students would be successful in the future.—Janki Patel
AIDS Response
CONTINUED FROM PAGE 1

a chronic disease associated with a nearly normal lifespan.”

What’s more, he continued, we can identify the regional, social and economic pockets of people where HIV is still gaining ground.

“The theme of community involvement could not be more important than it is right now,” Collins said. “We’ve made stunning progress, but we still have some distance to go.”

On the science front, he said, NIH has trials of three different vaccines underway and recently joined the Bill and Melinda Gates Foundation on a bold goal to develop a gene-editing cure for HIV in 10 years.

“Ending the epidemic is going to take more than money,” Collins acknowledged. “Community engagement is what’s desperately needed to bring disproportionately burdened populations into testing and treatment.”

That engagement will need to span a “continuum of outreach, consultation, involvement, shared leadership, ideas, responsibility and decision-making,” he said. “[In addition] communities affected by HIV play a key role in battling stigma, which presents a barrier to individuals getting tested and treatment. [That includes] stigma of all sorts—gender inequality, homophobia, transphobia, etc. Communities are best positioned to address those barriers.”

Remembering her first-hand experience with stigma was early HIV/AIDS community activist Jeanne White-Ginder, mother of Ryan White, who became a child spokesman on the issue after he contracted AIDS in 1984 via the blood transfusion treatment he needed to live with severe hemophilia. White-Ginder recalled her son’s battle against not only AIDS, but also against people’s ignorance, fear and bias about the disorder that made patient survival much more difficult.

Before all was known about how HIV was spread, White and others living with AIDS were virtually shunned in their communities, often barred from school or work or interacting with neighbors. White outlived his 6-month prognosis with the disease by 5 1/2 years, succumbing in 1990. But his mom’s recollection of the ordeal the family endured continues as a painful reminder that public education and compassion are integral components in efforts to end HIV/AIDS.

“It’s really hard to lose a child,” she concluded. “It’s the worst pain any mother could ever go through. Everybody says it gets better, but it doesn’t. You learn to live with it because you have to. Ryan always used to put his hand under my chin and say ‘It’s okay, mom...Everything is going to be all right.’ Well, I’m still waiting for everything to be all right.”

In addition to remarks by Collins and White-Ginder, the World AIDS Day event brought in several representatives from community organizations active in the pandemic. Many thanked NIH for its history of teaming up with citizen groups and individuals personally affected by HIV.
ORWH Announces Two Travel Awards

ORWH is offering two Science Policy Scholar Travel Awards to support the development of junior investigators focused on women’s health or sex and gender differences who are also interested in research policy. The awards provide up to $3,000 each to defray the costs of attending the Organization for the Study of Sex Differences’ annual meeting on May 4-7 in Marina del Rey, Calif.

Liver Cancer Patients Needed

National Cancer Institute researchers are testing a new treatment in people with liver cancer (hepatocellular carcinoma). The treatment uses nivolumab (immune therapy) given in combination with tadafelim and vancomycin (an antibiotic that changes the gut bacteria) to see if the tumors shrink. Participants do not pay for tests, treatments or procedures. Travel may be reimbursed. Contact the Clinical Center Office of Patient Recruitment at 866-444-2214 (800-877-8339 TTY/ASCII) or prpl@cc.nih.gov. Refer to study 19-C-0033. Read more at https://go.usa.gov/xpZx6.

“It was the voice of NIH and [NIAID director] Dr. [Anthony] Fauci’s leadership that informed us and it propelled us into action,” said longtime HIV activist/fundraiser Cornelius Baker, a former artist who currently serves as OAR special advisor and liaison to the President’s Emergency Plan for AIDS Research (PEPFAR). “The evidence you produce—whether it’s the most basic scientific evidence, to things that inform us about transmission patterns, to new drugs, etc.—the work you do here is so foundational to everything that we aspire to achieve with HIV/AIDS.”

Two sessions of panelists discussed their personal connection to community activism and HIV, the work of their organizations as well as strategies for engaging target populations.

“Building community trust means communicating with not just you and me, but in other venues, such as schools, churches [and] businesses,” noted Rev. Debra Hickman, co-founder of Sisters Together And Reaching, Inc. (STAR), a nonprofit, federally recognized community-based/faith-based organization created to address inequities in services to African-American women living with HIV/AIDS in Baltimore.

“The faith community is not something to fear—it is your mouthpiece. It is how we get our messages out. It is how we change social norms,” said Dr. Pernessa Seele, founder and CEO of Balm in Gilead, Inc., a nonprofit that offers training and services to faith institutions in the U.S. and Africa to promote health education and disease management.

“In order for us to learn from each other, we have to see people like ourselves so we can trust them,” said Consuelaa Lopez, director of operations at Casa Ruby, an organization established by transgender women of color to provide social services and support for members of the LGBTQ community.

“If we don’t have the workforce that looks like our community to get out the messages of change and treatment in that culturally humble way, then we’re going to continue to see significant inequities as it relates to HIV,” agreed Abby Charles, on behalf of community health workers—peers—who she called “the glue” that has kept community fastened to clinic.

As speaker after speaker pointed out, community engagement has always been crucial in the fight against HIV/AIDS. Strengthening and galvanizing its resources to finally put an end to the disease is a no-brainer.

Emphasizing the importance of eliminating silos, working in partnership and not letting momentum slip away, Mitchell Warren, executive director of AVAC (formerly the AIDS Vaccine Advocacy Coalition), reminded attendees of what successful partnership has already accomplished.

“The reason we can even talk about ending the epidemic now after 38 years is because science and advocacy came together,” he said. “Some of the greatest science has happened because of community. And some of the greatest community actions have happened because of the links with science.”

Liver Cancer Patients Needed

National Cancer Institute researchers are testing a new treatment in people with liver cancer (hepatocellular carcinoma). The treatment uses nivolumab (immune therapy) given in combination with tadafelim and vancomycin (an antibiotic that changes the gut bacteria) to see if the tumors shrink. Participants do not pay for tests, treatments or procedures. Travel may be reimbursed. Contact the Clinical Center Office of Patient Recruitment at 866-444-2214 (800-877-8339 TTY/ASCII) or prpl@cc.nih.gov. Refer to study 19-C-0033. Read more at https://go.usa.gov/xpZx6.
by President John F. Kennedy in 1961. The Peace Corps motto—Work for the World—extends to its support for the CFC, to provide critical assistance in local communities, across the nation and around the world, Olsen said.

The needs are great, both at home and overseas, she acknowledged. “What we do personally and professionally interacts with the work of CFC charities every day. And our choosing to make a contribution and/or volunteer with one of the charities to me is a natural extension of who we are as employees and as employees giving service.”

She applauded the NIH community for its continuing generosity to the CFC and for the agency’s commitment to improving the world’s health.

“For federal government employees, it’s about service—we do research, we do training, we manage, we give grants, we cheer on academics, but we’re serving,” she said. “As employees, we serve. And at Peace Corps, another federal agency, as volunteers, we serve and I think that’s a really common driver.”

A number of Peace Corps alumni are NIH employees and have formed a local chapter of Returned Peace Corps Volunteers (RPCV), where members continue their tradition of service, working with the Children’s Inn at NIH and other causes.

Everyone should consider volunteering in some capacity, according to the National Commission on Military, National and Public Service. “Largely it’s about being asked and being shown how easy it is to serve,” Olsen noted.

She encouraged NIH employees to consider taking time off to volunteer through the Peace Corps Response program, designed for experienced, mid-career professionals to undertake short-term, high-impact service assignments in the country of their choice. A background in health research is especially useful. For example, one volunteer helped an HIV facility in South Africa dramatically reduce the time it took to locate patient files for clinic visits. It’s a mutually beneficial experience, Olsen said. “What you would bring back is phenomenal.”

For the first year after returning to the U.S., RPCVs receive special hiring preference to help them enter the federal workforce, Olsen said. Hiring managers tell her they prefer returned volunteers because of their adaptability and unique perspective. In addition, 120 graduate schools award $11 million each year through a fellowship program for RPCVs, with an emphasis on those working in health fields.

Since its inception, more than 235,000 Americans have joined the Peace Corps, another federal agency, as volunteers, we serve and I think that’s a really common driver.”

As honorary CFC chair, Peace Corps director Olsen (c) visited NIH to encourage donations and volunteers. She was greeted by Fogarty’s director Dr. Roger Glass (l) and deputy director Dr. Peter Kilmarx, who was a Peace Corps volunteer early in his career.

Photos: Chia-Chi Charlie Chang

Peace Corps and served in 141 countries. Olsen—who grew up in Utah—enrolled after she graduated from college in 1966. She said she’d always wanted to get on a plane and was intrigued by the idea of living in a strange place.

She soon found herself standing in front of a class of Tunisian boys, tasked with teaching them English, she said. “That moment, as we all know very well, that you step forward and say this is the beginning of something…you embark on an adventure that forever changes your life.”

—Dr. Jody Olsen

In closing, Glass echoed Olsen’s support for the CFC and reflected on his own early-career experiences trying to save children with diarrheal diseases in Bangladesh.

“Giving back is part of what makes us human and demonstrates our caring for others, whether it’s at home or abroad,” he said.

Returned Peace Corps volunteers at NIH are encouraged to join the NIH RPCV group listserv at https://go.usa.gov/xperh.
Severity of Autism Symptoms Varies Among Identical Twins

Identical twins with autism spectrum disorder (ASD) often experience large differences in symptom severity even though they share the same DNA, according to an analysis funded by NIH. The findings suggest that identifying the causes of this variability may inform the treatment of ASD-related symptoms. The study was conducted by Dr. John Constantino of Washington University School of Medicine in St. Louis and colleagues. Funding was provided by NICHD. The study appears in Behavior Genetics.

ASD is a developmental disorder that affects how a person behaves, interacts with others and learns. Previous studies have found that when one identical twin has ASD, chances are extremely likely that the other twin has it, too. The authors analyzed data from three previous studies comprising a total of 366 identical twin pairs with and without ASD. The severity of autism traits and symptoms in the twins was measured by a clinician’s assessment or by parents’ ratings on a standardized questionnaire. Some cases were diagnosed by both methods. The researchers determined that there is a 96 percent chance that if one twin has ASD, the other has it, too. However, symptom scores varied greatly between twins diagnosed with ASD. The researchers estimated that genetic factors contributed to only 9 percent of the cause of trait variation among these twins. In contrast, among pairs of identical twins without ASD, the scores for traits were very similar.

The study authors do not know the reasons for differences in symptom severity, but they rule out genetic and most environmental causes because the twins share the same DNA and were raised in the same environment. Additional studies are needed to determine the cause.

Pregnancy Hypertension Risk Increased by Traffic-Related Air Pollution

A new report from the National Toxicology Program suggests that traffic-related air pollution increases a pregnant woman’s risk for dangerous increases in blood pressure, known as hypertension.

NTP scientists evaluated published research on the link between traffic-related air pollution, or TRAP, and hypertensive disorders broken down by pollutant measurements of TRAP, such as particulate matter (PM2.5). PM is the term for a mixture of solid particles and liquid droplets found in the air, and PM2.5 refers to fine inhalable particles, with diameters that are generally 2.5 micrometers or smaller. The average human hair is about 70 micrometers in diameter, about 30 times larger than the largest fine particle.

“TRAP comes from the combustion of fossil fuels by motor vehicles. These vehicle emissions are mixtures of gases and particles that are easily inhaled and have adverse health effects. TRAP is known to be a major risk factor for cardiovascular disease, including hypertension. Hypertensive disorders of pregnancy complicate more than 10 percent of pregnancies worldwide and are a leading cause of maternal and fetal illness and death. According to the American College of Obstetrics and Gynecology, mothers with hypertension during pregnancy are more likely to have a pre-term delivery. Their infants are at greater risk for low birthweight and a range of long-term health problems associated with premature birth.

NIH Researchers Discover New Autoinflammatory Disease

Over the last 20 years, three families have been unsuspectingly linked by an unknown illness. Researchers at NHGRI and other organizations have now identified the cause of the illness, a new disease called CRIA syndrome. The results were published in the journal Nature.

NHGRI scientific director Dr. Daniel Kastner, a pioneer in the field of autoinflammatory diseases, and his team discovered CRIA, which has symptoms including fevers, swollen lymph nodes, severe abdominal pain, gastrointestinal problems, headaches and, in some cases, abnormally enlarged spleen and liver.

The disorder has characteristics typical of an autoinflammatory disease, where the immune system appears to be activated without any apparent trigger. Although the condition is not life-threatening, patients have persistent fever and swollen lymph nodes from childhood to old age, as well as other symptoms that can lead to lifelong pain and disability.

When confronted by Clinical Center patients’ symptoms, researchers looked for infections and cancer as the cause. After those were ruled out, they sought answers in the genome, a person’s complete set of DNA. Kastner and his team sequenced gene regions across the genome and discovered only one gene—RIPK1—to be consistently different in all patients.

Researchers identified a specific type of variation in the patients: a single DNA letter at a specific location incorrectly changed. This change can alter the amino acid added to the encoded protein. These are called “missense” mutations.

Remarkably, each of the three families had its own unique missense mutation affecting the very same DNA letter in the RIPK1 gene. Each affected person had one mutant and one normal copy of the gene, while the unaffected family members had two normal copies of the gene.

The researchers also looked at 554 people with sporadic unexplained fever, swollen glands and other symptoms or diseases, and then at more than a quarter million people from public sequence databases to see if they encountered the same RIPK1 mutations. When they did not find such mutations elsewhere, it was clear that they were onto something new.

“It was as if lightning had struck three times in the same place,” said Kastner, who led the NHGRI team. “This discovery underscores the tremendous power of combining astute clinical observation, state-of-the-art DNA sequencing and the sharing of sequence data in large publicly accessible databases. We live in a very special time.”
Greene Retires from NCI

Dr. Mark H. Greene, senior principal investiga- tor in NCI’s Clinical Genetics Branch, retired after 33 years of distinguished service at the end of 2019. As inaugural chief of CGB, he initiated a research program of multidisciplinary studies on hereditary syndromes and cancer to leverage clinical observations into novel etiologic insights. As an investigator, Greene devoted his career to the study of genetic modifiers of cancer risk and treatment outcomes in hereditary cancers and to intervention studies in genetically at-risk populations.

In 1975, he came to NCI as a staff fellow in the Environmental Epidemiology Branch and became a senior investigator 2 years later. He and his collaborators identified and characterized the dysplastic nevus as a key precursor to melanoma and published the first full-color atlas of these lesions. Greene also co-led a series of studies that quantified the risks of acute leukemia associated with anti-neoplastic agents, the results of which had major implications for clinical use of these drugs.

After leaving government for private practice in hematology and medical oncology in 1985, he returned to serve as chief of the newly formed CGB in 1999. He served in that role for 14 years and received an NIH Merit Award for the creation, growth and leadership of an outstanding intramural program in clinical genetics.

Greene was pivotal in the launch of many hereditary breast/ovarian cancer studies such as the National Ovarian Cancer Prevention and Early Detection Study. For leading this project, he also received an NIH Merit Award.

He also developed and directed CGB’s Familial Testicular Cancer Study, which investigates the genetic causes of testicular cancer through studies of multiple-case families. More recently, Greene initiated the investigation of myotonic dystrophy as a potential cancer susceptibility syndrome, based on clinical observations.

Greene served on multiple working groups within NCI and mentored more than 33 individuals.

“As chief of CGB, Mark spearheaded projects which advanced our understanding of the etiology of familial cancers, resulting in clinically meaningful recommendations for patients seeking preventive care and yielding avenues of investigation for cancer risk in the general population,” said Dr. Stephen Chanock, director of the Division of Cancer Epidemiology and Genetics. “His exceptional leadership and collaborative spirit will be missed.”

In retirement, Greene will serve as scientist emeritus to the division.

NCI’s Wiest Retires After 18 Years

Dr. Jonathan Wiest retired in December after 18 years at NCI. He joined the institute in 2001 as associate director for training and education, Center for Cancer Research, to advance NCI’s cancer training efforts for both intramural and extramural research. After he was named the first director of the newly formed CCT in 2007, these efforts accelerated.

He developed NCI extramural training programs, streamlined training award mechanisms, increased support for physician-scientist awards and built career paths for trainees with the establishment of the F99/K00 mechanism leading to the transition to independence with the K99/R00 mechanism.

On the intramural side, Wiest pioneered innovative educational and career development programs such as the NCI Graduate Student Recruitment program, which brought outstanding postdocs to NCI research groups, and the electronic Individual Development Plan system, which helped postdocs establish career plans in concert with their mentors. The annual CCR-FYI Colloquium continues to give fellows the opportunity to explore potential career paths and learn about groundbreaking research.

Wiest also established workshops, courses and fellowships to help intramural fellows transition to their next career step.

“Jonathan leaves a legacy that will endure,” said Dr. Dinah Singer, NCI deputy director for scientific strategy and development. “By working to expand and transform NCI’s programs in cancer research training, career development and education, he helped develop a 21st century workforce capable of advancing cancer research.”

OSP’s Harris Wins Biosafety Honor

Dr. Kathryn Harris, a senior outreach and education analyst in NIH’s Office of Science Policy, was recently presented with the Arnold G. Wedum Distinguished Achievement Award by the American Biological Safety Association at its annual meeting in Birmingham, Alabama. The award, the highest honor bestowed by ABSA, is given for outstanding contributions to biological safety accomplished through teaching, research, service and leadership.

One of Harris’s most innovative approaches was spearheading the OSP Site Visit Program, which provided tailored
one-on-one advice to grantees on how best to comply with various federal biosafety standards. Over the course of the program, Harris visited more than 100 grantee institutions to help guide extramural programs.

Harris is also a well-known lecturer and educator on the biosafety circuit and has provided numerous keynote addresses relating to biosafety and biosecurity. She was also the founding organizer of OSP’s biennial biosafety conference, which provided a venue for the biosafety committee and the federal government to convene and discuss common challenges.

Prior to Harris’s tenure at NIH, she served as biological safety officer at Northwestern University, where she founded the Midwest Area Biosafety Network. Harris earned her B.Sc. in biology from Bangor University and her Ph.D. in biology from Cornell University.

She adds the Wedum Award to a list of honors that also includes several NIH OD Honor Awards and a Director’s Award.

“Kathryn’s leadership in the field of biosafety and biosecurity has allowed vitally important biomedical research to take place in a safe and responsible manner,” said Dr. Jessica Tucker, director of OSP’s Division of Biosafety, Biosecurity and Emerging Biotechnology Policy. “Her dedication has made NIH one of the most trusted government agencies with respect to biosafety, and you simply can’t put a price on that.”

**NICHD Alumnus Robbins Mourned**

Dr. John Bennett Robbins, co-developer of a vaccine that has spared thousands of children from a major cause of death and intellectual disability, died Nov. 27 after a long illness. He was 86 years old.

Robbins was chief of the Laboratory of Developmental and Molecular Immunity at the National Institute of Child Health and Human Development until his retirement in 2012. Together with his colleague and, later, co-branch chief Dr. Rachel Schneerson, Robbins received the 1996 Albert Lasker Medical Research Award for developing the polysaccharide-protein conjugate vaccine for *Haemophilus influenzae* type b (Hib). The award is bestowed annually to those who have made major contributions to medical science.

Before 1989, Hib infected an estimated 15,000 to 20,000 children each year in the United States. The disease can progress to meningitis, a potentially fatal infection of the membranes surrounding the brain. Although effective antibiotic treatment was available at the time, Hib infection resulted in 1,000 deaths annually. Another 4,000 survivors experienced nervous system damage resulting in intellectual disability, deafness or seizures.

The Hib bacterium’s polysaccharide coat, or capsule, allows it to slip undetected past a child’s immature immune system. Dr. Porter Warren Anderson and Dr. David Hamilton Smith, who shared the 1996 Lasker award with Robbins and Schneerson, developed a vaccine against the polysaccharide, but it failed to provoke a sufficient immune response to protect infants and young children from the infection. Robbins and Schneerson overcame this obstacle by linking, or conjugating, the polysaccharide to a protein.

The combination was easily recognized by the immune system, which could then mount an effective response against the polysaccharide. Since routine use of the Hib conjugate vaccine in 1990, Hib cases have plummeted. According to the Centers for Disease Control and Prevention, in 2015 there were .08 cases of Hib disease per 100,000 children younger than 5 years old.

Robbins earned his M.D. at New York University. He was appointed as NICHD’s first clinical director in 1970. In 1974, he joined the Food and Drug Administration, where he served as director of the Division of Bacterial Products in the Bureau of Biologics. He returned to NICHD in 1984, establishing the Laboratory of Developmental and Molecular Immunity to explore methods for developing vaccines against Hib and other encapsulated bacteria.

In subsequent years, Robbins, Schneerson and their colleagues developed a vaccine for pertussis and worked on conjugate vaccines against typhoid fever, *Staphylococcus aureus* and other bacterial diseases.

For his work with the Hib conjugate vaccine, Robbins also received the Albert B. Sabin Gold Medal in 2001, the World Health Organization Children’s Vaccine Initiative Pasteur Award (with Schneerson) in 2006, and Thailand’s Prince Mahidol Foundation Award for Public Health in 2017 (with Anderson, Smith and Schneerson).

Robbins retired from NICHD in 2012, after which he briefly joined the faculty of the Sophie Davis School of Biomedical Education at the City College of New York, before resigning for health reasons.

He is survived by his wife, Joan; his children Rob, Daniel, Ellen and David; and nine grandchildren.
SIGHTS, SOUNDS OF THE SEASON
Musical Groups Visit CC for Holidays
PHOTOS: DEBBIE ACCAME

Several groups brought festive holiday cheer to the Clinical Research Center atrium during December, including the University of Maryland Jazz Combo, the NIH Chamber Singers, the National Symphony Orchestra Horn Ensemble, the United States Public Health Service Music Ensemble, JewKvox, NIH Nerds In Harmony and the Capitol Hill Carolers.