**NIH Visitor Center Welcomes Variety of Guests**

High school students, foreign health ministers, college professors, industry scientists, potential employees, NIH employee families and congressional staff and leadership are all counted among the thousands of people who visit the NIH campus each year. Many are invited by colleagues or are participating in nearby conferences, some come to NIH to visit the place where their friends and relatives work and others visit NIH as part of the U.S. Department of State’s International Visitor Leadership Program. These varied guests, who travel to NIH from across the U.S. and around the world, are led on tours by the NIH Visitor Center (VC) and special events team, members of the OD Office of Communications and Public Liaison.

The VC team, under the leadership of Tara Mowery, includes tour guides Sharon Greenwell, Carol Jabir and Sharon Robinson. Scheduler and welcomer Dominic Lopiano rounds out the team. They act as ambassadors, tell-

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**Prenatal Testing Revolutionizing Fetal Care**

By Dana Talesnik

Recent advances in prenatal testing are transforming diagnosis and treatment of genetic conditions. A growing number of pregnant women are benefiting from a newer kind of noninvasive prenatal testing (NIPT) that analyzes cell-free fetal DNA circulating in the maternal blood. This blood test, which first became clinically available in 2011, can detect with great accuracy a range of aneuploidies (fetal chromosomal abnormalities) such as trisomy 21 (Down syndrome). These advances also are paving the way toward treating Down syndrome and other aneuploidies while the baby is still in the womb.

“We now can infer functional information about the developing fetus and change the course of disease,” said Dr. Diana Bianchi, director of the National Institute of Child Health and Human Development.

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**Precision Medicine Initiative Launches at NIH**

By Rich McManus

President Obama’s Precision Medicine Initiative (PMI) got an enthusiastic launch at NIH on Feb. 11-12 when a group of more than 80 scientists, patient advocates and representatives from academia, industry and professional organizations convened on campus to flesh out a proposal first mentioned at the State of the Union address on Jan. 20.

PMI has two components. The first is a near-term effort managed by the National Cancer Institute to capitalize on new knowledge about cancer genetics to target drugs more precisely. The second, longer-term component is to build a large national cohort of unprecedented scale—more than 1 million participants who choose to share health, clinical, lifestyle and behav-

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Deisseroth Wins FNIH’s Lurie Prize

The Foundation for the National Institutes of Health has selected Dr. Karl Deisseroth as the 2015 winner of the Lurie Prize in Biomedical Sciences. He is being recognized for leading the development of optogenetics, a technology for controlling cells with light to determine function, as well as for CLARITY, a method for transforming intact organs into transparent polymer gels to allow visualization of biological structures with high resolution and detail. The Lurie Prize will be presented on May 20 in Washington, D.C.

Deisseroth is the D.H. Chen professor of bioengineering and of psychiatry and behavioral sciences at Stanford University and a Howard Hughes Medical Institute investigator. He first pioneered the field of optogenetics—which has greatly expanded our understanding of normal behavior as well as of diseases such as Parkinson’s, schizophrenia and depression—by combining genetic manipulation and optics to activate or deactivate precisely targeted brain cells. His team also pioneered CLARITY, a chemical engineering method for making biological tissues such as the intact brain fully transparent and accessible. It has already enabled scientists to observe intricate molecular-resolution details within healthy brains as well as brains from Alzheimer’s disease and autism patients.

“Karl Deisseroth has opened exciting new fields of scientific endeavor that transform how we view and understand the brain,” said Dr. Charles A. Sanders, chair of FNIH. “This research provides great hope to understand biology at a deeper level and, in time, to assist people suffering from diseases such as Parkinson’s and depression.”

Endowed by philanthropist and FNIH board member Ann Lurie, the Lurie Prize recognizes outstanding achievement by a promising scientist age 52 or younger and includes a $100,000 honorarium.

Pestian Gives NLM Informatics Lecture, Mar. 18

Dr. John Pestian is the next speaker in the National Library of Medicine Informatics Lecture Series. He will discuss “Phenotypic Cohort Retrieval Using the Multi-Institutional Pediatric Epilepsy Decision Support (MiPeds) System” on Wednesday, Mar. 18 from 2 to 3 p.m. in Bldg. 45, balcony C.

The MiPeds system provides point-of-care surveillance of phenotypically similar pediatric epilepsy patients using electronic health records. The talk will describe the successes and challenges of developing MiPeds.

Pestian is a professor of pediatrics and biomedical informatics at Children’s Hospital Medical Center, University of Cincinnati. He has been active in translating neuropsychiatric innovations from the bench to the bedside.

The talk will be broadcast live and archived at http://videocast.nih.gov/. Sign language interpreters will be provided. Individuals who need reasonable accommodation to participate should contact Ebony Hughes, (301) 451-8038, Ebony.Hughes@nih.gov or the Federal Relay (1-800-877-8339). For more information about the event, contact Dr. Jane Ye, (301) 594-4882, yej@mail.nih.gov.
Dr. Gary Wand will deliver the 2015 Jack Mendelson Honorary Lecture on Thursday, Mar. 19 at 1:30 p.m. in Masur Auditorium, Bldg. 10. The title of his talk is “Cortisol Dysregulation and Alcoholism: Consequence, Correlation or Causality?” Wand is an internationally recognized neuroendocrinologist and the inaugural Rivière professor in endocrinology and metabolism at Johns Hopkins University School of Medicine.

Wand’s work has advanced understanding of the genetic and environmental determinants of the stress response and has elucidated how excessive stress hormone production may contribute to neurobiological conditions such as alcohol or drug disorders.

Bridging the fields of neuroendocrinology and substance abuse, Wand’s research is based on the hypothesis that certain stress hormones may contribute to alcohol- and other drug-seeking behaviors by altering the brain’s reward and reinforcement pathways. Some of his seminal discoveries include identifying unique pharmacological responses to naloxone in individuals at increased risk for alcohol use disorders, identifying specific hormonal responses in subjects with alcohol use disorders and characterizing human brain neurochemical changes using imaging in subjects with substance use disorders.

Currently, Wand is studying the epigenetic modulation of stress and cortisol exposure in rodent and human models, based on the hypothesis that specific epigenetic events affect how much cortisol an individual produces, which in turn influences dopamine transmission.

Wand received his medical degree and subsequent training in internal medicine from George Washington University. Following postdoctoral training in endocrinology and metabolism at Johns Hopkins University School of Medicine, he was a fellow in the peptide laboratories of Dr. Richard Mains and Dr. Betty Eipper in JHU’s department of neuroscience. Wand then joined the JHU School of Medicine faculty, where he remains to this day.

In 2000, NIAAA and NIH honored Wand with a 10-year MERIT Award to continue his research on the role of the HPA axis in alcoholism. He has also received numerous local and national “Best Doctor” awards. Wand is the author of more than 175 articles and chapters and is on the editorial board of several journals.

NIAAA established the lecture series as a tribute to Dr. Jack Mendelson, who made remarkable contributions to the field of clinical alcohol research. Each spring, the series features a lecture by an outstanding alcohol investigator whose clinical research makes a substantial contribution to our understanding of alcohol susceptibility, alcohol’s effects on the brain and other organs and the prevention and treatment of alcohol use disorders.

Neurosurgeon Sanjay Gupta, an Emmy Award-winning journalist, will deliver the annual J. Edward Rall Cultural Lecture on “Media and Medicine” on Mar. 25 at 10 a.m. in Masur Auditorium, Bldg. 10.

Gupta, chief medical correspondent for CNN, appears on several television shows on medicine and health news such as American Morning, Anderson Cooper 360°, CNN documentaries and anchors the weekend medical affairs program Sanjay Gupta, MD. He also contributes to CNN.com, CNNHealth.com and CBS’s 60 Minutes and Evening News with Scott Pelley.

Apart from being a successful practicing neurosurgeon and media guru, his journalistic approach and reporting have won him several awards. He visited both Japan in 2011 and Haiti in 2010 after the earthquakes hit and reported the effects of the disasters on human health. After joining CNN in 2001, he reported on the aftermath of the 9/11 attack from New York and was part of the “Devil Docs” unit during the Iraq war in 2003. He performed brain surgery onsite during his time in Iraq. In 2004, his coverage of the aftermath of the devastating tsunami in Sri Lanka contributed to the 2005 Alfred I. DuPont-Columbia Award for CNN. He has contributed stories to CNN’s Peabody Award-winning coverage of Hurricane Katrina (2005) and the oil spill disaster in the Gulf of Mexico (2010).

To inspire Americans to live a more active and healthy life, Gupta launched “Fit Nation” as part of CNN’s multi-platform, anti-obesity initiative. In 2010, he was offered the Laureate Award for leaders in health and wellness from John F. Kennedy University (Pleasant Hill, Calif.). He was also named as one of the “Ten Most Influential Celebrities” by Forbes magazine.

He has also authored two bestselling books, Chasing Life (2007) and Cheating Death (2009), is a member of the faculty at Emory University and is associate chief of neurosurgery at Grady Memorial Hospital, Atlanta.

He received his undergraduate degree from the University of Michigan and his M.D. from its medical school. Before joining CNN, he did neurosurgical fellowships at Semmes-Murphey Clinic in Tennessee and the University of Michigan Medical Center.

Seating for the lecture is on a first-come, first-served basis. For more information or to request reasonable accommodation, contact Jacqueline Roberts at (301) 594-6747 or robertsjm@mail.nih.gov.

The lecture honors the memory of Dr. J. Edward Rall, founder of the Clinical Endocrinology Branch (now within NIDDK) and scientific director of the National Institute of Arthritis and Metabolic Diseases, which is now represented by NIDDK and NIAMS.
about the developing brain in living fetuses,” said reproductive geneticist Dr. Diana Bianchi, whose research has had a dramatic impact on NIPT and opportunities for new fetal therapies. “That hasn’t been done before because most information about fetal gene expression is done post-mortem.”

Bianchi, executive director of the Mother Infant Research Institute at Tufts Medical Center and professor of pediatrics, obstetrics and gynecology at Tufts University School of Medicine, spoke at the NICHD Director’s Lecture in Lipsett Amphitheater recently.

NIPT is a blood test currently offered to women with high-risk pregnancies—due to advanced maternal age or previous pregnancy complications—as early as 10 weeks and up until delivery. The test screens for chromosomal disorders—primarily for trisomy 21 and trisomies 18 and 13—using massive parallel sequencing of cell-free DNA from the mother’s blood.

“One of the reasons the testing has become so rapidly incorporated into care is that the detection rate, the sensitivity, is excellent,” said Bianchi.

If the NIPT screens positive for aneuploidy, further testing is recommended to confirm the diagnosis. NIPT is so reliable that, if results are negative, it precludes the need for invasive diagnostic tests such as amniocentesis or chorionic villus sampling. In fact, there’s been a dramatic decline in such invasive testing since NIPT was introduced.

Prior to modern-day prenatal screening, Down syndrome was diagnosed by pelvic x-rays in the affected infant. In the early 1970s, it became possible to physically isolate fetal cells from the blood of pregnant women when Bianchi’s lab mentor, Dr. Leonard Herzenberg, invented a cell sorter called the flow cytometer. Herzenberg, who had a son with Down syndrome, had challenged Bianchi—a pre-doctoral scholar—to develop a noninvasive prenatal genetic test for the syndrome. Soon after, her research revealed that fetal cells could be detected in the mother’s blood.

From 1994 to 2004, in the NIFTY trial—one of the first NIH-funded clinical trials toward developing improved NIPT—Bianchi and her co-investigators isolated intact fetal cells from maternal blood and detected a higher number of fetal cells in aneuploid pregnancies. This sparked interest from industry and, as technology improved and costs decreased, advanced prenatal sequencing became a reality.

“Though progress has been largely achieved through industry support,” said Bianchi, “the NIFTY trial and NICHD support really provided a foundation upon which a lot of the later work came.”

Current research holds great promise for developing novel fetal therapies for Down syndrome. Bianchi and her team are identifying and analyzing biomarkers for changing physiology in utero and targeting pathways for treatment.

“Down syndrome is our first target because it’s the most common of the conditions,” said Bianchi. If Down syndrome is detected at the end of the first trimester, “that would give us a 28-week window of time to treat the mother and influence fetal brain development.”

Children with Down syndrome have an observable phenotype, said Bianchi. Researchers have found a consistent pattern of gene expression in the amniotic fluid supernatant of fetuses with Down syndrome. A major abnormality present in affected fetuses is oxidative stress, which induces mitochondrial dysfunction.

“Our hypothesis is that if we treat oxidative stress in utero, we will improve neurogenesis and brain morphogenesis at a time when the brain is actively developing,” said Bianchi.

One drug already in testing is apigenin, a potent antioxidant currently used in human clinical trials for Alzheimer’s that’s been shown to inhibit oxidative stress. The drug has shown improved memory and exploratory behavior in prenatally treated adult mice and, so far, no toxic effects on human cell proliferation.

“The hope would be that treatment would improve brain growth so that there would be the opportunity for these cells to be rescued and the important normal connections could be made within the brain,” said Bianchi.

Improved prenatal screening in the first trimester has led to earlier, more reliable diagnoses of aneuploidies and has created new opportunities for developing fetal individualized therapies.

“The future vision is that a woman would have a prenatal diagnosis of Down syndrome either via ultrasound, amniocentesis or noninvasive prenatal testing and if she chooses to continue her pregnancy, she could then choose to have fetal treatment,” said Bianchi. “She herself would take a drug for fetal benefit and then ideally there’d be an improved outcome.”
Health Care Decisions

Risk Calculators Help Doctors, Patients Choose Best Treatment

By Michaelle Scanlon

In 1989, young Michael Kattan was in business school working on a Ph.D. when he was diagnosed with Hodgkin’s disease. Unhappy with the chart his doctor used to predict his 5-year survival rate, Kattan decided to turn his quantitative skills to developing better prediction tools.

“I was told I was stage IV but the ‘little old lady’ with the walker and oxygen tank in the waiting room was also stage IV. The prediction model put us on the same survival curve,” said Kattan at a recent lecture at NIMH. “I knew I wanted a more tailored model that predicted likely outcomes based on information about me.” His goal was to produce patient-specific risk scores that would help doctors and patients choose treatments suited to each patient’s needs.

His first tool, called a “prognostic nomogram,” was based on data from 983 prostate cancer patients. The nomogram outperformed clinicians in predicting 5-year survival rates and its success inspired him to continue his work. Today, Dr. Michael Kattan is chairman of the department of quantitative health sciences at the Cleveland Clinic. He has developed a number of statistics-based risk calculators to predict health risks and outcomes that help doctors and patients weigh health care options. These nomograms, available for free online (http://rcalc.ccf.org), give doctors and patients more information on which to make health care decisions. NIH funding also helped Kattan offer an online tool to support scientists who want to develop their own models.

Most recently, Kattan teamed up with Dr. Tyrone Cannon, professor of psychology and psychiatry at Yale University, and other investigators involved in the North American Prodrome Longitudinal Study (NAPLS 2). Their joint goal was to use NAPLS data to create a practical tool for predicting first-episode psychosis among youth at heightened risk for psychotic disorders. “Our initial goal was to develop a calculator based on risk factors that are easily assessed in standard clinical settings and then to refine it by incorporating information on biological risk factors as those come to light.”

The Kattan-Cannon collaboration resulted in a new “2-Year Probability of Conversion to Psychosis” tool. This nomogram can help clinicians who have been trained on the interview used to diagnose prodromal risk syndromes to estimate an individual patient’s risk of moving from the prodromal phase of psychosis (showing early symptoms) to actual psychosis in the coming 24 months. Based on the patient’s risk score, the clinician and patient can decide on the best care strategy.

To develop the nomogram, Cannon and colleagues chose 8 variables that previous research has associated with psychosis risk, including the existence of a first-degree relative with psychosis, the number and types of traumas, difficulties with memory and verbal learning and problems with unusual thoughts and suspiciousness. Data from all eight variables are run through Kattan’s nomogram to create the individual’s risk score.

“Tools like the psychosis risk calculator can help patients and doctors discuss options and develop personal treatment plans,” said Dr. Robert Heinssen, director of the Division of Services and Intervention Research at NIMH. “There are several proven interventions available for people at risk for psychosis, such as cognitive behavior therapy, counseling and support for family members and outreach to schools or work settings. Using the nomogram, doctors and patients can discuss the patient’s level of risk and distress and decide on the best plan of action.”

In the future, Kattan and Cannon say they would like to see duration of prodromal symptoms included in the 2-year probability model and perhaps biological test results. They are also considering the possibility of developing a nomogram that can estimate the likelihood of remission and encourage use of the risk calculator in treatment studies. They hope that risk estimates can be strengthened by refining known risk factors and also by accounting for a particular intervention program.

NIDA’s Huestis Honored

The American Academy of Forensic Sciences recently conferred the honor of distinguished fellow on Dr. Marilyn Huestis, senior investigator and chief of chemistry and drug metabolism at the National Institute on Drug Abuse. She was recognized for her contributions to the academy and the forensic sciences profession. Huestis is also an adjunct professor at the School of Medicine at the University of Maryland. She has published 354 peer-reviewed manuscripts and book chapters and has presented more than 500 abstracts at national and international meetings. Huestis currently serves on six scientific editorial boards and regularly reviews for 60 journals. She also mentors doctoral students in toxicology.
Above:
The NIH Visitor Center staff includes (from l) Carol Jabir, Sharon Greenwell, Sharon Robinson and Tara Mowery.
PHOTO: ERNIE BRANSON

Below:
A recent VC tour included (from l) Madina Rahman, deputy minister of health, Sierra Leone; Bockari Kortu Stevens, Sierra Leone’s ambassador to the United States; Lydia Daniels of the United Nations Association of the National Capital Area; VC staffer Dominic Lopiano; Mowery; Stacy Wallick, Fogarty Center program director for Sub-Saharan Africa, North Africa and the Middle East; Obinna Okinna, UNA intern from Howard University; Johnson Sirleaf, Liberia delegate, business sector; Elizabeth Johnson Sirleaf, deputy minister for administration, Liberia; Pasco Temple, information attaché, Embassy of Sierra Leone.

Building special connections is a key part of the VC team’s success. Through networking with researchers and administrative staff, the team is able to provide the most useful and enlightening experience for a particular group’s needs. For example, recently, Sierra Leone’s ambassador to the U.S. Bockari Kortu Stevens, accompanied by delegations from Sierra Leone and Liberia, visited NIH as an educational stop arranged by the United Nations Association of the National Capital Region African affairs committee. VC team members took the basic tour request and arranged a meeting with NIAID director Dr. Anthony Fauci and Fogarty International Center acting deputy director Dr. Ken Bridbord and his staff. These meetings and a tour of the CC’s special clinical studies unit provided an important opportunity for sharing knowledge on Ebola research.

Some people have wondered what the “special events” part of the VC title means. When there are major visits to campus, such as recent tours and presentations by President Obama, Secretary Burwell, the Dalai Lama, Secretary of State Clinton and Bill Gates, the VC staff works across NIH with the Office of the Director, the institutes and centers and ORS/ORF’s police, fire department, facilities managers, AV and transportation experts on ensuring that every aspect of the experience and logistics of these events makes the best possible impression of NIH and its people.

The VC team often hosts student groups who are encouraged to consider returning to NIH in an internship or fellowship program. One recurring group is first-year college students in the Meyerhoff Scholars Program at the University of Maryland, Baltimore County, who visit the campus every summer and experience NIH through speakers and tours. The program focuses on students who aspire to become research scientists and engineers. Each group comes excited and leaves inspired.

Following another program designed for visiting students from the University of Califor-
nia, San Francisco, School of Management, Dr. Krishna Balakrishnan, senior technology transfer manager for the National Center for Advancing Translational Sciences—who presented to the group—sent the VC team a complimentary email: “I found your presentation, including the video clips, most inspiring—I am sure it left a strong mark on the young minds and may spur the best among them to make NIH a part of their future career or scientific life. It is also nice to know through this visit of the great service that the NIH Visitor Center provides to society at large.”

Some visitors have ties to NIH-supported Nobel laureates. One visiting scientist came to see the Bldg. 45 Nobel Wall display to locate the plaque honoring Dr. Michael S. Brown, who had been his mentor. Brown, along with Dr. Joseph L. Goldstein, was awarded the 1985 Nobel Prize in physiology or medicine for elucidating the process of cholesterol metabolism in the human body. On another occasion, a physicist came for a visit with his son. Guide Carol Jabir recalled, “When I mentioned that there are currently 145 NIH-supported Nobel laureates, the gentleman’s face lit up and he told me that he had been a childhood classmate of Kary Mullis.” Mullis, a 1993 NIH-supported Nobel laureate, invented polymerase chain reaction, a technique for amplifying small quantities of DNA that revolutionized the field of molecular biology.

The VC team finds that all visitors are overwhelmed by the richness of the science that goes on at NIH as well as the sheer size of the campus. When they realize that this campus represents a small percentage, yet significant part, of the research enterprise supported by NIH, they are amazed. They are given a sense of scale as well as an understanding of how research teams function and come to appreciate the individual passion and commitment of those engaged in biomedical research.

Every year, the VC team fields an increasing number of requests to visit and learn about NIH. They attribute the rise in tour requests to the increasing visibility of NIH’s work, excitement about new research and breakthroughs and the enthusiasm with which visitors continue to share the NIH story with coworkers, family and friends.

Visitors unable to visit NIH in person are encouraged to visit the “Explore NIH” web site for a virtual tour experience: www.nih.gov/about/explore/index.htm.

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APAO Presents Annual Awards

The NIH Asian & Pacific Islander American Organization held two events recently on the NIH campus. An annual awards ceremony and luncheon recognized the following recipients: Outstanding Scientific Achievement Award, shared by Dr. Zhenggang Liu, NCI, and Dr. Yihong Ye, NIDDK; Leadership Excellence Award, Capt. Sally Hu, OD; KT Jeang Distinguished Service Award, Dr. Dar-Ning Kung, NLM.

Dottie Li, managing director of TransPacific Communications, was the keynote speaker. Her topic was the importance of effective communication.

At a training session titled “Articulate Your Expertise with Polish and Credibility,” the presenter was Christine K. Jahnke, who has advised two First Ladies on media as well as women politicians and candidates in 34 countries. A communications expert, she addressed an audience of 350 in Masur Auditorium and 679 via live videocast. The seminar was co-sponsored by APAO and the Office of Equity, Diversity and Inclusion. It can be viewed at http://videocast.nih.gov/PastEvents.asp.

APAO is seeking volunteers for its next event, the observance of Asian Heritage Month at NIH in May 2015. For more information or to join the group, contact JoAnne Wong at wongj@mail.nih.gov.

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At the recent APAO awards ceremony in Wilson Hall were (from l) Dr. Chunzhang Yang, 2014 APAO president; Dr. Zhenggang Liu, NCI; Dottie Li, managing director of TransPacific Communications; Dr. Yihong Ye, NIDDK; Dr. Dar-Ning Kung, NLM; and Capt. Sally Hu, OD.

PHOTO: RUBY LEE

At the recent seminar on communications were (from l) Dr. Sara Kaul, 2015 APAO president; Christine K. Jahnke, founder of Positive Communications; and Tyrone Banks, Office of Equity, Diversity and Inclusion.

PHOTO: JOANNE WONG
ior data—in an effort to accelerate biomedical discoveries and generate new treatments, diagnostic and preventive strategies that take into account the characteristics of individuals.

The President has asked for $200 million for NIH in FY 2016 for PMI; NCI would receive $70 million and the cohort would get $130 million.

The recent meeting, webcast to the public and, according to a quip by NHGRI director Dr. Eric Green, harder to attend in person than the Super Bowl, focused on building the large national cohort, using the model of sizeable cohorts already in place in other aspects of research.

Speaker after speaker said the time is finally right to tackle precision medicine. According to the White House, PMI “will leverage advances in genomics, emerging methods for managing and analyzing large data sets while protecting privacy, and health information technology to accelerate biomedical discoveries.”

NIH director Dr. Francis Collins admitted that a similar proposal he argued for in a Nature paper published in May 2004 failed to gain traction. But that was before the cost of genomic sequencing shrank dramatically (a 100,000-fold drop in 15 years), many began carrying a smartphone and electronic medical records were adopted by more than 95 percent of U.S. hospitals.

"We have spent many years thinking about this kind of an enterprise," said Collins, who first broached the topic with Obama in a meeting last June at the White House. The President had asked for a plan of what an initiative focused on precision medicine might look like. Last fall, NIH, with the Office of Science and Technology Policy, FDA and HHS’s Office of the National Coordinator for Health Information Technology, produced a concept that impressed the President enough that Obama made PMI a part of his State of the Union address.

“We’ve been given an amazing charge by someone deeply convinced of the value of this enterprise,” Collins said of the President.

Collins noted that PMI is not a new idea—people are long familiar with prescription eyeglasses and are well aware that blood transfusions require cross-matches between donor and recipient. "The prospect of a broader application has been emerging for some time," he explained, adding that a 2011 report on precision medicine by the National Research Council laid out the need for a "rigorous research program to provide scientific evidence for PMI...not a monolithic, top-down enterprise.”

Collins said PMI is an opportunity, much like the Human Genome Project and the current BRAIN Initiative, to recruit the best and brightest to advise NIH on plans that are "specific, actionable and transformational...This is a nascent, compelling, exciting, promising idea.”

“We have only the barest framework for this initiative,” said Dr. Kathy Hudson, NIH deputy director for science, outreach and policy, who along with Dr. Rick Lifton of Yale University will co-chair a PMI working group to the advisory committee to the NIH director. She said the group will name its members soon and will provide Collins with a detailed report by September.

“This is the first of many conversations,” said Hudson, who noted that patients and the public, in addition to private industry, will be included in planning. Four cohort working groups produced white papers in advance of the workshop. They focused on: cohort identification/recruitment, participant engagement/privacy, data collection/mobile technologies and electronic health records.

Collins offered a hypothetical example of what PMI success would look like: a woman, 50, with type 2 diabetes would receive a tiny, implantable chip that would record her blood glucose levels. That would yield useful prescription information and dietary advice. “That could happen as soon as 2 years from now,” he said.

“Then, after 5 years, a new drug might be developed. At age 60, presumably she would be very happy she participated, and then her kids could join [the study]. That’s the kind of image I’d like to see, multiplied about a million times.”

At the end of day 2, Collins summarized some of the issues at stake for the national cohort, whose 1 million potential enrollees, he said, "should be considered a floor, not a ceiling...the power of analysis gets better and better with more and more participants.” These include identifying and testing biomarkers, achieving unbiased determination of risk, testing the concept of mHealth (mobile health, or smartphone-
based technology), testing pharmacogenomics (the right drug for the right patient at the right time), improving electronic health records and, crucially, speeding up the health care response to evidence, in order to “shorten a dreadfully long cycle time.”

As yet undecided are whether children should be enrolled, whether interventions should be part of the initiative, what data to capture on participants and whether the cohort should have tiers, with some enrolling in “cohort lite.”

Collins also said it’s important that any data returned to participants should be done “in a beneficial, not confusing, way.”

He concluded, “We are extremely enthusiastic about the potential [of PMI], but realize there are many uncertainties ahead…This could be really consequential for human health.”


Flavell Gives Director’s Lecture, Mar. 18

Dr. Richard A. Flavell, the Sterling professor of immunobiology at Yale University School of Medicine and a Howard Hughes Medical Institute investigator, will deliver the annual NIH Director’s Lecture (second of three) on “Inflammation, Dysbiosis and Chronic Disease,” on Wednesday, Mar. 18 at 3 p.m. in Masur Auditorium, Bldg. 10.

Flavell is the co-discoverer of introns in cellular genes; he showed DNA methylation correlates inversely with, and prevents, gene expression. As a postdoc, he was the first to develop reverse genetics and continued in this field, in his own lab, throughout his career. He is a pioneer in the use of this approach in vivo to study function. He identified key transcription factors that control T-cell immunity and showed that genes exhibit interchromosomal interactions that play a role in gene regulation, so called “kissing chromosomes.”

For information and reasonable accommodation, contact Jacqueline Roberts, (301) 594-6747. The event will be videocast.
Peanut Consumption in Infancy Prevents Peanut Allergy

Introduction of peanut products into the diets of infants at high risk of developing peanut allergy was safe and led to an 81 percent reduction in the subsequent development of the allergy, a clinical trial has found. The study was supported by the National Institute of Allergy and Infectious Diseases and conducted by the Immune Tolerance Network. The results appeared last month in the New England Journal of Medicine.

Researchers led by Dr. Gideon Lack of King’s College London designed their study based on observations that Israeli children have lower rates of peanut allergy compared to Jewish children of similar ancestry residing in the United Kingdom. Unlike children in the U.K., Israeli children begin consuming peanut-containing foods early in life. The study tested the hypothesis that the very low rates of peanut allergy in Israeli children were a result of high levels of peanut consumption beginning in infancy.

“Food allergies are a growing concern, not just in the United States but around the world,” said NIAID director Dr. Anthony Fauci. “For a study to show a benefit of this magnitude in the prevention of peanut allergy is without precedent. The results have the potential to transform how we approach food allergy prevention.”

NIH-Funded Scientists Create Potential Long-Acting HIV Therapeutic

Scientists have created a new molecule that shows promise for controlling HIV without daily antiretroviral drugs. The molecule foils a wider range of HIV strains in the laboratory than any known broadly neutralizing HIV antibody and is more powerful than some of the most potent of these antibodies. In addition, the molecule safely protected monkeys from infection with an HIV-like virus during a 40-week study period. Together, the data suggest that the molecule could, with further research, be used to subdue HIV in humans. The authors note that the molecule potentially could be used as both a preventive drug and as a treatment. The findings appeared in the Feb. 18 issue of Nature.

“This innovative research holds promise for moving us toward two important goals: achieving long-term protection from HIV infection and putting HIV into sustained remission in chronically infected people,” said NIAID director Dr. Anthony Fauci.

The new molecule is called eCD4-Ig and works by tightly binding to two unchanging sites on the surface of HIV that the virus uses to attach to receptors on cells called CD4 and CCR5. Typically, when HIV attaches to these receptors, it unlocks a door to the cell and gets inside. However, when eCD4-Ig binds to HIV, it effectively takes away the virus’s key, locking it out of the cell and preventing it from multiplying.

Molecule Hijacks Enzyme to Boost Alcohol Metabolism

An experimental compound empowers an enzyme to help process acetaldehyde, a toxic metabolite of alcohol, according to research supported by the National Institute on Alcohol Abuse and Alcoholism. The findings, published in the Proceedings of the National Academy of Sciences, might lead to new treatments to help people with impaired ability to metabolize acetaldehyde and other toxic substances.

“This intriguing finding could have important implications,” said NIAAA director Dr. George Koob. “Developing pharmacologic agents that alter an enzyme’s substrate specificity is a unique approach that may have wide clinical application in treating patients with impaired ability to detoxify toxic substances. We look forward to further research aimed at translating these laboratory discoveries into possible treatments for people.”

After alcohol is consumed, it is first metabolized into acetaldehyde, a toxic chemical that can cause DNA damage and cancer. In the liver, aldehyde dehydrogenase 2 (ALDH2) is the main enzyme responsible for breaking down acetaldehyde into acetate, a nontoxic metabolite. It also removes other toxic aldehydes that can accumulate in the body. An estimated 560 million people in East Asia, and many people of East Asian descent, carry a genetic mutation that alters the enzyme’s ability to metabolize acetaldheyde and other toxic substances.

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“This innovative research holds promise for moving us toward two important goals: achieving long-term protection from HIV infection and putting HIV into sustained remission in chronically infected people,” said NIAID director Dr. Anthony Fauci.

The new molecule is called eCD4-Ig and works by tightly binding to two unchanging sites on the surface of HIV that the virus uses to attach to receptors on cells called CD4 and CCR5. Typically, when HIV attaches to these receptors, it unlocks a door to the cell and gets inside. However, when eCD4-Ig binds to HIV, it effectively takes away the virus’s key, locking it out of the cell and preventing it from multiplying.

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Addressing the need for culturally appropriate health research within American Indian/Alaska Native (AI/AN) communities, the National Institute on Minority Health and Health Disparities recently held a research forum to provide an opportunity for researchers to highlight their studies and share challenges in conducting biomedical research both inside and outside AI/AN communities. Held at NIH, the forum featured presentations by several prominent NIH-funded AI/AN researchers and a panel discussion about conducting biomedical research in AI/AN communities.

NIMHD acting director Dr. Yvonne Maddox welcomed participants, recognizing the significant contributions to biomedical research made within native communities. She also cited advances both in community-based research practice and in understanding the impact of social determinants of health on health outcomes.

"We have outstanding researchers here with us today," Maddox said. "We're here to learn about some of the best research taking place in the U.S. and we want to know what the critical issues are that we need to address to move forward."

Recognizing workforce diversity as one of the critical issues affecting biomedical research progress in AI/AN communities, NIH principal deputy director Dr. Lawrence Tabak acknowledged the potential impact of the forum.

"This is a unique moment and opportunity to try to find greater ways of helping those underserved in research," he said. "As we recognize contributions made, we also have to acknowledge the challenges day-to-day. We need to diversify the workforce to ensure we have everyone participating. To not have a diverse workforce really threatens our mission."

Tracing his scientific journey over the last 35 years, panelist Dr. Spero Manson of the University of Colorado, Denver, discussed his key findings from studies that informed major innovations in reimbursement for care for traditional treatment of post-traumatic stress disorder in Vietnam veterans and creative approaches to address the unmet mental health needs of the AI/AN population. He also expressed concern about the lack of diversity among peer reviewers and attention to minority inclusion in the scientific review process and the NIH workforce.

"Native researchers get caught up betwixt and between," Manson said. "People like me need [NIH’s] support. We look at you as champions. I need NIH…to [help] explain to our leadership the desirability of diversity in science."

Panelist Dr. Jeffrey Henderson of Black Hills Center for American Indian Health spoke about cancer in the AI/AN communities. He said recent research shows a profound geographic variation of cancer incidence and mortality rates across six major geographic regions of the United States. For example, for some tumor types, such as kidney, stomach and cervix, AI/ANs have higher cancer incidence rates than non-Hispanic whites. For this reason, non-Hispanic whites are not always an adequate group for comparison. More meaningful comparisons may be within-group comparisons. This calls for an examination of the causes of the profound geographic variation and the design of an integrated set of case-control studies. Henderson also expressed his concern with community-based initiatives in the AI/AN communities.

"In a variety of different discussions around the institutes, I think we realize community-based initiatives have a primary role," he said. "Community-based organizations are not being as well supported. I would like to see a bigger discussion on how we could better support [them]."

Dr. Valarie Blue Bird Jernigan of the University of Oklahoma Health Sciences Center reported that few studies have assessed the environmental correlates of obesity in tribal communities and none have developed interventions to improve the food environments of Oklahoma tribal nations.

Through her study, Tribal Health and Resilience in Vulnerable Environments with Chickasaw and Choctaw Nations of Oklahoma, Jernigan is implementing healthy “makeovers” within tribally owned and operated convenience stores to increase fruit and vegetable consumption.

The afternoon panel looked at how to navigate challenges in conducting research. Led by NIH deputy director for extramural research Dr. Sally Rockey, discussion ranged from lack of AI/AN mentors and role models to the unique role NIH plays in promoting diversity in the biomedical, behavioral, clinical and social sciences research workforce.

"Even though scientists have nationalities, science doesn’t have a nationality," said Rockey. "We’re trying to find a way to pick up all the great science that gets left behind."
milestones

Greenberg Named NIGMS Deputy Director

NIGMS director Dr. Jon Lorsch has appointed Dr. Judith Greenberg as the institute’s deputy director. Greenberg has served as acting deputy director since October 2013.

“Dr. Greenberg is a trusted advisor and a vital member of the NIGMS leadership team,” Lorsch said. “I am extremely pleased that she will continue her dedicated service to the institute and to NIH in this key position.”

A developmental biologist by training, Greenberg has served as director of the NIGMS Division of Genetics and Developmental Biology since 1988. She also twice served as the institute’s acting director for a total of more than 3½ years.

Greenberg has a strong interest in research training and bioethics issues and has advised NIH on topics that include human embryonic stem cells and gene therapy. Additionally, she served as principal leader of the NIH Director’s Pioneer Award program from 2004 to 2012 and of the NIH Director’s New Innovator Award program from its inception in 2007 to 2012.

Prior to joining NIGMS as a program administrator in 1981, Greenberg conducted research in the intramural program of what is NIDCR. Her focus was on cell migration and differentiation in early embryonic development.

Greenberg earned a B.S. in biology from the University of Pittsburgh, an M.A. in biology from Boston University and a Ph.D. in developmental biology from Bryn Mawr College.

Garcia has served more than 30 years in administration, research, public health, teaching and dental practice at the local, state and national level and for the past 19 years has held leadership roles at NIDCR. She joined what was NIDR in 1995 as a special assistant for science transfer and became director of the institute’s Office of Science Policy and Analysis in 2003. In 2007, she was appointed deputy director and from 2010-2011 assumed the role of acting director during a transition between directors.

Garcia spearheaded the development of three strategic plans and the institute’s first plan for eliminating health disparities. She also directed the development of numerous initiatives in diverse areas of science, including oral disease risk assessment, biomarker development, comparative effectiveness research, global health, behavioral and biological determinants of oral disease in vulnerable populations and population and community-based studies to prevent oral diseases and conditions.

Widely sought after for her experience and expertise, she served on numerous committees and councils including the department’s oral health coordinating committee, the NIH management and budget working group and the secretary’s tribal advisory committee. As part of a Presidential initiative, she represented NIH and PHS on the humanitarian mission of the U.S.N.S. Comfort, a Navy hospital ship sent to provide medical, surgical and dental care to people in 12 countries in Latin America. She also has collaborated extensively within and across professional boundaries, heading partnerships with professional organizations, community groups, patient advocates and others to enhance NIDCR’s work.

She has served as a lecturer, a faculty advisor and as a mentor to more than 30 dental public health residents. From 2005-2014, she directed NIDCR’s Residency Program in Dental Public Health, which plays an important role in expanding oral health disparities research capacity, with many of its graduates holding leadership positions in the U.S. and abroad.

Garcia received a B.S. from the University of Mary Washington, a D.D.S. from the Medi-
cal College of Virginia and an M.P.H. from the University of Michigan, where she also completed a residency in dental public health. She is a diplomat of the American Board of Dental Public Health and a member of the American College of Dentists. She has held elected positions in the American Association of Public Health Dentistry and the oral health section of the American Public Health Association and is past director of the American Board of Dental Public Health.

Her accomplishments have been recognized with numerous honors and awards, including the NIH Director’s Award for mentoring and the American Association for Dental Research Jack Hein Public Health Service Award. She is also the recipient of the PHS Jack D. Robertson Award for outstanding long-term dedication and service to improve the oral health of the nation.

Portnoy, OD’s Senior Prevention Advisor, Retires

Since preventing illness is usually easier than treating it, NIH, which mainly supports curative research, has increasingly turned to disease prevention. Few have contributed to this paradigm shift more than Dr. Barry Portnoy. Before his retirement in January, he had spent 30 years at the agency helping to find scientific ways to promote healthy lifestyles.

As a senior advisor in the Office of Disease Prevention, Portnoy served on several trans-NIH coordinating committees that oversee research on disease prevention, nutrition and smoking cessation. He was also the NIH liaison to the U.S. preventive services task force and the task force on community preventive services—expert panels that develop evidence-based recommendations for disease prevention.

Earlier, as a program director at NCI, Portnoy led the first program to introduce tobacco education into public schools. He was on the team that developed the 1990, 2000, 2010 and 2020 objectives for the Healthy People initiative, a national think tank that maps 10-year priorities for improving public health.

Before joining NIH in 1985, Portnoy was a professor at the University of Virginia, where he evaluated prevention interventions for chronic disease. He grew up in Brooklyn and attended the City University of New York. He went on to obtain his master’s and Ph.D. at Ohio State University and the University of Toledo.

“Barry is a widely published researcher who also understands the inner workings of NIH,” said ODP director Dr. David Murray.

In his work, Portnoy has championed the idea of prevention as a whole-system change supported by healthy built environments—neighborhoods with sidewalks, parks, health-food restaurants and quality care.

Portnoy has seen his share of change. Along with the NIH community, he welcomed the budget doubling of the late 1990s, saw the fences go up around the campus after 9/11 and weathered more than one fiscal storm. What he enjoyed most about his time at NIH was trading ideas with talented colleagues. At NCI, Portnoy crossed paths with intern John Burklow, now NIH associate director for communications and public liaison, and met a group of long-time scientist friends who called themselves the “pizza pals,” as they used to debate the latest science while sampling local pies.

In retirement, Portnoy will continue to lecture and mentor at the University of Maryland. He is an avid cyclist and a fly fisherman. His wife Lynn retired recently from the Library of Congress and together they look forward to many leisure trips, no longer hindered by regulations on government travel. — Andrey Kuzmichev

Tran Named Chief of CSR Branch

Tho-Van Tran has been named chief of the Administrative Services Branch at the Center for Scientific Review. She comes to CSR from the National Heart, Lung, and Blood Institute, where she was an administrative officer for the Office of the Director, executive officer and Office of Science Policy, Engagement, Education and Communication.

“We are very pleased Ms. Tran has joined CSR,” said CSR Executive Officer Joanna Bare. “She is known for building highly effective teams, improving and simplifying administrative processes and having an exceptional ability to research and interpret administrative policy.” Bare also noted that Tran has extensive experience in financial management, travel, recruiting and human resources, project management and analysis.

Tran will oversee federal travel, property administration, purchasing, time and attendance administration and space planning and management for CSR.

Prior to her tenure at NHLBI, Tran worked in the Clinical Center, the National Institute of Mental Health and in the private sector, where she served as assistant treasurer/junior officer for the OBA Federal Savings and Loan Association in Maryland. Tran holds an associate’s degree in accounting from France and a bachelor’s degree in business administration from Strayer University.

Circus Premiere Night, Mar. 18 at Verizon Center

The NIH R&W invites you to the 18th annual Children’s Premiere Night—hosted by R&W and benefiting the NIH Charities—on Wednesday, Mar. 18 at 7 p.m. with a free pre-show at 6 p.m. The theme of this year’s show is Legends. Mythology meets reality as the audience encounters Pegasus, the Unicorn and other mystical legends. Tickets are available at the R&W Activities Desk in Bldg. 31, Rm. B1W30 or call (301) 496-4600 or (301) 496-6061. Orders can be placed for tickets at any R&W store. You don’t need to be an R&W member to purchase.
Former NIAID Director Krause Mourned

Dr. Richard M. Krause, director of the National Institute of Allergy and Infectious Diseases from 1975 to 1984, died Jan. 6 in Washington, D.C. He was 90 years old.


"Richard was among the first scientists in the modern era to sound a clarion call about the persistent threat of infectious diseases, and during his leadership he kept scientists and policymakers focused on the concepts of emerging and re-emerging infectious diseases," said Dr. Anthony Fauci, who succeeded Krause as NIAID director. "His scientific recognition that humanity faces a perpetual challenge from emerging and re-emerging microbes was prophetic. I will miss his fierce intelligence, insatiable curiosity and quick wit. We all have benefited from his myriad contributions to NIH and to science over his long career."

Krause was born in Marietta, Ohio. Following three semesters at Marietta College, he was drafted into the U.S. Army, where he worked in a venereal disease control program. He received a B.A. from Marietta College in 1947 and an M.D. in 1952 from Western Reserve University School of Medicine, now Case Western Reserve. In the course of his medical studies, he participated in epidemiologic research with Prof. Charles H. Ram melkamp on the immunology and prevention of rheumatic fever, which spurred his interest in the relationship between infection and immunity.

In 1954, following training at Barnes Hospital in St. Louis, he joined the Rockefeller Institute and Hospital (now Rockefeller University) where he rose to the rank of professor. His research focused on substances that stimulate the body’s immune system, as exemplified by his research on the immune response to streptococcal polysaccharides. These studies led him to examine the genetic factors that influence the immune response. In recognition of his research achievements, he was elected to the National Academy of Sciences in 1977.

Appointed NIAID director in 1975, Krause guided the institute through a period of growth to address the re-emergence of microbial diseases as health threats and to stimulate research on the complexity of the immune system. He was an innovator who reorganized NIAID along pro-

grammatic lines and restructured the Rocky Mountain Laboratory into independent laboratories. He also led NIAID into the field of recombinant DNA research and technology.

Responding to the emergence of the AIDS epidemic in the early 1980s, Krause organized field studies in Haiti and Zaire in the search for the origins of the causative virus.

In July 1984, he retired from the Public Health Service and became dean of medicine at Emory University. In 1989, he returned to NIH to become a senior scientific advisor at the Fogarty International Center. He worked into his late 80s both at Fogarty and as an investigator emeritus in the NIAID Laboratory of Human Bacterial Pathogenesis, where, for more than a decade—and up to 2 months before his death—he led an ongoing joint Indo-U.S. effort examining the incidence of streptococcal pharyngitis and rheumatic fever in schoolchildren in India; some have said the project yielded some of his best work. Previously he taught at Rockefeller University in New York (1954-1961 and 1966-1975) and at Washington University in St. Louis (1962-1966).

Krause was an active patron of the arts, collected works of art and was a historian and philanthropist.

He was preceded in death by brothers Orville and Karl, sister Mary and nephew Karl Krause Jr. He is survived by niece Virginia (Ginger) O’Connor, and nephews Kent E. Krause and Irvin E. Hobba, nine grandnieces and grandnephews and nine great grandnieces and grandnephews.

Marietta College is planning a memorial service open to the public, but details are not yet available.

NIGMS’s Mickey Dies at 50

Olivia Mickey, an extramural support assistant in the NIGMS Division of Training, Workforce Development and Diversity (TWD), died unexpectedly on Nov. 25. She was 50 years old.

Mickey began her federal career in 1989 as an executive secretary at the Department of Commerce. She joined NIH in 2004 as a DEAS employee, where she was assigned to the former NIGMS Division of Minority Opportunities in Research. In 2012, Mickey transitioned to an extramural support assistant position in the division, which was renamed the Division of Training, Workforce Development and Diversity.
“Olivia had a beautiful spirit,” said Janet Shoemaker, a colleague who worked next to Mickey for several years. Shoemaker recalls how Mickey served as a mentor to her after she transferred to NIGMS from NCRR. “She took me under her wing and made it easy to adapt to NIGMS,” Shoemaker said.

In addition to handling her duties at NIGMS and caring for her 13-year-old daughter, Mickey was working toward completing her undergraduate degree.

“Olivia was learning all the time, from new software at work to college classes at night,” said TWD acting director Dr. Alison Hall. “It was a joy to see her growing stronger and improving all the time. We lost a lovely member of our division family.”

Mickey was also active in her church choir and served as a youth mentor.

She is survived by her mother, Frances C. Tyler; two children, Devon and Laurie; and five siblings.

Record Staff Writer
Waring Mourned
By Dana Talesnik

NIH Record staff writer Belle Waring, 63, lost a long battle with cancer on Jan. 31. She had enjoyed a multifaceted career; she was an acclaimed writer and poet, neonatal nurse, exhibit curator, archivist and teacher. Waring loved literature, animals and nature and could easily converse on almost any topic. Colleagues and friends described her as insightful and inquisitive, forthright yet compassionate.

“Belle was an important part of our staff and a brilliant writer—and a wonderful human being. We will all miss her terribly,” said John Burklow, NIH associate director for communications and public liaison.

“We spent hours talking about life in general, philosophy, my kids,” recalled Calvin Jackson, deputy associate director of NIH’s Office of Communications and Public Liaison. “Belle was a genuinely good person who took a great interest in people.”

Waring started her NIH career in 2002 as a prints and photographs technician in the History of Medicine Division, National Library of Medicine. In 2006, she joined OCPL as a writer-editor for the NIH Record.

“Belle loved NIH and said so many times, “said Rich McManus, Record editor. “Her respect for its science and public health mission and her affection for its people were evident in every story she turned in. She wrote as if she were talking to an intelligent, sympathetic and curious friend. That’s what she transformed all of us into.”

Waring’s 2010 story on a knit-a-cap campaign to help save infants in Rwanda earned her an NIH plain language award. That year, she took a 2-year stint as NIH coordinator for the Public Information Officers Network, which connects communications professionals from NIH institutes and centers with grantee institutions across the country. Waring returned to write for the Record from 2012 until her passing.

“With the NIH Record, the stories Belle enjoyed the most were about the ordinary people that make this place run,” said Jackson. “Belle was also a great mentor to a lot of people around here. She took people under her wing and nurtured them.”

Waring made friends everywhere she went. “We were two people interested in books,” reflected Walter Cybulski, a preservation librarian who worked with Waring at NLM. “Belle was a keen, astute reader and a serious fact-checker. That made her a very accurate reporter. She applied her writing skills and nurse’s background to what she did here in communications.”

Prior to joining NIH, Waring worked at Children’s National Medical Center as a writer-in-residence and a creative writing teacher for kids. She also was a registered nurse and had spent 9 years as a neonatal intensive care nurse at George-town University Hospital. Her observations during this demanding job inspired much of her award-winning poetry.

Waring’s first published poetry collection, Refuge (University of Pittsburgh Press, 1990), won the Associated Writing Programs’ Award for Poetry in 1989, the Washington Prize in 1991, and was cited by Publishers Weekly as one of the best books of 1990. Her second book, Dark Blonde (Sarabande Books, 1997) won the 1997 San Francisco State University Poetry Center Book Award and the first annual Larry Levis Reading Prize in 1998.

Cybulski said a highlight of their years of friendship was a reading they did for the Library of Congress for “The Poet and the Poem” podcast series in 2011. Waring’s poetry often would delve into heart-wrenching life experiences and turbulent subjects. “That fighter is always there,” said Cybulski. “She wasn’t interested in dwelling on the darker aspects of her poetry for long; she wanted to reach agreement with the world, to turn the reader’s attention toward light.”

At Waring’s funeral, Cybulski read a poem of his that Waring told him could serve as her epitaph, “For Belle, Out on the Ledge”: “I did not journey this far to end up so terribly alone. Under the cold aluminum sky the occasional snowflake dances, and I long for the energy to dance like that, to rise up and leap in the light like a girl discovering her first butterfly. How can it be that within me remains a longing so intense I feel that only God can respond to it, that only pure light can respond to this fierce searchlight? And summon from somewhere deep within me the sweet sad fury that only angels can abide.”

Long-time friend Cyndi Burrus-Shaw, who works in Bldg. 1, met Waring nearly 20 years ago when they worked together at the American Psychological Association.

“Belle was funny, lighthearted and selfless...Those of us who really knew her felt lucky,” said Burrus-Shaw. “Belle was a great listener and always saw the best in everybody...My kids—both aspiring writers—came to know her. She was a great teacher, empathetic and results-oriented. She got great joy from making things right. She was genuine and thoughtful; that’s what I miss.”

Waring is survived by her mother, Patricia Waring, of Chestertown, Md.
Fulbright Scholar Cheung Integrates Brain Therapeutics, Culture to Treat Huntington’s

By Cherie Duvall Jones

Introducing herself with the traditional Māori greeting, Fulbright scholar Dr. Melanie Cheung (Ngāti Rangitīhi, Te Arawa) shows that her feet are planted firmly in the world of her indigenous people of New Zealand. It is this commitment to exploring both indigenous and Western scientific paradigms that brought Cheung to NIH recently to present her research findings on a neurodegenerative illness affecting her people—Huntington’s disease.

Cheung painted a picture of the rich culture, mythology and distinctive crafts of the approximately 600,000 people in New Zealand identifying as Māori. But, she revealed that Western-centered approaches are currently failing indigenous people when it comes to Huntington’s disease, a progressive brain disorder that, according to Cheung, is 10 times more prevalent in the Māori people than any other population in the world. The familial disease involves changes in personality, movement and thinking and inevitably ends in death. With no cure, Māori families have been watching the disease destroy their loved ones’ ability to feel, think and move.

“What’s very interesting with this disease is it’s in families,” she said. “We have big families. That has to do with our culture. My tribal elders wanted us to do research in a Tikanga Māori type of way—using ceremonies to acknowledge spirit. We believe there’s continuity between the physical and spiritual worlds, that there is no separation between the two. The work I’m doing is really about making a Māori-responsive, brain plasticity-based training program to treat Huntington’s disease.”

Based in San Francisco at the Brain Plasticity Institute, Posit Science, Cheung is proving to be a leader in the science of health disparities since her research is about integrating biomedical science and cultural aspects—exploring both indigenous and Western scientific paradigms to help people with neurodegenerative diseases.

Her work combines experimental neuroscience, bioethics, tikanga (ceremony/customary practice) and Mātauranga Māori (Māori traditional knowledge).

“Respect is the most important thing and knowing cultural practices is important,” she said. “Māori have a process of welcoming strangers with ceremony, then they become family. I recognized that I needed to do the same ceremony with the post-mortem human brain tissue that I was growing primary cell cultures from.”

When a person and their family gives the gift of their brain, Cheung honors that gift through ceremony, which is about acknowledging the relationships that extend out of that brain.

“The brain has come from a person, a human being who belongs to a family and community,” she explained. “I acknowledge their passing. I ask that their family is comforted in their grief. I acknowledge the gift that they have given our research. Then I welcome the brain to its new home in our laboratory and welcome a new function to the cells that may help us to understand more about the disease.”

Over the past 7 years, she and her research team have worked closely with a large Māori family with Huntington’s disease. Her current research projects include:

- Developing and testing a novel brain plasticity-based training program for Huntington’s disease;
- Developing a model of mutually beneficial partnership between Māori families and biomedical scientists and clinicians;
- Researching clinical and translational aspects of Huntington’s disease; and
- Teaching indigenous students as part of the Mahina Project, a biomedical and behavioral health training program. It is an NIH-funded T37 Minority Health and Health Disparities International Research Training Program conducted through the Indigenous Wellness Research Institute at the University of Washington.

In her research, Cheung, who received a doctorate in pharmacology from the University of Auckland, believes clinical excellence, cutting-edge science and cultural responsiveness are equally important.

Knowing that neuroplasticity-based therapeutics have the potential to change the ways doctors and researchers treat brain diseases, she said indigenous research methods—which incorporate spirituality, ethics and community—also have the potential to provide innovation and inspiration in the laboratory and clinic.

“Building relationships with indigenous communities takes a long time,” she said. “We worked with a large Māori Huntington’s family for 6 years before we even contemplated starting a science project with them. Our research has both [short- and long-term] goals. Short-term is about developing practical clinical solutions for them—right here, right now. Whereas, long-term is about the science, developing the treatments that probably won’t benefit them, but may benefit their children or their grandchildren. This gives them hope.”

Cheung’s lecture was hosted by NIMHD, NINDS and the Fogarty International Center.