

## ARTIST, SCIENTISTS, SOULMATES Streisand Delivers Rall Cultural Lecture

BY CARLA GARNETT

Barbra Streisand isn't a doctor, although she has played one on screen. She's graced stages big and small across the globe, from Hollywood and Broadway to London and Sydney. At NIH on May 15, the world-renowned singer-actor-director used her voice in a less-familiar venue to amplify a topic that's been close to her heart throughout her six-decade career: gender equity, especially in science and health.

"The closest thing I have to a medical credential is my role in *What's Up, Doc?*," Streisand joked as she began her remarks at

the J. Edward Rall Cultural Lecture.

Focusing on women's health and underrepresentation of women in medical research, the event—"Taking Women's Health to Heart: An Afternoon with Barbra Streisand"—later featured a conversation with NIH director Dr. Francis Collins, who introduced her.

"We are blessed indeed to have with us such a remarkable leader in the arts, but also in the promotion of human medicine and the



Barbra Streisand delivers the Rall Cultural Lecture at NIH.

need to focus on women's health," Collins said.

Addressing a packed Kirschstein Auditorium in the Natcher Bldg., Streisand drew parallels between NIH's expertise and her own.

"The Rall lecture is a recognition that scientists

and artists have much in common," she said. "We're both obsessed with the quest for beauty, understanding and truth. We're both seeking answers to the big questions

SEE STREISAND, PAGE 6

## PAINLESS GWAS

### Attractions of Commercial Genome Testing

BY RICH MCMANUS

If you haven't been to the drug store lately, it may come as a surprise to find, there on the shelves as you search for toothpaste, deodorant and a greeting card, little boxes inviting you to spit in a tube and find out about your genetic past.

A representative of one of those companies—23andMe—visited NIH recently to explain what these kits are all about.

Dr. Joanna Mountain is senior director of research at 23andMe, a Silicon Valley company now in its 10th year, and a self-described latecomer to the scientific life. She was already in her mid-20s and finished with 2 years of Peace Corps service in Kenya when lab life beckoned. She gave up a faculty position at Stanford to join a company that is steeped in research.

SEE GENE TESTING, PAGE 4

## Fogarty Marks 50 Years of Global Health Partnerships

BY ANN PUDERBAUGH

A half century of global health research and training accomplishments were celebrated May 1, as more than 500 NIH leaders, researchers, advocates and trainees gathered from around the world to mark establishment of the Fogarty International Center in 1968.

Part scientific symposium, part family reunion, the day was devoted to a review

SEE FOGARTY AT 50, PAGE 8



At a reception marking the 50th year of the Fogarty International Center, FIC director Dr. Roger Glass (l) and NIH director Dr. Francis Collins (c) reminisce with former FIC grantee Dr. Warren Johnson.



Rhode Island senator visits NIH. See p. 12.

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## NIH Safety, Health & Wellness Day Coming to CC South Entry

June 27

NIH Safety, Health and Wellness Day will be held Wednesday, June 27, rain or shine, at the Clinical Center south complex from 10:30 a.m. to 1:30 p.m. All are welcome to come and enjoy the activities and learn about safety, health and wellness opportunities at NIH.

The focus of this year's event is to enhance employee nutrition, wellness, physical fitness, safety awareness and prevent or reduce work-related injuries and illnesses. A wide range of activities and exhibits will be presented including health screenings, safety and health promotion exhibits, nutrition demonstrations and tastings, physical fitness activities, adult dependent care and elder care information fair, NIH IC exhibits and NIH Library virtual reality demonstrations.

Plan to stay for lunch and choose from menu items prepared by food trucks or shop for a variety of fresh foods at the farmer's market. For more information, visit <http://go.usa.gov/xXnfe>.

The annual event is sponsored by the Office of Research Services, Office of Research Facilities, NIH occupational safety and health committee, IC safety chairpersons committee, laboratory sustainability group and NIDDK.

Individuals who need reasonable accommodation to participate should contact Linda Kiefer at (301) 402-8180 and/or the Federal Relay at 877-709-5798.

## NCATS, FDA To Host Gene Therapy Workshop

Aug. 20-21

NCATS and the Food and Drug Administration's Center for Biologics Evaluation and Research will host a 2-day gene therapy workshop Aug. 20-21. This event, "The Growing Promise of Gene Therapy Approaches to Rare Diseases," will take place in Masur Auditorium, Bldg. 10.

Participants will review the state of current gene therapy approaches, identify challenges and strategies to overcome them and discuss how to collaboratively scale and accelerate gene therapy development. Proposed panel sessions will cover pre-clinical development, clinical innovation, manufacturing, partnerships and transitions, business models and patient access and gene therapy as a precision medicine tool. The ultimate goal of advancing gene therapies is to benefit patients with rare diseases.

Visit [https://events-support.com/events/NCATS\\_Gene\\_Therapy\\_2018](https://events-support.com/events/NCATS_Gene_Therapy_2018) to learn more and to register. There is no admission fee to attend and the workshop also will be videocast at <https://videocast.nih.gov>.



### Geese Commute, Too, You Know

By the dawn's early light, this family of Canada geese marched off, like federal workers, to the day's duties. "I do not know how to take good pictures," said Shashi Shrivastav of NIDDK's kidney disease section. The Bldg. 10 employee continued, "I was going to Metro and saw this wonderful sight." The family was crossing South Dr. in an unhurried manner; they must be on AWS.

PHOTO: SHASHI SHRIVASTAV



Shown at the dinner are (from l) Dr. Nishadi Rajapakse, Dr. Roselyn Hicks, Stephanie Nisson, Stephanie Mariette, Dr. Anna Nápoles, Dr. Eliseo Pérez-Stable, Dr. Maryline Laude-Sharp, Dr. Dottie Castille, Dr. Rick Berzon, Becky Newton and Kesi Williams.

## SCIENCE OF SERVICE

### NIMHD Staff Serve Dinner at Children's Inn

On May 14, Dr. Eliseo Pérez-Stable, director of the National Institute on Minority Health and Health Disparities, along with several of his staff, prepared and served an Italian dinner for families at the Children's Inn at NIH, which provides "a place like home" for approximately 1,500 families and children from around the world each year during treatment in research studies at NIH.

Despite torrential rain and thunder, neither the storm nor the brief shelter-in-place could dampen the high spirits and glee of more than 40 attendees, who enjoyed an array of meatballs, salads, lasagna, pizzas, breads and desserts.

This was not the first time NIMHD staff served at the inn and it will not be the last. Another dinner is planned for later this year.

## Smartphones May Be Lifeline for Diagnoses of Tuberculosis

BY RAYMOND MACDOUGALL

Researchers funded by the National Institute of Biomedical Imaging and Bioengineering have launched a 6-month pilot study in Lima, Peru, using smartphones and computer-aided tools to rapidly screen people for tuberculosis. The smartphone-based system will shorten the wait time for diagnosis from weeks to hours. Rapid diagnosis, in turn, will reduce the transmission of TB to others and hasten the start of medications.

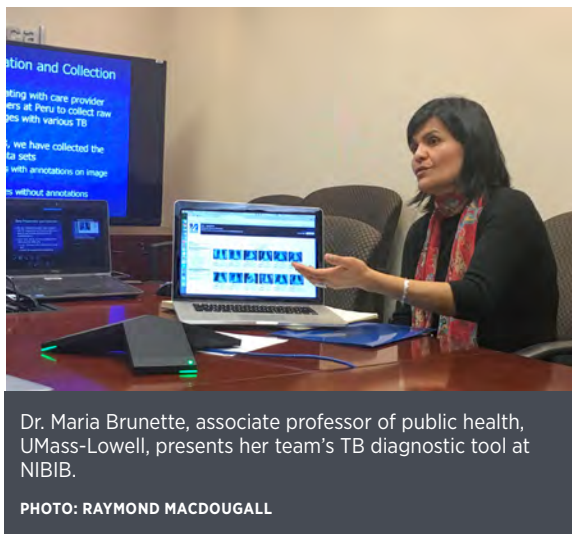
The researchers are from the University of Massachusetts at Lowell's department of public health and department of computer science. In 2015, they received a 4-year, \$1.3 million grant from NIBIB and the National Science Foundation. They presented their project at NIBIB recently.

TB is a curable bacterial infection, but it kills 1.7 million people per year globally, according to the World Health Organization. The Centers for Disease Control and Prevention reported that in 2016, 9,272 TB cases were reported in the United States. Peru is one of the countries with the highest number of TB cases in the Americas.

Dr. Maria Brunette, associate professor of global public health at UMass-Lowell and project director/principal investigator, demonstrated the tools her team has developed. Fellow principal investigators Dr. Benyuan Liu, professor of computer science, and Dr. Yu Cao, associate professor of computer science, participated remotely in the demonstration from Lowell.

"We find that health care professionals are really engaged and excited about the use of mHealth—using mobile devices or apps—to facilitate and speed up processes," Brunette said. "It's not as simple as developing the app, but also how we can integrate the technology into the health care system and nurses' work processes and procedures."

The mHealth system that the team has



Dr. Maria Brunette, associate professor of public health, UMass-Lowell, presents her team's TB diagnostic tool at NIBIB.

PHOTO: RAYMOND MACDOUGALL

begun to implement in Peru includes a smartphone and a tablet that are connected to cloud-computing servers. Researchers developed computer systems modeled to process data in the way a human brain

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*"This is a project that can have valuable outcomes for the people of Lima, who contend with such a high disease burden from tuberculosis."*

-DR. TIFFANI LASH

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would, also called neural networks, which they trained to automatically analyze chest X-ray images for telltale signs of active TB.

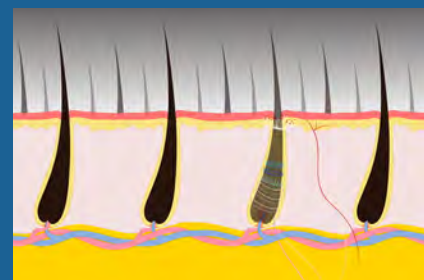
The networks access a dataset of thousands of X-rays, accumulated through collaborations with Peruvian TB care providers and researchers. According to Cao, the 15,000-plus X-ray images may be the world's largest TB dataset that includes a variety of manifestations of the disease—from haziness of imaging to signs of the presence of fluid or enlarged lymph nodes.

The team is conducting the pilot project in health care clinics in two districts in Lima affected by urban poverty. Nurses and nurse technicians at remote TB clinics will use smartphones to take digital photographs of X-rays to be shared through a secure, web-based platform. A pulmonary

specialist will view the images remotely and make diagnoses.

"This is a project that can have valuable outcomes for the people of Lima, who contend with such a high disease burden from tuberculosis," said Dr. Tiffani Lash, director of the NIBIB programs in connected health (mHealth and telehealth) and point-of-care technologies. "Lessons from the use of mobile technologies for improved health care processes may also prove to be beneficial for low-resource communities in the U.S. as well."

The project is anchored in the community-based participatory research platform, a partnership approach to research. It includes research partners at Boston University, the Peruvian Ministry of Health's TB National Program, Partners in Health Peru and Cayetano Heredia University. [R](#)



ON THE COVER: Neuron responds to pulling of single hair. An NIH study has uncovered specialized mouse neurons that play a unique role in pain.

IMAGE: JEREMY & NICHOLE SWAN

### The NIH Record

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**Editor:** Rich McManus  
[Rich.McManus@nih.gov](mailto:Rich.McManus@nih.gov)

**Associate Editor:** Carla Garnett  
[Carla.Garnett@nih.gov](mailto:Carla.Garnett@nih.gov)

**Staff Writers:**  
Eric Bock • [Eric.Bock@nih.gov](mailto:Eric.Bock@nih.gov)  
Dana Talesnik • [Dana.Talesnik@nih.gov](mailto:Dana.Talesnik@nih.gov)

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## Gene Testing

CONTINUED FROM PAGE 1

About 5 million people, and more every month, have—out of curiosity about whether they are at risk of Alzheimer’s disease, prone to motion sickness or perhaps really descended from Irish royalty—purchased the 23andMe kit.

Buyers provide a saliva sample and mail it to the company. Within 2-4 weeks, they get details on their risk of dozens of conditions, ancestry information and hints about dozens of traits, Mountain said.

“Something in there will be novel and interesting and engaging,” she said. “Some people actually discover new relatives they didn’t know about before. It’s happening quite often.”

★ ★ ★

***“Our customers tend to trust us. We’re conservative with our data. Participation is easy, geography is no barrier and almost everyone is in multiple studies.”***

—DR. JOANNA MOUNTAIN

★ ★ ★

How people self-identify doesn’t always correlate with their genetic ancestry, she added.

Although participants can sign up for as many studies as they wish, enrollees typically receive 7 reports on their genetic health risk, more than 40 reports on their genetic carrier status, more than 5 ancestry reports, 8 wellness reports and information on more than 20 traits, Mountain said.

The company uses sequencing arrays from Illumina and scans only a half-million or so positions on the genome that are known to be informative. Whole-genome sequencing is currently too expensive, Mountain said, but 23andMe is “keeping an eye on cost, and accuracy. We haven’t made that leap yet.”

Many kit buyers are worried about specific health risks. “So many people asked for information on Alzheimer’s disease,” said Mountain. “They worry about a higher than average risk. We have no reports yet on early-onset genes. But an important part of our service is the education we can provide. We encourage our customers to be skeptical and thoughtful.”

Also of great public interest is one’s

proportion of ancestry from different parts of the world, Mountain noted.

Customers of 23andMe can participate in as many surveys as they want—about 80 percent consent to be part of a research program overseen by an institutional review board—and are free to cease participation at any time. Mountain herself is in at least 60 genome-wide association studies (GWAS), including one on myopia. More than 20 genetic variants have been associated with myopia so far, she said, “mostly genes linked to the visual cycle.”

The average 23andMe customer is age 49, and 50.6 percent are female. More than 75 percent are of European ancestry, with 9 percent Latino, 4 percent East Asian, 4 percent African American and 6 percent “other.”

“Our customers tend to trust us,” said Mountain. “We’re conservative with our data. Participation is easy, geography is no barrier and almost everyone is in multiple studies.” There’s even a smartphone app.

Hoping to draw on the big-data power of large cohorts, 23andMe embarked in March 2009 on its first focus initiative, on Parkinson’s disease. More than 711,000 people are currently enrolled in that GWAS effort. There are also initiatives in irritable bowel syndrome, lupus, fertility and bipolar/major depressive disorder, Mountain reported. Genetic data, she explained, is likely to be a boon for drug development.

New initiatives are planned for wellness research and weight-loss research. “We’re looking for hundreds of thousands of people,” she said. Researchers want to know, for example, if it is genetically easier for some people to lose weight.

Some 100 research papers have been published so far using 23andMe data, Mountain said. Her company hires science writers to craft blog posts that explain these papers in plain language that customers can understand.

Her company is looking to expand the



Dr. Joanna Mountain of 23andMe

diversity of its data sets, Mountain said, especially from under-represented populations around the world.

In February, 23andMe launched its Global Genetics Project, which is targeting 60 countries and hoping to attract at least 400 people from each.

Mountain said the rewards of research participation are many. “People get direct rewards and are also part of a ‘virtuous cycle.’ We publish all our results in open-access journals.”

Enrollees can push a button on their accounts page and find out how many papers their data has contributed to, either as a case or control; Mountain counts 62 such personal contributions.

While most company data adds to academic research at the moment, “We have lots of public-health opportunities in our future,” Mountain concluded. [R](#)

## VOLUNTEERS

### Study Needs Healthy Volunteers

Vaccine Research Center researchers seek healthy volunteers, 18-50 years old, for a study evaluating an investigational product that targets HIV. Compensation is provided. There is no risk of infection. For more information, call 1-866-833-5433, email [vaccines@nih.gov](mailto:vaccines@nih.gov).

## NHLBI'S 70TH ANNIVERSARY

## Harvard's Seidman Discusses Heart Research

BY COURTNEY COOMBES

Dr. Joan Postow is no stranger to cardiology offices. As early as age 3, she was diagnosed with a heart murmur and by age 20 she began experiencing chest pains. Later in life, both she and her brother were diagnosed with hypertrophic cardiomyopathy—a condition in which the heart's muscular walls become thicker. The thickened walls reduce the heart's ability to pump blood and increase the risk of heart failure. This is how she came to know and be treated by Dr. Christine Seidman, director of the Cardiovascular Genetics Center at Brigham and Women's Hospital and a professor at Harvard Medical School.

There are several known causes of heart failure, but for some patients like Postow and her brother, the disease is genetic and can seemingly come from nowhere. Seidman has been studying families who experience this type of out of the blue or idiopathic heart failure to better understand the molecular pathways that might cause more gradual-onset, common kinds of heart failure. In a lecture given recently as part of the NHLBI 70th Anniversary Lecture Series, she talked about her work to identify the genes that contribute to hypertrophic cardiomyopathy (HCM) and dilated cardiomyopathy (DCM), in which the heart muscle becomes thinner.

Work by Seidman and her colleagues implicate gene mutations that impair muscle contraction—and in particular the basic contractile units in muscle, called sarcomeres—as the major cause of genetic cardiomyopathies. They discovered that mutations in a gene encoding a large muscle protein called titin are the most common genetic cause of DCM. Seidman's lab was able to reproduce these mutations in isolated heart-like cells and found that those cells had far fewer sarcomeres and reduced contractile function, potentially the mechanism for the decrease in pumping contractions seen in patients.

## Insight from Spiders

The researchers found that mutations in sarcomere protein genes are also the most common genetic cause of HCM. These mutations commonly cause a small



Dr. Christine Seidman answers questions from Dr. Jonathan Kaltman and the audience after her lecture.

PHOTO: NICHELLE LEWIS

change in the protein myosin, which is the molecular motor of heart cells. Surprisingly, HCM mutations cause small changes in myosin and actually increased the power of contraction instead of reducing it—a phenomenon that did not at first seem to explain patients' symptoms. That is, until Seidman's collaborator Dr. Raúl Padrón, an investigator at the Venezuelan Institute for Scientific Research in Caracas, was able to visualize myosin protein from tarantulas,



Dr. Lisa Postow (l) with her mother Dr. Joan Postow (c) and Seidman

PHOTO: MARK SAMPSON

which is remarkably similar to human myosin protein yet easier to isolate, using cryo-electron microscopy.

Working together, these labs were able to deduce specific sections of the myosin protein that are altered by HCM mutations in patients and discovered that these mutations restrict myosin's ability to fully relax. Poor relaxation of the heart muscle walls can lead to irregular heartbeats, inadequate oxygenation and ultimately wasted energy, so the mutations' effects turned out to be consistent with the symptoms found in HCM patients.

## Sweet Spot of Science

Seidman said that her work to identify gene mutations that cause disease and then conduct laboratory studies to determine their effect on muscle function occupies “a sweet spot of basic science.” Potentially, this knowledge could be used to screen patients who may be more susceptible to cardiomyopathy and provide them with care sooner. However, “The real question and opportunity is can we fix the failing heart?” she asked. Seidman and her colleagues are on their way to answering that question.

By performing a small molecule screen, they discovered a molecule that allows myosin to more fully relax in mouse and human heart cells and protects against the development of HCM in mice that carry myosin mutations.

This part of the lecture was the most fascinating to Postow, who said she is “active and well” after heart surgery in April 2012 arranged by Seidman.

“It gave me hope that better methods will soon be available to treat this disease and that someday it will be possible to prevent it,” Postow said. However, more work is needed before such targeted therapies become available.

“It will require bringing more people into the endeavor and will likely come from discoveries that we never anticipated,” Seidman said.

NHLBI will continue its 70th Anniversary Lecture Series on June 28 with renowned cardiologist and former NHLBI clinical director Dr. Eugene Braunwald. **B**

## Streisand

CONTINUED FROM PAGE 1

about causes and consequences, hows and whys, origins and endings, life and death. We both see magic in the smallest details—a film cell or a stem cell.”

Pointing out that genius artists Michelangelo and Leonardo DaVinci were both known to also study anatomy, Streisand said, “[Likewise] brilliant scientists have turned to the arts and culture for inspiration.”

As examples, she mentioned Einstein and his violin as well as two of NIH’s own—Collins and his guitar and campus legend (and fellow Brooklyn, N.Y. native) the late Dr. Ruth Kirschstein, who trained as a classical pianist before concentrating on a career in biomedical research.

“Most of all, what links our two communities is the focus on what it means to be human,” Streisand emphasized. “Our life’s work, our passion is in improving and uplifting humanity. So it’s no accident that you see such mutual respect across our fields.”

Streisand’s lifelong advocacy for social issues and her philanthropy are well-documented. In 1986, she formalized such efforts by establishing the non-profit Barbra Streisand Foundation, which funds grants on diverse issues from civil, human and women’s rights to global climate change.

### The Yentl Syndrome

Several years before that, though, after deciding to write, direct, produce and star in the film *Yentl*, Streisand came face to face with the issue of gender inequality.

She said she experienced both overt and subtle discrimination “in a big way.” Hollywood heavyweights weren’t convinced that a woman director—even an experienced “so-called bankable star” such as Streisand—could handle a movie budget or bring a film vision to profitable reality. Would an audience even appreciate the story of a bookish young Jewish girl who masquerades as a boy in order to get an education?

“Running into this kind of bias was a life-changing moment for me,” she recalled. “But I couldn’t give up. More important it mobilized my commitment to women’s equality. I became passionate about trying to



NIH director Dr. Francis Collins chats with Streisand on the stage of a packed Kirschstein Auditorium.

PHOTOS: WOMEN’S HEART ALLIANCE

ensure that women get the same chances in life as men.”

### Secondhand Woes, Unique Symptoms

Several years later, Streisand was intrigued when she heard about a *New*

*England Journal of Medicine* article written in 1991 by then NIH director Dr. Bernadine Healy.

A cardiologist, Healy presented evidence of what she called “The Yentl Syndrome”—disparities in diagnosis and treatment of

### LAB DEMO, RESEARCH BRIEFING Streisand Sees Science Up Close, in Person

Not long after delivering the Rall lecture, Barbra Streisand got to sample a bit of NIH research in progress. NIAID principal investigator Dr. Irini Sereti and her team in the HIV pathogenesis unit hosted the superstar in their Clinical Center laboratory.

Sereti’s group is conducting an intramural trial called ECSTATIN, which has enrolled about 50 people with HIV who are at risk for developing heart disease. ECSTATIN is evaluating whether baby aspirin (used to decrease clotting) or atorvastatin (used to lower cholesterol and limit inflammation) can influence the chronic inflammation related to HIV and cardiovascular disease.

The study also demonstrates NIH’s commitment to advance sex and gender equity in science: About 20 percent of HIV-positive people in the U.S. are women, Sereti explained. “We have 30 percent enrolled women in ECSTATIN.”

For Streisand’s visit, Sereti led her through the study’s stored samples, showing the freezer and

how they use liquid nitrogen to preserve participants’ cells, which are alive, but frozen.

“[Visit planners indicated that Streisand] had never been in a laboratory before,” said Sereti, “and that she wanted to get the impressions and experience of being in a lab. We showed her the biosafety hood and the flow cytometer, and we explained how we thaw the cells and look for the production of inflammatory cytokines.”

Streisand spent about 10 to 15 minutes with the research team, posing for photos with them afterward.

“She was engaging and funny, very smart, personable—just fabulous,” Sereti recalled. “She was asking a lot of good questions. We were so inspired by her lecture and truly honored to host her.”

After the lab tour, Streisand met with two ECSTATIN participants.

This is not Sereti’s first brush with celebrity in her scientific career. She was a medical resident at Northwestern in 1996 when Princess Diana visited in an effort to raise funds for breast cancer research and toured the hospital where she met with patients in the HIV ward.

women with cardiovascular disease versus men with the ailment.

Unless women showed the same signs of CVD that characterized the disorder in men, females were often turned away from the emergency room, their own unique symptoms misdiagnosed and under-treated.

“The more I learned about women’s heart health, the more astonished and upset I became,” Streisand said. “For much too long, CVD has been perceived as a man’s disease—not only from the patient’s point of view but also in the way it’s been treated and studied...Most of the research has been conducted primarily on men, right down to male mice in the lab. Most treatments and therapies were tested on men. Sex-specific differences have been neglected all the way from the lab to the ER—even though women’s bodies and biology are so different.”

Such realities led the rare EGOT (winner of all four of entertainment’s biggest awards—Emmy, Grammy, Oscar and Tony) to get involved with the Women’s Heart Center at Cedars-Sinai in Los Angeles, which “focuses on identifying female-patterned heart disease.” She established the Barbra Streisand Women’s Heart Center there in 2012.

“I wanted to raise women’s awareness

“I didn’t actually get to meet her, but I was there when she was,” said Sereti, who enthusiastically added that her group would welcome other superstars who want to support research. “We are open to more, definitely. Anyone interested in HIV—Elton John, Prince Harry!”

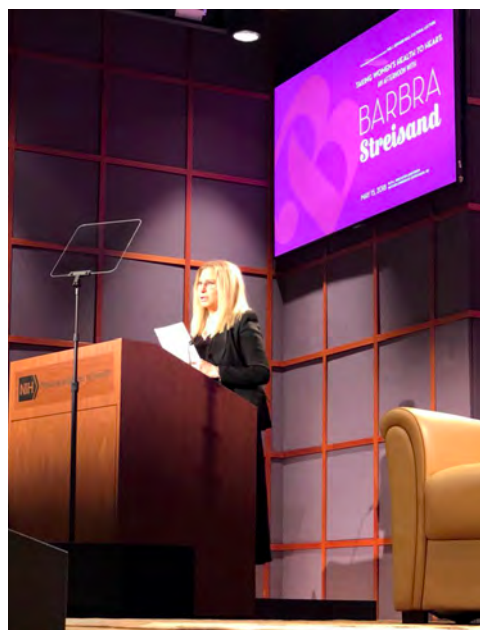
By encountering Streisand up close and personal, Sereti also became somewhat of a superstar in her own household, particularly with her 12-year-old daughter.

“*What’s Up, Doc?* was one of our first family movie nights and she really enjoyed it,” said Sereti. “Then



Streisand meets PI Dr. Irini Sereti (front, third from r) and her research team.

when we watched *Yentl* she liked that one too. She became a fan after that, so there was lots of excitement when I came home and told her I had met Barbra Streisand...My favorite movie is still *The Way We Were* though.”



**Social media abuzz.** Above, one of several images posted to Twitter, Facebook and other online outlets during Streisand’s visit to NIH.

of heart disease and drive policy change at every level,” she said.

### ‘Women’s Hearts, Everyone’s Minds’

In 2014, Streisand cofounded the Women’s Heart Alliance, whose mission is to advocate and fund research and treatments on gender differences in CVD.

“We want to make sure women’s hearts are on everyone’s minds,” Streisand emphasized.

That quest brought her and several of the Alliance’s top leaders to NIH, which she thanked “for being a great partner in research,” particularly on the 21st Century Cures legislation that her Alliance championed to look at sex differences in biomedicine.

Streisand also acknowledged NIAID director Dr. Anthony Fauci and the REPRIEVE trial as an example of leadership in that regard. She and Fauci had teamed up in 2016 to write a *Health Affairs* article about inclusion and gender equity in research.

“In order for science and art together to have their greatest impact on society,” the filmmaker said, “we need to ensure that all people are included as creators and as subjects. We need everyone’s perspective at the table, at the bench, in the studio and in the lab. We need everybody’s stories reflected in our research, in our studies, on our stages and on our screens.”

Streisand concluded with words of encouragement for all NIH’ers: “My wish for all of you is that your work will make history that shapes a future where all men and women can live their best possible lives... Keep searching for beauty in every cell.”

After her talk, the only recording artist to have number one albums in six consecutive decades sat down with Collins for an open chat on stage, where they discussed several topics from the personal (her early childhood realization of gender differences when she attended *shul* with her grandfather) to the professional (how the art of storytelling can effectively raise awareness about health issues such as CVD). A lab tour (see sidebar) in the Clinical Center followed the chat.

“I want to thank you for the way in which, by being here, you inspire us,” Collins said, giving Streisand an NIH “National Institutes of Hope” pin. “By the way in which you’re leading your life you inspire us, by the way in which your gifts in music, in filmmaking have blessed generations...You give us hope by the way in which you’ve conducted yourself...We think of ourselves as the ‘National Institutes of Hope’ and by being here you’ve taken our hope up a notch.”

View the archived lecture online at <https://videocast.nih.gov/summary.asp?Live=27824&bhcp=1>. **R**



At left, Mary Fogarty McAndrew, Rep. John Fogarty's daughter, toasts FIC's accomplishments and commitment to her father's dream of fostering scientific partnerships to improve global health. At right, NIAID director Dr. Anthony Fauci (l) assists Glass with his emerald green bow tie, worn in honor of the center's namesake Fogarty, who used bow tie-shaped billboards in his political campaigns.

PHOTOS: ANDREW PROPP, ANN PUDERBAUGH

## Fogarty at 50

CONTINUED FROM PAGE 1

of progress in the development of research capacity in low- and middle-income countries (LMICs), its role in advancing science to reduce death and disability and an exploration of new frontiers of global health research ripe for future exploration.

"Never before in the history of global health has global collective action been more important," said Dr. Richard Horton, editor of *The Lancet*, in his keynote address. With nationalism and anti-science rhetoric on the rise, evidence-based decision-making is on the decline, he continued.

"It feels like we are living through a counter-enlightenment, that some believe that the world is unsafe, unstable and insecure, that the idea of progress is actually a myth, that the promise that we have given society for what science can deliver is actually a lie."

Horton urged the audience to stay committed to advancing science to improve health and carefully consider the evolving threats posed by climate change and environmental hazards. Fogarty should continue to provide global leadership and promote its "values of partnership, of collaboration and most importantly of all, equality among and between nations."

FIC remains faithful to the vision of its namesake, according to Sen. Jack Reed (D-RI), who recalled that Rep. John E. Fogarty (D-RI) was known for his effectiveness, decency and kindness. Not only a champion for NIH, Fogarty also believed

the U.S. had an obligation to improve health around the world. He argued for a "Health for Peace Center," which would embody Americans' commitment to use science for the good of mankind.

"That vision permeates this center," said Reed.

### Towards Ending HIV/AIDS

He pledged continued support for FIC and acknowledged the effective advocacy conducted on its behalf by Fogarty's daughter, Mary Fogarty McAndrew, and her husband Tom McAndrew, who attended the celebration with their children and grandchildren.

In the first panel discussion, devoted to HIV/AIDS and infectious disease, NIAID director Dr. Anthony Fauci said the NIH investment in research that led to antiretroviral therapy (ART) literally transformed the lives of those living with HIV. ART and other advances in prevention and treatment give him optimism.

"We have no excuses," he said. "We have the tools to end HIV/AIDS."

Fogarty grantee Dr. Quarraisha Abdool Karim said young women in Africa pose a critical challenge to ending the epidemic there, with 5,000 new infections occurring each day. Papers published with contributions by Fogarty trainees give glimpses of the physical and

behavioral reasons young women hold the key to reducing transmission, she said.

Panelists emphasized the need for implementation science to study interventions in key populations and proposed taking a community approach, addressing the underlying poverty of those at risk and examining stigma and other social factors that prevent diagnosis and treatment.

### IC Directors Laud FIC Impact

The growing burden of chronic, noncommunicable diseases was also explored, with case studies presented on cancer and sickle cell disease.

NCI deputy director Dr. Douglas Lowy discussed progress in making cervical cancer screening accessible in low-resource settings using mHealth solutions. Two former Fogarty fellows who are now co-principal investigators on an NCI grant told how NIH support has changed the landscape of cancer care and research in Malawi.

NHLBI director Dr. Gary Gibbons noted that NIH programs empower country-driven contextual solutions to bend the curve and



The growing global threat of chronic diseases was examined by former FIC fellow Dr. Satish Gopal (l), NCI deputy director Dr. Douglas Lowy and president of the South African Medical Research Council Dr. Glenda Gray.





At left, Sen. Jack Reed (D-RI) said FIC remains faithful to the vision of its namesake, Rep. John E. Fogarty. At right, keynote speaker at the center's 50th anniversary symposium Dr. Richard Horton said the best thing about 1968 was FIC's creation.

help eliminate health inequities. He detailed his institute's global efforts to reduce household air pollution exposure, study low-cost hypertension interventions and translate advances in sickle cell disease to LMICs.

Brain disorders also cause an enormous disease burden in the developing world.

NINDS director Dr. Walter Koroshetz and his grantee Dr. Gretchen Birbeck jointly presented on stigma and epilepsy. Birbeck says her studies in Zambia have found working with peer groups and schools can be effective.

Another team, made up of NIA director Dr. Richard Hodes and grantee Dr. Kenneth Kosik, described an extended family of Colombians with a genetic mutation that brings early-onset Alzheimer's disease. Kosik said he used Fogarty funds to build local scientific capacity to study the population and has established a brain bank there that is waiting to be explored.

NIMH has also had "fruitful partnerships" with Fogarty, said NIMH deputy director Dr. Shelli Avenevoli, and has future plans to develop LMIC data infrastructure

and analytic capacity, advance implementation science and conduct research in the humanitarian context.

NIMH grantee Dr. Vishwajit Nimgaonkar presented his genomic studies of schizophrenia in India and Egypt, which he says have built capacity and formed partnerships between the countries.

### Return on Investment—a Testimonial

The final session focused on the multi-generational impact of Fogarty's research training programs.

Peruvian grantee Dr. Patty Garcia recalled how she received FIC support to earn advanced degrees in the U.S. Since returning home, she has helped build a cadre of well-trained scientists—including co-presenter Dr. Magaly Blas—that has drawn significant research funding from NIH and other sources.

Fogarty programs in Peru helped advance understanding of infectious diseases, develop expertise in informatics, incorporate electronic medical records into the national health system and expand research into the Amazon region and other underserved areas. All the while, Garcia advanced in her career, serving as university dean, director of Peru's NIH and recently as health minister.

"Every step you take in life shapes who you are," she said. "And the steps I've walked with the help of Fogarty were instrumental in helping me to achieve a great deal, including being appointed health minister."

### FIC, 'Great Global Village'

In South Africa, ongoing FIC support since 1992 has helped train more than 600 scientists.

"For me, the most important thing is that almost every study on HIV going on in South Africa today involves a Fogarty trainee in some way or another," said Dr. Slim Abdool Karim. He introduced his protégé, Dr. Vivek Naranbhai, who said his experience as a Fogarty fellow was life-changing.

Naranbhai said he entered the program feeling he was an inconsequential physician, but during orientation at NIH quickly realized he had something to offer. "It introduced me to a community of like-minded people—to suddenly have access to this great global village is extraordinary."

Fogarty programs that develop these local research leaders are the key to the future, said NIH director Dr. Francis Collins. "We want to increasingly empower investigators in-country to be able to be in charge of their own efforts, to figure out what the most important research questions are in their environment and then to help them build support for that within their own countries," he said. "Even with its modest budget, Fogarty can be an incredible catalyst."

The other ICs at NIH have been Fogarty's greatest partners in building these international collaborations, with almost 90 percent of Fogarty grants receiving co-funding, noted FIC director Dr. Roger Glass.

"By forming and supporting these scientific partnerships, the center has tried to expand the envelope of research," he said. "The principal value of Fogarty is investing in people and their careers."

Watch the whole webcast at <http://bit.ly/Fogarty50th>. [B](#)

### NIAID Workshop Fosters Independent Researchers

The National Institute of Allergy and Infectious Diseases recently hosted its inaugural fellowship workshop in Rockville. The workshop was designed to help scientists find a path to becoming independent researchers.

Participants were all currently awarded National Ruth L. Kirschstein Service Award (NRSA) recipients, including pre-doctoral fellows (F31s), dual degree fellows (F30s) and post-doctoral fellows (F32s).

Awardees gathered for the 2-day event to hear presentations focused on the theme of "Resources for Successful Transition into Research Independence." Speakers from the institute, other



parts of NIH and outside organizations covered a wide range of topics to give participants a well-rounded view of what is needed to prepare for the next funding phases of their career. Additionally, the workshop featured breakout groups and panel discussions as well as networking and poster sessions to engage the fellows, hear their concerns and give them a chance to present their work.

The workshop covered a lot of ground, including Roads to Research Independence, Strategies for Successful Grant Applications: Scientific

Review Officer Perspective and NIAID Career Development (K) Awards.

NIH awards NRSA individual fellowship grants to provide research experience to students and scientists at various stages of their careers. Fellowships require full-time effort, 12 person months a year. For questions about NIAID-related fellowships, contact Diane Adger-Johnson ([dadger@niaid.nih.gov](mailto:dadger@niaid.nih.gov)) and visit <https://www.niaid.nih.gov/grants-contracts/fellowship-grants>.

## NIDCD Director Battey Retires After 35 Years of Public Service

For more than two decades, Dr. Jim Battey Jr. has been a pillar of support and leadership for the National Institute on Deafness and Other Communication Disorders, guiding research in hearing, balance, taste, smell, voice, speech and language. On June 1, he retired as NIDCD director. He was a dedicated public servant for 35 years, joining NIH in 1983. He also served as a member of the Public Health Service Commissioned Corps for more than 21 years, until retiring as a rear admiral in 2008.



After 35 years at NIH, Dr. Jim Battey Jr. retires as NIDCD director. Below, he chairs the first NIH human embryonic stem cell research symposium in 2003.

“Jim’s leadership has helped carry NIH through historic challenges and opportunities over the years,” said NIH director Dr. Francis Collins.

Under Battey’s leadership, NIDCD-supported researchers developed the tools and programs necessary to implement newborn hearing screening. He fostered the partnership between NIH, the Health Resources and Services Administration and the Centers for Disease Control and Prevention that established and maintains this program. Today, nearly all babies in the U.S. now have their hearing tested shortly after birth. “Early hearing screenings allow parents to assess their options and decide on the best way to support their child’s developing communication,” said Battey.

He also fostered initiatives to improve the accessibility and affordability of hearing health care. Even though about 28.8 million U.S. adults could benefit from hearing aids, only 1 in 4 has ever tried one, with many citing cost as a deterring factor. NIDCD’s research laid an evidence-based foundation for a law passed in August 2017 that will make hearing health care more accessible and affordable for many Americans. The law requires the Food and Drug Administration to create a category of over-the-counter hearing aids for adults with perceived mild-to-moderate hearing loss.

Battey contributed significantly across NIH and the broader scientific community. “Jim’s

leadership was crucial for launching NIH’s research initiatives using human embryonic stem cells,” Collins said. In 2002, Battey became the first chair of the NIH stem cell task force and testified in Congress on several occasions. Under his leadership, the task force brought together leaders in the field to identify barriers to stem cell research and to develop ideas to overcome them.

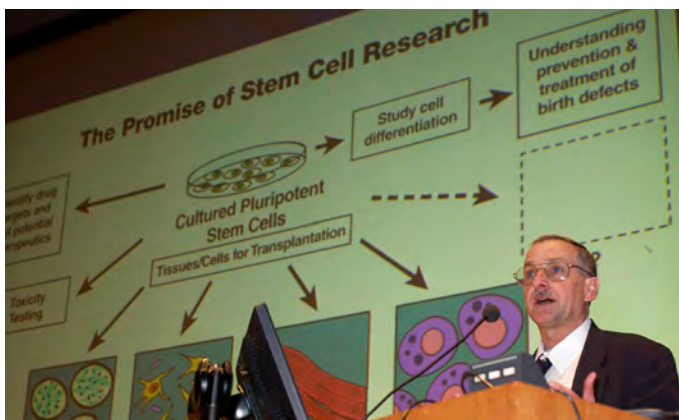
“Jim has been instrumental in some of the biggest advances in our field, including identifying dozens of genes and genetic mutations linked to hearing loss, language development and stuttering,” said Dr. Judith Cooper, NIDCD deputy director. She will serve as acting NIDCD director until a permanent director is named.

Battey is widely recognized for his own discoveries about G-protein-coupled receptors, particularly a subgroup of these receptors responsible for taste perception. During Battey’s tenure as director, NIDCD supported a Nobel Prize-winning researcher credited with clarifying the molecular and cellular bases of our sense of smell.

“I am proud to have served NIDCD, an institute that pushes the boundaries of knowledge to improve the lives of tens of millions of Americans with communication disorders,” reflected Battey. “I feel honored to have worked with so many dedicated and creative staff and researchers through the years. We could not have accomplished what we have so far without their contributions.”

Battey received a B.S. in physics from the California Institute of Technology in 1974, and an M.D. and Ph.D. in biophysics from Stanford University in 1980. He started his NIH career in 1983 at the National Cancer Institute, where he served as a senior staff fellow, then senior investigator. He later headed the molecular neuroscience section at the National Institute of Neurological Disorders and Stroke and the molecular structure section when he returned to NCI in 1992. He joined NIDCD in 1995, when he was appointed scientific director, and was named NIDCD director on Feb. 10, 1998. Among his many honors, Battey was awarded the PHS Commendation Medal in 1990 and the PHS Outstanding Service Medal in 1994.

Battey will return to his home state of California to spend more time with his family and to volunteer tutoring public school students in science.



## NIH Legal Adviser McGarey Bids Farewell

BY DANA TALESNIK

After 38 years in the federal government, including 3 decades at NIH, Barbara McGarey is laying down the law. The deputy associate general counsel of HHS’s Office of General Counsel (OGC), known on campus as the NIH legal adviser, retired in June.

“For a health lawyer, serving NIH is just a dream,” said McGarey. “I have a deep respect and love for science and public health, and it really has been an honor to dedicate my entire professional career to advancing these priorities.”

McGarey has led OGC for the past 17 years, providing in-house counsel and managing a staff of 13 attorneys. Over the years, she has advised NIH senior leaders on a range of issues ranging from intellectual property, grants, gifts and technology transfer to clinical research and hospital operations.

“You have become one of my most trusted advisers,” wrote NIH director Dr. Francis Collins in a letter to McGarey, “and I will profoundly miss your sound counsel.”

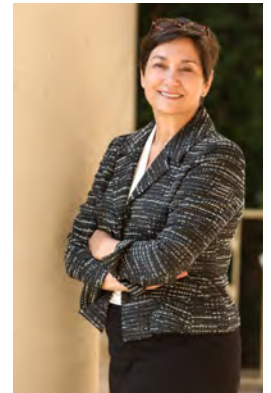
“I’ve been in and around NIH in many different capacities, and the perspectives I gained allowed me to more fully understand and support the agency and facilitate NIH research programs,” McGarey said.

She first learned of NIH while interning at the NCI Baltimore Cancer Research Center in 1978. She’d been living in New York, finishing nursing school at Cornell, unsure where she’d wind up next. In Baltimore that summer, her mentor spoke of a renowned hospital in Bethesda that might be a good fit if she was interested in research. After graduation, she headed south.

McGarey recalled, “I loved the combination of clinical nursing with research. That’s why I came.”

Just out of nursing school, McGarey started her NIH career in NHLBI’s hyperlipidemia unit but soon yearned for something more fast-paced and demanding. She got her wish when she transferred to the cardiac surgery unit, where she worked for 4 years.

But it was in her blood to study the law. Inspired by her father, a lawyer-turned-judge, McGarey attended Catholic University’s Columbus School of Law while continuing work part-time at the Clinical Center. At that time, there was limited upward



Barbara McGarey ends NIH career after more than 3 decades.

mobility for nurses and the law made sense as a second act. "Support and advocacy are at the heart of both professions," McGarey reflected.

After a 2-year stint with the Department of Justice through its Honors Program, McGarey arrived at HHS's OGC, providing legal counsel to the Alcohol, Drug Abuse and Mental Health Administration for 6 years.

In 1993, McGarey found herself back at NIH as deputy director of NIH's Office of Technology Transfer. In 2000, she took a year-long detail with the then newly established Foundation for the NIH and has since provided extensive legal advice on public-private partnerships, particularly institutional gifts.

McGarey said she's especially proud of her legal efforts on the many public-private partnerships over the years, the human embryonic stem cell research guidelines and litigation, the NIH Research Tools Guidelines, the CellPro march-in case and the

ongoing challenge of the reasonable drug pricing debates. Tackling these and other issues put her in close contact with many administrative offices—Freedom of Information Act, communications, management, ethics, grants, contracts, legislative and science policy, to name a few.

"I've always felt like a small-town lawyer working on big-city issues," she said.

Asked about post-retirement plans, McGarey pleaded the 5th. Her husband Patrick, who is associate director of finance and legislation at NCI, is not retiring anytime soon. They have 3 grown sons and 2 young grandchildren.

McGarey said she's sad at the idea of leaving NIH and will deeply miss her clients, many of whom are colleagues and friends. "NIH is such a community," she said. "I hope I'm not leaving NIH; I hope I find a way to stay involved because this is such a wonderful place with a noble mission."

## CREATED NOVEL RESEARCH

### NIBIB's Gorbach, Infrared Imaging Expert, Is Mourned

BY RAYMOND MACDOUGALL

Dr. Alexander Gorbach, an NIBIB staff scientist and chief of the infrared imaging and thermometry unit, an NIH Biomedical Engineering & Physical Science (BEPS) shared resource, died May 11 after a brief illness. He was 69.

Gorbach provided state-of-the-art expertise and specialized instrumentation for patient monitoring during surgeries. His innovative research included techniques for monitoring tissue perfusion, oxygen content and temperature, as well as wireless electronic sensors and applications of mobile phone technology.

Along with his colleague, NIBIB deputy scientific director Dr. Henry Eden, Gorbach became a familiar figure at student expos and science fairs with their presentation of thermal imaging.

Gorbach obtained his Ph.D. in 1989 from the Russian Academy of Sciences in Moscow then joined NIH, first as a visiting research fellow and guest researcher at NIDDK. He transitioned into a role as a special expert in surgical neurology at NINDS and staff scientist at the Clinical Center.

With the founding of NIBIB's intramural program in 2003, Gorbach launched his 15-year leadership of the BEPS infrared and thermometry unit, conducting research in remote sensing and *in vivo* functional imaging.

The scale of Gorbach's studies ranged from single cells to intact humans, using various tools including infrared imaging, near-infrared hyperspectral and multispectral functional imaging, laser-speckle imaging, infrared microscopy and microwave thermometric mapping. These imaging methods do not require artificial contrast substances, so adapt well to clinical research. He described these methods as "infrared photography."

NIBIB scientific director Dr. Richard Leapman said Gorbach anchored an important aspect of the intramural program. "Alex participated in numerous clinical collaborations across the NIH employing his methods," Leapman said. "Over the past decade, Alex mentored some 20 post-baccalaureate students, all of whom were accepted into medical schools or other graduate schools."

Gorbach's collaborations involved research with scientists and clinicians across the NIH campus—including at NINDS, NIEHS, NHLBI, NCI, NIAID and the Clinical Center—and around the world, including those at the Naval Medical Research Center, the National Institute of Standards and Technology and various universities in the United States and Europe.

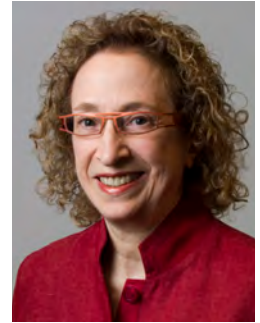
Gorbach is survived by his wife, Marina, and sons Yuri and Michael and their families.



Dr. Alexander Gorbach

## Linet Wins Career Achievement Award

Dr. Martha Linet, senior investigator in NCI's Radiation Epidemiology Branch, recently received the Career Achievement Award from the Department of Health and Human Services. It recognizes her decades of international leadership in epidemiology. During her 30 years at NCI, Linet has conducted groundbreaking research on the epidemiology of leukemia, lymphoma and brain tumors and the effects of radiation and benzene on cancer incidence and mortality.



## ORS 'Cheerleader' Jenkins Mourned

BY MICHAEL WOESTEHOFF

If someone asked who our employee cheerleader is, the answer would be Pamela Jenkins. She passed away on Feb. 15.

As a quality assurance specialist in the Division of Amenities and Transportation Services, Office of Research Services, Jenkins made sure her office was full of energy. Colleagues say she brought out the best in everyone and was a dedicated, motivated and passionate person. Jenkins grew up in Maryland and joined NIH in 1990, beginning her public service as a telephone operator.

During the holidays, she was known for her candy count contests and amazing costumes. When Take a Hike Day was implemented in 2007, Jenkins brought life and heart to the event. It was her vision that created the Take a Hike Day logo, which is still used today. She made it a fun and memorable event for everyone who participated. "And for the reluctant ones," a coworker reported, "Jenkins took your hand and made sure you were a part of the NIH family."

While in the Division of Space and Facility Management, Jenkins worked with the Office of General Counsel and NIH to eliminate tobacco sales in facilities managed by the Maryland Business Enterprise Program for the Blind.

A recent memorial celebration for Jenkins drew many of her co-workers, who were also friends, to join together to remember and celebrate her life and nearly 30 years of public service at NIH. **R**



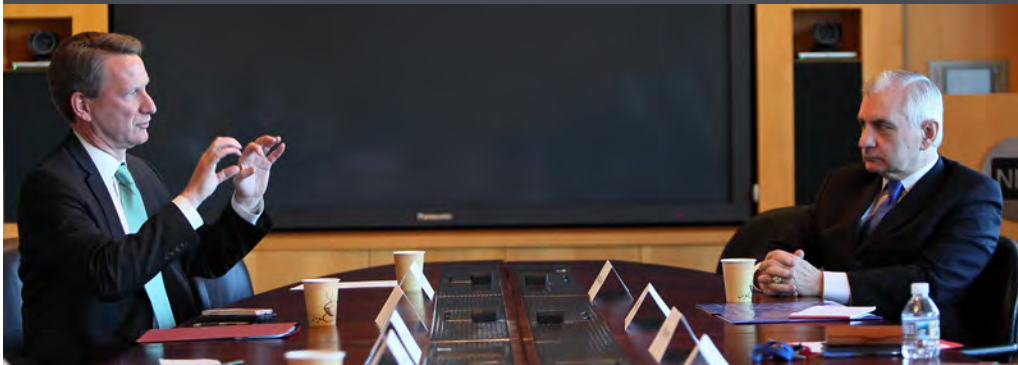
Pamela Jenkins



Rhode Island Sen. Jack Reed (c) meets NIH director Dr. Francis Collins (second from l) and gets a tour of the Children's Inn at NIH from its CEO Jennie Lucca (second from r). Below, he is briefed by NCI director Dr. Ned Sharpless.



While visiting NIH, Reed (above) recalled Rhode Island's late Rep. John Fogarty, for whom FIC is named. Below, Dr. Jack Shern explains a device that performs single-cell analysis to study relapsed disease and identify specific cell characteristics driving resistance and relapse.



### Rhode Island's Sen. Reed Visits NCI, Fogarty

Sen. Jack Reed (D-RI) visited the National Cancer Institute's Pediatric Oncology Branch on May 1, learning about survivorship research, psychosocial care and brain tumor studies. At the end of his visit, Reed spoke at the Fogarty International Center's 50th Anniversary Symposium at Natcher Bldg. (see p. 1).

PHOTOS: CHIA-CHI CHARLIE CHANG



ABOVE: At left, Sharpless and Reed greet patient Lilly Ann Brooks and her mother Candee Brooks. At right, Reed pays a call on Scarlett Clarkson in the NCI pediatric oncology unit in the Clinical Center.