

nih record



ABOVE • Rapt attention was paid to the NSO's fifth visit to the Clinical Center. See coverage on p. 11.

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Welcome Mat for Potential Participants

'Clinical Trials and You' Site Uses 'Front Porch' Approach

By Carla Garnett

Nicholas, a high school honor student who enjoys Brazilian jujitsu, joined a clinical trial so doctors could learn more about sickle cell anemia. He was diagnosed with the disorder as an infant. Melanie has always been interested in public service and wanted to contribute to science. She signed on as a “healthy volunteer” in clinical research because she lost a sister to cancer. Alyssa has a bone disorder that affects only one in a million people worldwide. She and her family found out about taking part in medical studies after they met a scientist conducting research on her condition. Physician-researcher Susan Shurin is a pediatrician. She says that for her and other doctors who become clinical investigators, the rewards multiply “because you end up having an impact that goes way beyond the patient you’re taking care of.”

People involved in clinical research are fascinating. You can learn more about them

SEE **CLINICAL TRIALS**, PAGE 6



Web site about participating in clinical research offers personal appeal.



NIH director Dr. Francis Collins blows the whistle starting heat 1 of the 31st NIH Institute Relay.

31st NIH Institute Relay Draws 91 Teams

By Eric Bock

“On your mark, get set...” And with that, NIH director Dr. Francis Collins blew his whistle, signaling the start of the 31st NIH Institute Relay.

The crowd roared as the runners took off and cheers continued as the relay teams ran laps around Bldg. 1.

On Sept. 18, 91 teams ran the half-mile course in two heats under perfect weather condi-

SEE **RELAY**, PAGE 4

Science on a Shoestring Post or Find Equipment, Supplies at NIH FreeStuff

By Dana Talesnik

Do you need a reagent, a printer or other office equipment? Before you order it, or call your administrative officer in a panic, check out NIH FreeStuff; you just might find it there.

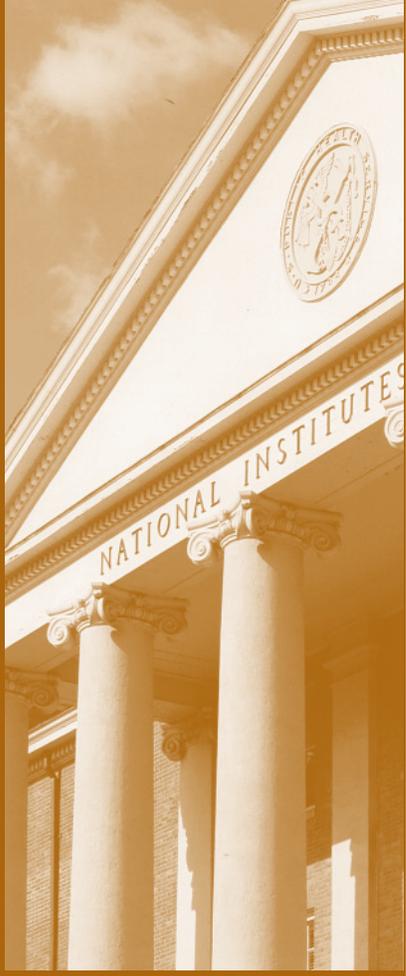
NIH FreeStuff—<http://stuff.nih.gov>—is a user-friendly web site that lets NIH'ers post and exchange office and lab supplies, equipment and chemicals. You'll find everything from freezers, centrifuges, incubators and microscopes to laptops, printers, chairs and file cabinets, and even small stuff like hole punchers and staplers. With just a few clicks, that office item you really need could be yours, for free.

“Just go on FreeStuff and look at it,” said co-founder Gwendolyn Shinko, director of the Office of Intramural Research Administration at the National Institute of Mental Health. “If you have any extra items—reams of paper or a

SEE **FREE STUFF**, PAGE 8



briefs



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NIH...Turning Discovery Into Health
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Local chef Spike Mendelsohn is joined by Children's Inn guests Anthony and Christina Moundros.

D.C.'s Top Chefs Turn Out for Inn Event

Some of D.C.'s most talented chefs helped to celebrate the opening of two highly anticipated, remodeled kitchens at the Children's Inn at NIH on Sept. 15. The chefs, along with Erika Williams, TV news personality and wife of Washington Nationals Manager Matt Williams, donated their time and culinary talents to benefit the inn.

The chefs, who prepared a fine meal for the occasion, included Spike Mendelsohn (Good Stuff Eatery, Béarnaise and We, The Pizza), Will Artley (Pizzeria Orso), Chris Clime (PassionFish), Ris Lacoste (RIS/RIS Union Market), Matt Newland (Wildwood Kitchen), Shizu Okusa (JRINK Juicery), Kirk Francis (Captain Cookie Food Truck) and mixologist Josiah Alexander.

"We are grateful to these wonderful chefs for donating their time, talents and delicious food to help the inn thank those who gave generously to renovate these kitchens," said Kathy Russell, inn CEO. "These kitchens provide our families with the opportunity to cook, eat and gather together as they would at home."

Visit Wellness@NIH Site

Visit the Wellness@NIH web site (<http://wellnessatnih.nih.gov>). The new site is the first one-stop resource for information, services, online tools and events to support NIH workplace wellness. Topics covered include fitness, nutrition, work/life balance, being tobacco-free and health & safety.



Gala Raises Funds for Children's Inn

"From Every State, for Every Child," was the theme of the 26th annual Congressional Gala held in Washington, D.C. on Sept. 16. The event raised \$400,000 for the Children's Inn at NIH. NIH director Dr. Francis Collins (l) highlighted the inn's important role in pediatric medical research. Ezmee Hutton (r), a 24-year-old who is currently undergoing treatment at NIH for an immune system disorder, talked about what a difference it has made for her to have the support and comfort of staying at the inn.

NIDA Grantee Volunteers to Fight Ebola

National Institute on Drug Abuse grantee Dr. Timothy P. Flanigan is in Liberia for the next 2 months volunteering his services to help fight the Ebola crisis. He is working with Catholic health centers, clinics and hospitals to provide additional training and assessment of readiness. Most recently, he led training at St. Joseph's Catholic Hospital, which recently suffered from an Ebola outbreak. Unfortunately, a dozen staff members became infected and died. Flanigan is principal investigator on a NIDA-funded institutional training grant that supports training of clinicians in the field of drug abuse and co-occurring infections, including HIV. "We are very proud of him and wish him the best for his safe return," said Dr. Jag Khalsa of NIDA's Division of Pharmacotherapies and Medical Consequences of Drug Abuse, who has known Flanigan for 20 years. Flanigan is also chief of the division of infectious diseases in the department of medicine at Brown University. At Miriam Hospital Immunology Center, he provides comprehensive HIV care and participates in clinical care and research at Rhode Island Prison.





NEI's Dr. Santa Tumminia is an eyeGENE veteran.

From Startup to Success NEI's eyeGENE Enrolls 5,000th Patient

By Robin Latham

In 2003, NEI held a meeting of national and international experts in ophthalmology, genetics and bioethics to discuss inherited eye disease research. A burst of discoveries linking specific genetic mutations to inherited eye diseases, many of them rare, had happened over the previous decade, raising hopes that the field could be getting closer to treatments that would be targeted and gene-specific. To develop those therapies, however, researchers had to do more than just identify the genes. They had to understand what alterations in the genes did to cause the disease—their biological mechanisms—and they also needed to recruit patients to participate in clinical trials.

The outcome of the meeting was the National Ophthalmic Genotyping and Phenotyping Network (eyeGENE). The pilot program launched in 2006 and coupled two goals: developing capacity for diagnostic genetic testing (or genotyping) in the United States and Canada and creating a sample biorepository and patient registry to become a community resource for researchers. This past June, eyeGENE announced recruitment of its 5,000th patient.

“This project was ahead of its time,” said Dr. Santa Tumminia, associate director for strategic science and initiatives and programs at NEI. “There was nothing like it. People were storing DNA samples, but they didn’t have clinical information attached to the genetic information.”

One of the obstacles eyeGENE faced was that there were very few federally approved labs that could gather DNA samples from individuals with inherited eye disease, perform genetic diagnostics and relay results to patients. Testing and genotyping were mostly happening in



NEI's Alexandra Garafalo works on eyeGENE project.

Clinical Center, where the DNA is extracted and shipped for testing in an FDA-approved laboratory. The remainder is stored in the biorepository for research purposes. The clinical information is de-identified and entered into a secure web-based application.

“When we started, the network tested 20 known disease-causing genes across 10 disease categories,” said Tumminia. “Now we test over 100 known disease-causing genes in over 35 disease categories. Since we’ve begun, along with our research partners in the network, we’ve helped identify 15 new disease-causing genes and more than 200 new mutations in known genes. The discoveries are important since so many of these samples are from individuals with rare inherited eye diseases.

“Because of the program, we’ve identified a number of genetic variants that may be associated with inherited eye diseases, although we’re not sure what they do or if they’re significant,” Tumminia continued. “So we’re starting to upload all the variants into a public database [<https://grenada.lumc.nl/LOVD2/NIH/eye-gene/home.php>] for researchers to use.”

Researchers can request access to the eyeGENE data and DNA samples by submitting a research proposal that is reviewed by a data access committee. Upon approval, researchers can also use the network to identify potential individuals for participation in gene-based clinical trials.

As the program continues, testing will move towards next-generation sequencing and whole exome or genome testing, as well as gathering more thorough clinical information including, for example, imaging studies. Other organizations are also beginning to pay attention to eyeGENE. The program has received many requests to share its standard operating procedures with laboratories and research institutions in the U.S. and abroad. eyeGENE will start a pilot program in Italy in the coming year.

“We’re beginning to see the fruits of our labor,” said Tumminia, “in scientific publications and patients being recruited into clinical trials. It’s a very exciting time for vision research.”

research labs at universities that weren’t allowed to share results with patients. The first initiative of the program was to issue grant supplements to build genotyping capacity and establish 11 labs across the country that could do molecular diagnostics according to federal standards.

Currently, the network enrolls about 500 new individuals each year. Patients do not register on their own. Instead, recruitment is done through eye health care professionals such as ophthalmologists, optometrists or genetic counselors with access to patient records.

eyeGENE pays for the genetic testing. In return, each participant agrees to be part of the research program and pay any out-of-pocket costs for eye exams, blood draws and shipping of their samples to eyeGENE. The blood samples are sent to NEI’s eyeGENE laboratory, located in the



RELAY

CONTINUED FROM PAGE 1

Above, from 1: Catherine Rehm of NIAID's outpatient clinic 8 in Bldg. 10 describes her race attire: "Woman Running from NIH Bear, So Scared [Her] Hair Turns Blue."

Dino Maglic of Fast Twitch Fascicles finishes his heat triumphantly. His team finished sixth.

A well-executed baton pass should feature both a spent runner and an exuberant receiver, as demonstrated here by Tao Jiang (l) and Charles Renner of Wu Tang Runners.

PHOTOS: ERNIE BRANSON

tions. NIDDK's Run from Obesity finished first in 13:33. Their name will be engraved on the Allen Lewis NIH Memorial Trophy in the Bldg. 31 Fitness Center.

"It's a pleasure to be associated with the NIH Institute Relay. It affords us the opportunity to promote health and fitness on the NIH campus," said NIH Recreation and Welfare Association president and relay organizer Randy Schools.

He explained that each team had to include 5 runners, with at least 2 women and 2 men.

The course starts on Center Dr., in front of Bldg. 1. From there, runners turn right onto South Dr., passing Bldgs. 5, 8 and 50 along the way. Next, runners make another right onto Memorial Dr. On their left, they pass the Clinical Center. Then they make one final turn back onto Center Dr. From there, it's a sprint to the finish.

The relay's first four runners must hand a baton off to the next runner in an exchange area in front of Bldg. 1. The final runner turns right up a chute onto the Bldg. 1 driveway where the finish line is located.

How each team prepares for the relay is up to them. Some teams practiced for months—commuters could see folks running laps at daybreak and at dusk. Other teams didn't practice at all. This year's winner rehearsed during the lunch hour.

"We practiced handing off the baton a lot," said NIDDK's Dr. Michael Krashes, a member of the winning team.

The practice paid off.

"The first two runners had really good hand-offs," said Jesse Carlin, Run from Obesity's group leader. "That put us in a good position down the stretch."

The second place team, NIA's Charm City Trailblazers, practiced twice a week for the last 4 months with their coach Dr. Mark Mattson.

The first NIH Institute Relay was held on May 24, 1978, when 315 runners, including then NIH director Dr. Donald Frederickson, divided into 63 teams (the director's team was Donald's Ducks). Back then, a running club known as



Top three teams (from 1): Finishing first in 13:33 was Run from Obesity (from 1): Ramon Piñol, Danielle Friend, Mike Krashes, Joe Tiano and Jesse Carlin. Finishing second in 13:47 were the NIA Charm City Trailblazers (from 1): Ben Becker, Ben Peterson, Krisztina Marosi, Coach Mark Mattson, Erez Eitan and Jess Curtis. Finishing third in 14:14 were BOLD Diggers (from 1): Beth Moroney, Lizzie Harkins, Mark Plitt, Sophie Wohltjen and Adam Steel.

Health's Angels organized the event, with help from R&W. For the first 18 years, it was held in the spring. But due to construction on campus, which affected the race course, and other factors, the event was not held from 1996 to 2001. The race was revived in 2002, as a fall classic.

Schools appreciates the help he receives from relay volunteers, R&W staff, the NIH Police, the original members of Health's Angels, the Office of Research Services' Division of Amenities and Transportation Services and everyone else who helps make the event happen.

He hopes this year's runners are getting ready for next year's relay. 🏃



Dr. Patricia Grady (c) with senior faculty members at the UCSF School of Nursing commencement

PHOTO: ELISABETH FALL/FALLFOTO.COM

Grady Highlights Person-Centered Health At UCSF Commencement

At the University of California, San Francisco School of Nursing commencement, NINR director Dr. Patricia Grady noted that UCSF and NINR strive for the same objective—to improve clinical care and health outcomes. She told the audience that leadership, collaboration and shared decision-making are among the many different factors necessary to improve health and health care.

“Family or person-centered health is the keystone to transforming our health care system and empowering those for whom we care,” said Grady. She noted that including patients and families in decision-making helps people to live healthier lives and improves quality of life. When families are involved in their health care decisions, they learn and become active partners with providers.

Grady closed by encouraging graduates to be lifelong learners and follow their ambitions to make a difference in our nation's health. The graduates are now part of the nursing science community that assumes the challenge of addressing critical health care needs.

Recruitment for 2015 Leadership Programs

Are you interested in further developing your leadership acumen? If you are just embarking on your career as a leader, or if you've been a successful leader for many years, the NIH Training Center (NIHTC) offers two leadership programs to meet your needs. Consider one of the programs to help you reach the pinnacle of your career and explore current best practices in the leadership discipline.

A key benefit of participating in NIHTC leadership programs is the informal networking that occurs. You will form meaningful relationships with colleagues throughout NIH who have varying roles and areas of expertise. Program alumni continue to provide feedback to NIHTC about the value of these contacts.

NIH Mid-level Leadership Program (MLP)

Filling a gap between junior-level development and senior/executive leadership programs, the Mid-level Leadership Program (MLP) lessens the impact of impending retirements and turnover in leadership positions. Long requested by the NIH community, this program launched successfully in 2011 and garners consistently high regard from participants and their supervisors. The program develops IC-nominated employees in GS 12-14 and equivalent positions by preparing them to fulfill current and impending demands as front-line leaders. Rather than targeting technical supervisory skills, which are addressed through mandatory NIH supervisory training, the program provides employees with individual leadership skills and knowledge that will aid them in leading from both supervisory and non-supervisory positions.

NIH Senior Leadership Program (SLP)

The NIH Training Center, in collaboration with the University of Maryland School of Public Policy, is entering the 15th year of offering this cornerstone NIH program. Highly praised by senior scientists and administrators for its relevant content, experiential learning activities and exceptional faculty, the program focuses on leadership competencies that will enable high-performing participants to achieve organizational goals. Twenty-eight participants will work with peers and scholar-practitioners while developing a strong trans-NIH cohort. Four program series are included in this call for nominations. Nominations consist of 4 to 6 managers within your IC from both the scientific and administrative communities. An individual application is not required, but ICs can opt to use a sample application template for internal vetting purposes.

Note on NIH Executive Leadership Program (ExLP)

After several successful years of the NIH Executive Leadership Program, this program will not be recruiting for FY 2015. As all option periods on NIH's 5-year contract with the Brookings Institution to deliver this program are complete, this program is currently undergoing a formal assessment to help us plan for future offerings designed for our aspiring and existing “Top 5” leaders of science. While applications for the ExLP will not be accepted at this time, leaders within your IC who prefer not to wait until FY16 to apply to the 2016 ExLP are encouraged to consider the following NIHTC resources:

- NIH Senior Leadership Program
- Executive Coaching/Team Coaching
- NIHTC Courses

Unsure of how MLP and SLP compare? For a brief side-by-side overview or for other training details, visit www.trainingcenter.nih.gov/continuum_of_leadership.html. If you have questions, contact your executive officer or: Mid-Level Leadership Program—Derrick Prather, pratherd@od.nih.gov; Senior Leadership Program—Hannah Alexander, hannah.alexander@nih.gov.

NIH CLINICAL RESEARCH TRIALS AND YOU

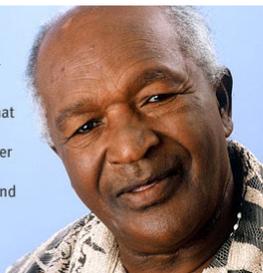
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- Finding a Clinical Trial
- List of Registries
- Personal Stories
- For Parents and Children
- For Health Care Providers
- Educational Resources
- Glossary of Common Terms
- If You Have a Question
- In the News

“Why should I participate in a clinical trial?”

It's your involvement that helps researchers to ultimately uncover better ways to treat, prevent, diagnose and understand human disease.

Learn More ▶



Highlights



Kayla's Story: A Bright Future Through NIH Research
NOMID is a rare disease that is often fatal.



NIH Launches Down Syndrome Registry
Connecting the Down syndrome community to information, resources, and research.

View All Highlights ▶



Help Get the Word Out!

You can help raise public awareness of clinical trials with these promotional materials.



of clinical research from the perspective of the patients and the researchers, the people actually engaged in asking—and answering—important questions in science and medicine. It was designed as a platform for highlighting and showcasing NIH research and to help people unfamiliar with what NIH has to offer.”

Data Backs Site Development

Back in early 2011, NIH data showed that 85 percent of trials did not finish on time because they had too few patients participating. In addition, 30 percent of trials failed to enroll even one patient. Awareness, or lack thereof, seemed to be the culprit. OCPL formed a clinical research awareness working group to find ways to increase what people knew about partnering with scientists in medical research.

With the help of market research agencies contracted by NCI, NIH conducted surveys to determine the public's knowledge and attitudes. Results indicated NIH needed a “user-friendly public-facing web site where individuals can visit and learn about clinical trials.”

OCPL started a voluntary—and unfunded—effort with a collaborative trans-NIH panel to develop the more-accessible, plain-language site that became CRAY. Panelists include registered nurses as well as experts on legal policy, ethics, communication and patient recruitment.

So far, 14 NIH components have supplied “highlights,” researcher anecdotes, participant testimonials or other content for the site. Resources continue to expand. The newest addition is a centralized list of NIH-related registries where prospective participants can one-stop-shop for studies by diagnosis or condition. Thirty registries and a handy FAQ section currently are listed on the “registry of registries,” Allen said.

Recently, the panel also brought in more partners to the site. Panel members have reached out to the American Medical Association and other professional organizations to join.

Matchmaker, Matchmaker

“Another recent addition is a link to Research-Match database,” noted OCPL's Jill Bartholomew, who serves on the CRAY panel. Part of a Clinical and Translational Science Award (CTSA) at Vanderbilt University, the secure database connects people looking to participate in clinical studies with clinical investigators looking for participants. Anyone can use the tool to register to be considered for a study. Any scientist at a CTSA organization can access the registry. A kiosk located in the Natcher Bldg.

CLINICAL TRIALS

CONTINUED FROM PAGE 1

Above: NIH's *Clinical Research and You* web site, www.nih.gov/health/clinicaltrials/index.htm, celebrates its third birthday later this month. The newest addition is a centralized list of NIH-related registries where prospective participants can one-stop-shop for studies by diagnosis or condition.

and get different perspectives on participating in medical research when you visit NIH's Clinical Research and You (CRAY) web site, www.nih.gov/health/clinicaltrials/index.htm. The site celebrates its third birthday later this month.

Getting Familiar

Originally launched Oct. 19, 2011, CRAY puts clinical research into familiar terms. Language on the site is conversational. If clinicaltrials.gov, which contains technical study criteria and abstracts from scientists, is NIH's online home for clinical research, then CRAY serves as a sort of “front porch,” offering a more casual welcome.

Using easy-to-navigate sections—“The Basics” or “Finding a Clinical Trial,” for example—CRAY encourages potential participants to explore clinical research at their own pace, in simple terms.

Under the heading “Personal Stories,” you'll find details on Nicholas, Melanie and Alyssa as well as on Shurin and her colleagues—in their own words, often in video clips. The “In the News” section lists links to clinical study stories from the headlines. A site “Glossary” translates study-speak into common terms.

“Folks are getting a lot more assertive about their own health care,” said Dr. Marin Allen, deputy director of the NIH Office of Communications and Public Liaison (OCPL), which led development of CRAY. “This site tells the story

lobby lets people on campus check it out now.

“We have almost 190 enrollments, which is within the top 10 of enrollments among 90 institutions,” noted fellow CRAY panelist Dinora Dominguez, a patient recruitment specialist at the Clinical Center. Not specific to one research team, the enrollments to intramural protocols represent NIAAA, NIAID, NICHD, NIDDK, NINDS, NIDA, NHGRI, NHLBI and CC.

By the end of July, more than 38,800 individuals accessed the resource via CRAY; of those, about 23 percent registered for a study. Registrations in Match via all NIH campaigns topped 12,000. That’s 19 percent of the people signed up in the database.

“CRAY was also designed to address why intramural research is important,” Dominguez pointed out. “It requires a different approach because the criteria is broader. The majority of intramural clinical research involves phase I and phase II trials that are just beginning the [clinical study] process. Many of the protocols involve first-in-humans research. There’s often not a lot of incentive to enroll in terms of a participant’s personal health. We’re looking for very focused, dedicated individuals who decide to participate in studies for altruistic reasons... although intramural clinical trials often promise little to no direct benefit to an individual patient, it is through these trials that we acquire the knowledge to improve the health of future generations.”

Engaging Underserved Communities

CRAY also set its sights on recruiting other groups of people—minority and other communities typically underrepresented in clinical research.

According to OCPL public affairs specialist Carla Alvarez Mells, results from RAND research indicate that many individuals feel they have not been asked to participate in clinical research. “We have a mandate that all government services be translated for limited-English-proficient individuals, so a lot of the resources we’re working on now involve engaging those specific communities with easy-to-read and understand information and graphics,” she said.

As site content and partners continue to amass, CRAY developers hope popularity of the resource keeps pace.

“It’s fulfilling a need in both the public and scientific communities,” Allen concluded. 🗨️

Researchers Review Research Progress, Treatments at Rare Tumor Symposium

Researchers, medical practitioners, patients and their families met at Bldg. 60 recently for a 2-day symposium on pheochromocytoma and paraganglioma, two rare tumors. Pheochromocytoma and paraganglioma form on the adrenal glands or in the neck, chest, abdomen or pelvis. They can produce hormones involved in the stress response, leading to symptoms such as sweating, feelings of anxiety, palpitations and high blood pressure. Because these symptoms mimic other conditions—such as anxiety disorders—they are often difficult to diagnose. The delay in diagnosis means that many patients may go a long while without appropriate treatment.



Dr. Karel Pacak speaks at pheo symposium.

The delay in diagnosis means that many patients may go a long while without appropriate treatment.

The third annual International Patient Symposium on Pheochromocytoma was sponsored by NICHD and the Pheo Para Alliance, a group of patients, their family members and professionals with an interest in research and treatment for these conditions.

Dr. Karel Pacak, head of NICHD’s section on medical neuroendocrinology, reviewed progress in the field, including the discovery of a new biomarker in patients with certain types of the disease.

Pacak said that 18 genes that cause the tumors have been identified; he expects more will be identified in the months to come. Identifying these genes has important implications for treating the disease, he said. The genes involved influence how the tumors behave and provide important information for treatment. For example, some genes predispose patients to develop tumors on both adrenal glands and others make the tumor much more likely to metastasize, or spread.

Dr. Electron Kebebew, chief of the Endocrine Oncology Branch at NCI, explained that understanding how tumors are likely to behave is important for making decisions about how to care for patients. “Patients really need to know their condition and their options,” he said, adding that an experienced, interdisciplinary team is critical to treatment of the disease.

Pacak, a longtime pheochromocytoma researcher, also offered his vision for the future. More efficient imaging techniques and additional biomarkers are under development, he said. He stressed the need for researchers to collaborate—the key to studying a rare disease—and to speed promising treatments into testing in clinical trials.

Other speakers reviewed complementary and alternative medicine practices as supplements to conventional medicine for the side effects of chemotherapy and other treatments and for the stress involved in coping with a rare disease. Topics included a mind-body intervention to reduce stress, traditional Chinese medicine and how its framework can be applied in modern clinical practice and studies of acupuncture.

FREE STUFF

CONTINUED FROM PAGE 1

-80 degree freezer—before you throw them away or send them to surplus, post it. It's easy!"

FreeStuff can only be accessed via the NIH network. Go to the site, enter your NIH network username and password and you're ready to post or search. All items are listed within a category, such as lab equipment or office supplies. If you're a stickler for protocol, you might wonder, what about inventory procedures? FreeStuff has that covered. There is, naturally, a form to complete for obtaining a property pass for certain equipment and the site explains the process.

Did you know the NIH campus generates more than 4,000 tons of trash a year? And of the more than 8,800 tons of solid waste generated last year alone, only about half was recycled, said Ariell Lawrence, recycling coordinator with NIH's Division of Environmental Protection. She said NIH could reduce the amount of trash significantly by putting recyclables and compostable items—such as biodegradable food containers—in their proper bins.

So before you toss unneeded office items, keep FreeStuff in mind. The program helps reduce waste and operational costs. As of June 2014, more than 640 items have been transferred among the NIH community, with an estimated savings of \$560,000.

One warm spring day in 2011, Shinko was out running and the idea hit her for a free supplies exchange. She'd been working as an intramural administrative branch chief at the National Institute of Allergy and Infectious Diseases and noticed labs and offices often had working equipment they no longer needed. But there was no way to communicate what extra items staff had that would be free to a good office or lab.

When Claro Yu, a long-time NIH lab tech, approached Shinko about a part-time detail in administrative work, he got energized by her idea and the two founded FreeStuff. It started as a small NIAID initiative, built by inspired volunteers in the IT office. The site expanded and launched NIH-wide in 2013.

Around that time, NIH industrial chemist Crispin Hernandez-Wong was working on a program for chemical surplus redistribution and stumbled upon FreeStuff during Shinko's and Yu's initial presentation; he would soon have a chemicals and reagents tab on the site. Often, researchers must



Crispin Hernandez-Wong added a chemical surplus program to NIH FreeStuff. So far, it has saved NIH many thousands of dollars.

buy chemicals in bulk but they may only need a small amount. Now there's a chemical surplus program through NIH FreeStuff that accepts unused, sealed, unexpired chemicals for redistribution. There's also the Solvent Recovery Program that takes used or unused, even expired, alcohol, xylene or formalin for recovery and redistribution.

Hernandez encourages researchers to use NIH FreeStuff. "With the high cost of chemical disposal and of buying new solvents, you can use this program, pursue your research and know these chemicals will get used," he said. "It will eliminate you having to buy these chemicals over and over, and it will save you time and money." So far, the chemical exchange on FreeStuff has saved NIH many thousands of dollars.

Before FreeStuff, "You could either send a clunky mass email to your colleagues," Shinko said, "or you could send the item to the surplus warehouse." But the warehouse had no way to advertise equipment, so if your item wound up there—in the great abyss—it was not likely to make its way back to anyone at NIH again. Sometimes nobody requests a listed item in the specified time frame and it winds up going to surplus anyway. Shinko said they're working on a site enhancement that would allow the warehouse to reactivate the post.

FreeStuff is good for the budget and good for the environment. Said Shinko, "Now we just need everyone to use it and spread the word." 🗣️



NIH FreeStuff cofounders are Gwendolyn Shinko and Claro Yu. Said Shinko, "Now we just need everyone to use it and spread the word."

milestones

UCSF Honors NINR Deputy Director

Dr. Ann R. Knebel, deputy director of NINR, was recently honored by the University of California, San Francisco School of Nursing with the Jane Norbeck Distinguished Alumni Award. The award recognizes UCSF graduates “who have made significant contribu-



tions to the nursing profession and have demonstrated service and/or leadership that contributed to the growth and development of the UCSF School of Nursing and/or the profession.” The award, established in 1984, is named for former School of Nursing dean Jane Norbeck, who was a member of Knebel’s dissertation committee nearly 25 years ago.

Knebel, a retired rear admiral in the Commissioned Corps, has served as deputy director of NINR since 2012. Prior to that, she was deputy director of the Office of Preparedness Planning, HHS. In this role, she applied scientific principles and research expertise to the evolving scientific field of disaster preparedness, leading to the development of handbooks, planning guides and peer-reviewed publications.

Knebel earned her Ph.D. in nursing science at UCSF in 1990. She also has a baccalaureate degree in nursing and a master of nursing science degree from the University of Evansville. The award presenter noted, “Dr. Knebel has lived a life of clinical practice, research and service at the highest levels and exemplifies the ideals of the award.”

Nine Named to Council of Councils

The Division of Program Coordination, Planning and Strategic Initiatives recently welcomed nine new advisory members to the Council of Councils who will advise on DPCPSI policy and programs. The new members are:

Dr. Philip O. Alderson, dean of the School of Medicine, vice president for medical affairs, Saint Louis University, served as a professor of radiology and previously chaired the department of radiology at Columbia University. He has developed imaging

technologies that focus on the cardiovascular and central nervous systems.

Dr. Marlene Belfort, distinguished professor of biological sciences in the School of Public Health at the University of Albany, focuses on attracting and nurturing a cluster of accomplished young scientists. Her research interests include genetics, specifically the study of organisms’ hereditary information encoded in DNA and RNA.

Dr. Ana M. Cuervo, professor of the departments of development and molecular biology, medicine and anatomy and structural biology at Albert Einstein College of Medicine, serves as co-director of the Einstein Institute for Aging Research. She is a leader in the field of protein degradation in relation to biology of aging.

Dr. Judy E. Garber, director of the Center for Cancer Genetics and Prevention at Dana-Farber Cancer Institute, works as a medical oncologist and clinical cancer geneticist. Her research interests include identifying individuals with genetic factors that place them at high risk of developing cancer and strategies to reduce cancer risk.

Dr. Lila Gierasch is distinguished professor of biochemistry and molecular biology and chemistry at the University of Massachusetts. Her research focuses on protein folding and the cellular machinery that helps maintain folded, functional proteins.

Dr. King K. Holmes, professor and chair of global health and director of the Center for AIDS and STDs at the University of Washington, is a global expert in AIDS and STIs and principal investigator for the International Training and Education Center on Health, one of the world’s largest HIV/AIDS training programs.

Dr. Norma Sue Kenyon is professor of surgery, medicine and biomedical engineering and executive director of the Wallace H. Coulter Center for Translational Research at the University of Miami School of Medicine. She is involved in basic as well as clinical diabetes research including islet cell transplantation as a therapeutic approach for managing diabetes.

Dr. Terry Magnuson, vice dean for research at the University of North Carolina School of Medicine, is director of the new Carolina Center for Genome Sciences. His work focuses on the role of mammalian genes in unique epigenetic phenomena such as genomic imprinting and X-chromosome inactivation.

Dr. Norbert J. Pelc, Boston Scientific applied biomedical engineering professor and chair of bioengineering at Stanford University, is renowned for his work in the field of biomedical imaging. He developed a multidisciplinary pre-doctoral program at Stanford to train the next generation of biomedical imaging scientists.

DPCPSI director Dr. James Anderson (c) meets with members of the Council of Councils (back, from l) Drs. Norma Sue Kenyon, Steven DeKosky, Philip Alderson, Marlene Belfort, Terry Magnuson and Norbert Pelc; (front, from l) Drs. Lila Gierasch, Anderson and Ana Marie Cuervo. Not shown are Drs. Judy Garber and King Holmes.



NIAMS Welcomes Five Council Members

NIAMS has appointed five new members to its advisory council. They include:

Dr. Gary A. Koretzky, dean of Weill Cornell Graduate School of Medical Sciences and senior associate dean for research at Weill Cornell Medical College. His research focuses on T cells, a subset of white blood cells involved with fighting infection and destroying cancer cells.

Dr. Grace K. Pavlath, professor in the department of pharmacology at Emory University School of Medicine. Her research centers on the cellular and molecular mechanisms that regulate the function of satellite cells, stem cells found in skeletal muscle that are critical for muscle growth and repair.

Dr. Christy Sandborg, professor of pediatrics in the division of pediatric rheumatology at Stanford University School of Medicine. Her research involves designing new models of care and health care delivery for children with complex chronic illnesses.

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Alexander Silver, co-founding partner of P2 Capital Partners LLC in New York City. He also is founder and chair of the Jackson Gabriel Silver Foundation, a non-profit organization dedicated to finding treatments and cures for epidermolysis bullosa, a rare blistering skin disease.

Dr. Gwendolyn Powell Todd, a professional leader, educator and advocate for patients with cicatricial alopecia, a rare disorder in which hair follicles are replaced with scar tissue. She applies leadership, teaching and coaching expertise in business, education, health care and community service environments.

Etcheberrigaray Named CSR Deputy Director



Dr. René Etcheberrigaray is the new deputy director of the Center for Scientific Review. He had been serving as director of CSR's Division of Neuroscience, Development and Aging.

"René brings to this key position highly valued management skills and a strong commitment to NIH peer review," said CSR director Dr. Richard Nakamura. "He also shares my vision for peer review and complements my NIH background."

He noted that Etcheberrigaray has "a great depth of experience with NIH peer review policies and practices and he has a remarkable ability to rapidly master new challenges." He came to CSR in 2002 to be scientific review officer of the clinical neurosciences and disease study section. In 2005, he was promoted to chief of CSR's brain disorders and clinical neuroscience integrated review group and was named a division director in 2008.

Etcheberrigaray will help manage the center's 460 employees, who each year receive more than 80,000 grant applications, recruit about 17,000 reviewers and convene about 1,500 review meetings.

Etcheberrigaray obtained his M.D. from the University of Chile in 1987. He then came to NIH as a Fogarty International Center post-doctoral fellow, studying ion channel physiology and molecular neurobiology in an NINDS intramural lab. He continued there as a visiting associate and then a visiting scientist. Etcheberrigaray later moved to Georgetown University, where he started a laboratory that focused on potential therapeutic targets for Alzheimer's disease and the role of calcium regulation and amyloid processing in the pathogenesis of Alzheimer's. Before coming to CSR, he was laboratory director and senior scientist at a biotech company in Rockville. 

NIAMS director Dr. Stephen Katz (c) and deputy director Dr. Robert Carter (second from r) welcome new members to the institute's council. They are (from l) Dr. Christy Sandborg, Dr. Gwendolyn Powell Todd, Dr. Gary Koretzky, Dr. Grace Pavlath and Alexander Silver.



APAO Donates to Children's Inn

The Asian and Pacific Islander American Organization (APAO) recently donated \$250 from the proceeds of its Ethnic Food Fair to the Children's Inn at NIH. Each year, APAO organizes a fair in May on the patio of Bldg. 31 with food,

demonstrations and entertainment, to celebrate Asian Pacific Islander American Heritage Month. Shown at the gift presentation are (from l) Kausik Ray; Aaron Bell; Lauren Stabert, representing the inn; Shioko Kimura; JoAnne Wong; Chunzhang Yang; Chuan-Ming Li; and Jimmy Do. Since 1990, the inn has served more than 13,500 families.

PHOTO: CHRIS PARKER



feedback

Have a question about some aspect of working at NIH? You can post anonymous queries at www.nih.gov/nihrecord/index.htm (click on the Feedback icon) and we'll try to provide answers.

Feedback: Is there someplace where we can get updates on the F-wing project? It seems to be terribly behind schedule. We've had postdocs come and go during the construction—meaning that this project has gone on too long. And then there's a rumor that the closed off N-corridors will never reopen, leaving the Bldg. 10 west-end residents permanently orphaned from the rest of Bldg. 10.

Response from the Office of Research Facilities: The F-wing renovation project is a 5-year, 2-phase project that was funded through the American Recovery and Reinvestment Act. Phase A (floors 2-5) is behind schedule. At this time, these floors are not due to reopen until early 2015. The remaining upper floors of Phase B (floors 6-13) are actively under construction with planned completion in late summer 2015. As the floors are completed, the north corridors will reopen for access between the east and west sides of Bldg. 10.

Feedback: I park in MLP-8 almost every day and while the spaces are a tight fit, I usually get in and out without issue. Some days, however, the cars next to me are parked so terribly (over the line, diagonal, etc.) that I cannot open my driver's side door at all and I have to climb in over my passenger's seat. The other day both cars next to me were terribly parked and I could barely open my passenger door—meaning I could barely get in my car. In the event both cars next to me block any chance of getting to the driver's seat, what can I do? Am I supposed to wait for one of them to leave? Should I contact Colonial Parking or NIH Police? Could the car get towed? I do not want to be delayed getting home because other drivers cannot be bothered to park correctly and considerately!

Response from the Office of Research Services: This is a wonderful opportunity to remind our fellow NIH staff to be considerate and courteous when parking their vehicles. Your frustration is natural and hopefully people will read this and understand the impact their actions have on their fellow co-workers.

The NIH Police can be contacted if you are unable to enter your vehicle due to cars being too close, in multiple spaces, double parked or parked over the lines. You can reach them at (301) 496-5685 and they can determine the best method of resolving the issue.



NSO Makes Fifth Visit to Clinical Center

The National Symphony Orchestra made its fifth visit within the past year to the Clinical Center on Sept. 17, giving a 75-minute concert before a standing-room-only audience assembled not only on the CRC atrium floor, but also on the floors above. Conductor Ankush Kumar Bahl (above, c) led the orchestra through five selections, concluding with Mozart's well-known Eine kleine Nachtmusik, K. 525. In addition to the concert, an NSO women's committee hosted an instrument petting zoo and NSO ensemble performance at the Children's Inn on Sept. 22. The NSO returns to the CC in mid-November as part of its Sound Health Initiative, which brings orchestral music to area hospitals and medical centers. The NIH concerts are sponsored by the CC and the Foundation for Advanced Education in the Sciences.

PHOTOS: BILL BRANSON



NIH Research Study Seeks Healthy Moms

Healthy moms ages 18-50 are invited to participate in an outpatient research study examining the role of reproductive hormones in postpartum depression. Eligible participants must be medication-free. Compensation is provided. Call to learn more: (301) 496-9576, TTY 1-866-411-1010. Refer to study 95-M-0097.

NIMHD Holds First Scientific Operational Planning Meeting

By Gerda Gallop-Goodman

The National Institute on Minority Health and Health Disparities held its inaugural scientific operational planning session recently to pave the way for a research agenda to help define the science of health disparities.

“The meeting enabled us to identify important initiatives that can be implemented,” said Dr. Yvonne Maddox, NIMHD acting director. “The process will help us achieve our long-term scientific goals and create a strategic agenda that will allow us to develop a clear definition of health disparities research, how it is conducted and how best to support it.”

During the meeting, ongoing program initiatives were reviewed for scientific merit, cost, productivity and impact, including signature research and infrastructure programs, as well as career development, training and small business programs.

Some priority areas that were presented for review include American Indian/Alaska Native health and HIV/AIDS and obesity.

“It was inspiring for all of us to hear the importance of the field of health disparities research, what NIMHD has done to date and our committed roles in this field,” Maddox said.

“We agree on how critical it is to focus the NIMHD research agenda in such a way that we can not only address and reduce health disparities and improve the health of underserved populations, but also that we should do this using innovative, unique, thoughtful and, where possible, cost-effective approaches,” she added. “This means engaging the full complement of NIMHD staff and our available funds... through targeted collaborations across NIH, HHS and with other public and private-sector organizations to provide not only additional funding, but also other ideas to help address our complex mission.”

Staff attending the meeting received a surprise visit from NIH director Dr. Francis Collins, who acknowledged the historical legacy of the institute in its efforts to improve minority health and eliminate health disparities.

“Thank you for giving me the opportunity to tell you, on behalf of all NIH, how very much your work here is appreciated,” Collins said. “Your mission is so critical to our future. Advancing the cause of health disparities is one of my personal priorities. NIH has a major role in identi-

NIH director Dr. Francis Collins and NIMHD acting director Dr. Yvonne Maddox at NIMHD's first scientific operational planning meeting

PHOTO: ERNIE BRANSON



fying interventions and causes and your institute is central to those goals.”

Collins highlighted the institute’s accomplishments from its beginnings in 1990 as an office to designation as an institute in 2010 with passage of the Patient Protection and Affordable Care Act. While securing access to health care is instrumental in efforts to decrease health disparities, problems with quality of health care and outcomes still persist in certain underserved communities; we need to find ways to close these gaps, he explained.

NIMHD helps set priorities for minority health and health disparities at NIH, conducts and supports this research and promotes and supports the training of a diverse biomedical workforce, Collins added. “The institute advances and translates knowledge in ways that inform the public, helping them to make better health choices,” he said.

Collins spoke of a future where medicine will be more focused on the individual, not a one-size-fits-all approach. He said an important part of personalizing medicine comes from understanding the causes of health disparities and determining how to eliminate them. “If we can chip away at health disparities, everyone can experience the better health they deserve,” he said.

“Using the tools of research and our creativity to address our task, we have a moral responsibility to address health disparities,” he concluded. “What a privilege to be engaged in this noble enterprise that has real promise to give every person the opportunity to have better health. Thank you for what you are doing.”

Fulbright Visiting Scholar To Give Lecture, Nov. 4

Dr. Melanie Cheung (Ngāti Rangitihi, Te Arawa), a Fulbright New Zealand scholar developing a brain resilience training program for Huntington’s disease, will deliver a special lecture on Tuesday, Nov. 4 at 1 p.m. in the Porter Neuroscience Research Center, Rm. 620/630.



Huntington’s disease is a progressive brain disorder affecting an estimated 3 to 7 per 100,000 people of European ancestry. Cheung is committed to exploring both indigenous and Western scientific paradigms to help people with neurodegenerative diseases. Her work integrates experimental neurobiology, bioethics, tikanga (ceremony/customary) and Mātauranga Māori (Maori traditional knowledge).

The lecture is free and open to the public and sponsored by NIMHD, NINDS and the Fogarty International Center. For reasonable accommodation, call (301) 402-1366 or the Federal Relay at 1-800-877-8339.