

- Young professionals, former staff volunteer in hospital
- Dental Clinic humming with enhanced capacity for clinical care and research

Changes in records management, streamlined patient-doctor communication coming soon

The NIH Clinical Center Health Information Management Department celebrated Health Information Professionals (HIP) Week, April 3-9, 2016, and hosted educational sessions for staff on the benefits of e-faxing medical records, the upcoming launch of a Clinician Portal, future features to the Patient Portal and an updated way to schedule patients' appointments.

With ongoing education and cross-training as a top priority of the week, the department kicked off the conversation with the implementation of e-faxing consents and other documents that need to be placed in the electronic medical record system quickly. Spurred by the 2015 Health Information and Management Systems Society (HIMSS) Analytics Stage 7 certification award for the Clinical Center's leading electronic medical record system, the department

is now using the e-fax for important documents such as transfusion consents, advance directives (end-of-life care), medication reconciliation (a list of all medications a patient is taking) and emergency response records, among other things. The documents are placed in a patient's electronic medical record (CRIS) for clinicians to easily access in as little as 10 minutes and within 24 hours of being sent.

During HIP week, the department also announced the launch of a pilot Clinician Portal. The portal will allow a patient at NIH to grant access to two of their non-NIH physicians to set up an account, log in and view the patient's NIH medical documentation, including radiology images. Currently, NIH sends paper copies of a patient's file via fax or mail.

HIMD UPDATES *page 4*

The personal side of experimental gene therapy

Just over twenty-five years ago experts at the Clinical Center, along with colleagues from the National Cancer Institute (NCI) and the National Heart Lung and Blood Institute (NHLBI), performed the first gene therapy in the U.S. On Sept. 14, 1990, a team of researchers, nurses and other dedicated staff

administered the novel technique that uses genes to treat or prevent disease.

Gene therapy involves replacing a mutated gene that causes disease with a healthy copy of the gene; inactivating, or "knocking out," a mutated gene that is functioning improperly; or introducing a new gene into the body to help fight a disease.

While still considered an experimental therapy decades later, the CC celebrates the milestone of this accomplishment in helping advance the science, motivate others in the medical field to continue the research and save lives. And, of course, this advancement couldn't have happened without the incredible patients and families who participated in the clinical trial and are partners in research.

At the age of just 4-years-old, Ashanthi De Silva, was the first patient to receive gene therapy. Now, 25 years later, De Silva is "doing very well!" she said. "My husband and I [just] celebrated our five-year anniversary. Although I have experienced my fair share of hospitalizations and complications, it hasn't kept me from traveling the world, completing my education, and living a full life with friends and family."



Ashanthi De Silva, the first patient to receive gene therapy in the NIH Clinical Center, and her husband.

Dr. Anthony Fauci lectures on Zika Virus

On March 18, Dr. Anthony S. Fauci, director of the National Institute of Allergy and Infectious Diseases (NIAID) presented a lecture on the Zika Virus: Pandemic in Progress.

"We really have to stop meeting like this between Ebola and Zika," Fauci said lightheartedly to a full Masur Auditorium and to nearly 1,500 viewers watching live online. "This is a perpetual challenge of emerging and reemerging infectious diseases."

Fauci provided background information on the Zika virus, which is a single stranded enveloped RNA virus first being isolated in 1947.

"We have a lot of experience with [this type of virus]," he said. Zika is a flavivirus closely related to dengue, yellow fever, Japanese encephalitis and West Nile virus. It is predominately transmitted by a mosquito to a person.

"About 80 percent of people have no symptoms," he said. The incubation period is between 3-12 days. Symptoms are mild and last about a week. Tests that are

readily available now often don't distinguish between Zika and the other types of viruses prevalent in those regions, like dengue and yellow fever. There are no current Zika treatments available but supportive therapy is given, including fluids, rest and acetaminophen.

As of March 2016, Fauci stated there are 37 countries/territories with active Zika virus transmission.

While "there's almost no mortality," Fauci said, there's been "an explosion of microcephaly cases in pregnant women's fetus who are infected during pregnancy."

Fauci then reviewed the current evidence for Zika Virus as a likely cause of microcephaly, which is a rare neurological condition which causes reduced life expectancy and abnormal neurocognitive development.

In the U.S., Fauci said there may be two types of cases of Zika Virus seen: imported cases – nearly 40 million people travel to involved regions a year, and local spread – people who never leave the country.

ZIKA LECTURE *page 4*

GENE THERAPY *page 4*

Former Clinical Research Training Program participant returns to NIH

In 2004, Dr. Robert Allison arrived at the NIH Clinical Center as a Clinical Research Training Program (CRTP) student. Now, 12 years later, he has returned to a permanent position as deputy section chief of the Infectious Disease Section in the Department of Transfusion Medicine (DTM). Allison will focus on viral hepatitis and transfusion-transmitted infections research. He will be working closely under the chief of the section, Dr. Harvey Alter.

"I am thrilled to be back at the NIH and back home in the Department of Transfusion Medicine," Allison said. "After working in several academic centers, and for federal and international agencies before coming back to NIH, I can say that our institution is by far the best place to work. The fact that so many are still here after my departure about 10 years ago is a testament to that."

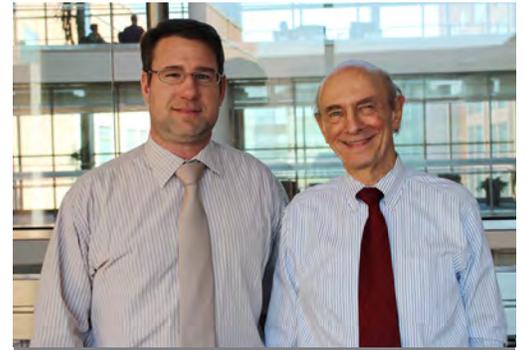
Over the past decade, the CRTP transitioned into the Medical Research Scholars Program (MRSP), which is a comprehensive, yearlong research enrichment program designed to attract the most creative, research-oriented medical, dental and veterinary students to the NIH.

From 2004 to 2005, Allison conducted research on hepatitis C virus (HCV) and enjoyed it so much that, after medical school, he came back to the Clinical Center for a two-year postdoctoral clinical research fellowship in Alter's section, with a focus on HCV and why some people with chronic HCV who are immunosuppressed (HIV/HCV) have more rapid progression of liver fibrosis, after organ transplantation.

"My CRTP research on hepatitis C virus with Dr. Alter is the primary reason why I've returned to the NIH."

Most recently, Allison served as medical epidemiologist and the focal point for hepatitis B control in the World Health Organization's Eastern Mediterranean Region for the Center for Disease Control and Prevention (CDC) Global Immunization Division in the Center for Global Health. He was also the Medical Management and Patient Safety Lead for the CDC-led Vesicular Stomatitis Virus-Ebola Virus vaccine.

Alter, who has reduced hours in 'semi-retirement,' hopes that Allison will continue to thrive as a leader in DTM even after he has left. Allison has become like 'family' to Alter and others in the section.



Dr. Robert Allison and Dr. Harvey Alter.

"The great part of this story is that Rob started as a CRTP/MRSP student which initiated his love affair with NIH and then induced him to return as a fellow," Alter said. "Now he is a full-time member of our department. It is this type of clinical research progression that was one of the original goals of these programs. Rob is perhaps the poster child for this program, and we have mutually and equally benefited from the concept of clinical research training for aspiring medical students."

Learn more about MRSP and similar training programs: <http://go.usa.gov/cAYtA>

Dental Clinic now has enhanced capacity for clinical care and research

In the NIH Dental Clinic, located on the first floor of the Clinical Center, a new cadre of specialists manage dental emergencies for study participants but also perform screenings for dental, oral health and craniofacial problems. The clinic, which has recently expanded its clinical talent, has also seen an increase in the number of patients seeking treatment. During a recent week, the clinic managed the care of more than 70 patients, which is nearly three times the weekly average in 2014.

"We have brought board-certified specialists onto the team so that we can offer an enhanced capacity for clinical care and clinical research," said Dr. Janice Lee, clinical director for the National Institute of Dental and Craniofacial Research (NIDCR).

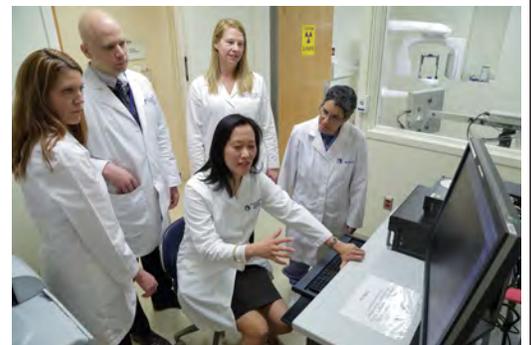
In addition to offering hospital dentistry, pediatric dentistry and oral medicine specialists, the clinic has experts who can perform oral and maxillofacial surgery and diagnose

and treat periodontal disease. Because oral manifestations can be a component of a number of systemic inflammatory diseases, such as Sjögren's syndrome and rheumatoid arthritis, the NIDCR team includes two rheumatologists.

"The clinic is humming and people are smiling despite being so busy," Lee said.

About 85 percent of patients are referred to the clinic from other Institutes, such as the NCI, NHLBI and NIAID. An investigator or research nurse will often refer a patient for an exam to see if there's an infection or other oral health problems as well as to receive a comprehensive evaluation and dental hygiene appointment.

Clinical investigators who refer their patients to the clinic are obtaining dental, oral and craniofacial treatment planning that they would otherwise not have access to. When clinic staff examine patients and prepare them to take part in clinical stud-



Dr. Janice Lee, NIDCR clinical director (seated), discusses a 3-D x-ray with her team (left to right): Laurie Brenchley, Dr. Bob Range, Dr. Pamela Gardner and Mercedes Garcia. Range and Brenchley are among the newest members of the expanded dental clinical team.

ies, the specialists sometimes discover unexpected dental, oral or craniofacial issues that have become topics of new research collaborations between the Institutes. To request a dental consult, email pamela.gardner@nih.gov and bob.range@nih.gov.

Read more online! Scan the barcode or visit www.cc.nih.gov/about/news/newsletter.html



- Clinical trials seek people with fatty liver disease; mild cognitive impairment or early stage Alzheimer's Disease for studies
- NIH celebrates Pi Day across campus
- Focusing on hospital administrators

Use a downloaded app on a smartphone or tablet to scan the Quick Response (QR) barcode. You will be directed to the CC News online.

Clinical Center News

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Young professionals, former staff volunteer in hospital



Janet Logan (left), Ezii Umejiego (center) and Gideon Wolf (right) are just a few of the volunteers who enjoy the personal satisfaction that comes from helping others.

Amongst the hustle and bustle of staff, patients and researchers in the NIH Clinical Center stands a strong workforce of volunteers who support a variety of tasks that help the hospital maintain the highest levels of patient care and clinical research.

In honor of Volunteer Week, April 10-16, 2016, the Clinical Center thanks the more than 200 volunteers who have given back roughly 12,500 hours over the past year. This is equivalent to more than six full-time employees.

Janet Logan, who worked in the NIH's National Institute of General Medical Sciences, has volunteered at the Clinical Center for 20 years. On the outpatient clinic on the 12th floor, she sits and talks with patients, restocks important informational brochures and chaperones female patients' pelvic exams when a male doctor performs them. As a two-time cancer survivor, she uses her own experience to help cancer patients better understand and cope with their diagnoses.

"In 1991, I was diagnosed with breast

cancer and was in a clinical trial at NIH that included undergoing surgery and chemotherapy," said Logan. "When I retired from NIH in 1996, I came back as a volunteer because it was pay-back time. I wanted to give something back to the program which had done so much for me. I can empathize with patients, instead of simply sympathizing with them."

Ezii Umejiego, a postbaccalaureate Intramural Research Training Award (IRTA) participant originally from Africa, volunteers as a patient ambassador in the Department of Perioperative Medicine. He picks up patients heading to surgery from their rooms and performs the critical task of a first check to make sure the patients he picks up are the correct patients with the correct identification. He also ensures the patients are prepared for surgery and have not eaten anything after midnight the previous evening and speaks to them and their families as they make their way to the operating room. Umejiego helps

patients and their families relax during an often stressful time while also ensuring patient safety.

"It is so amazing to see the teamwork that takes place at the NIH Clinical Center," said Umejiego. "I am the first person of many who ensures the safety of our patients, and we all work together to make sure that our patients are taken care of."

Gideon Wolf, a young professional hoping to attend medical school, enjoys volunteering in the hospital setting. Wolf, a postbaccalaureate IRTA, sits in the Phlebotomy waiting room and restocks the food and coffee cart for patients. Often, patients come very early and are not able to eat before their appointments. After their blood draws, hot coffee and sweet treats are available.

"It's very fulfilling helping patients and their families feel at home at the Clinical Center," said Wolf. "The food cart helps bring a little happiness into the hospital."

More information: <http://go.usa.gov/cAcE5>.

Photon-counting CT scanner used in patients for the first time

The Clinical Center at the National Institutes of Health is investigating the potential use of a new generation of a computerized tomography (CT) scanner, called a photon-counting detector CT scanner, in a clinical setting. The prototype technology is expected to replicate the image quality of conventional CT scanning, but may also provide health care specialists with an enhanced look inside the body through multi-energy imaging. Patients could receive a minimum amount of radiation, while the maximal amount of information needed would be delivered to health care providers.

Over the next five years, Dr. David Bluemke, chief of the Department of Radiology and Imaging Sciences, and his

team will continue to develop scan protocols and image processing algorithms, which could improve screening, imaging and treatment planning for health conditions like cancer and cardiovascular disease.

"The NIH Clinical Center has helped shape and share research advances and health care for decades. Now is an exciting time for us and for our study participants here in the Clinical Center as we help test and develop this CT technology so that it may one day help patients around the world and impact the health care they receive," said Dr. Bluemke.

As the world's largest hospital solely dedicated to research, the NIH CC sees



A study participant receives a scan in the Clinical Center.

thousands of patients every year, many of whom have rare and complicated illnesses. In the treatment and study of disease, surgery is often viewed as the last option. CT scanning is one way that doctors can examine the body's internal features in a non-surgical way. Read the complete CC News story online: <http://go.usa.gov/cAggR>

GENE THERAPY *from page 1*

De Silva has adenosine deaminase (ADA) deficiency, a genetic disease that is one form of severe combined immunodeficiency (SCID). Her weakened immune system left her defenseless against infections from bacteria, viruses and fungi. Doctors in the CC used a modified virus to deliver the correct ADA gene to De Silva's immune cells and to the cells of another 9-year-old girl. Each girl was given repeated treatments over a period of two years.

White blood cells, which help protect the body from infection, were taken from De Silva and the other patient through apheresis (a process that withdraws blood, separates the needed cells and returns the remainder to the body). Under the direction of CC biologist Charles C. Carter, researchers then used the blood samples to isolate T lymphocytes, a type of white blood cell, and expose them in the laboratory to a retrovirus modified to carry the normal ADA gene. The normal genes for making adenosine deaminase were inserted into the cells. After given four-day's time to multiply and grow, the corrected cells were then reinjected into the girls.

"It took months before Sept. 14, 1990, to collect my cells and watch them grow," she said. "On the day when the corrected cells were supposed to be infused back into my body, a room had been set up for press and was filled with cameras and reporters. The doctors and my parents never took their eyes off me during the entire treatment."

De Silva added, "I was given stickers, balloons, toys, yet I never cracked a smile.

It must have been a pleasure for all to work with me."

While the pioneers of gene therapy, Dr. Michael Blaese, with NCI, and Drs. Kenneth Culver and W. French Anderson both with the NHLBI have since moved on from their work at NIH, another key team member still remains – 25 years later.

In 2015, Bonnie Sink, a clinical nurse specialist in the Blood Services Section of the CC Department of Transfusion Medicine, fondly reflected on September 1990 at her desk.

"It was an exciting time," Sink said as she quickly located a folder marked gene therapy from her files spilling over with newspaper clippings and journal articles from 1990. "I was a registered nurse working in the apheresis clinic, and I did the collections of the cells that they were going to then insert the gene into."

"In the end, it boils down to one word: hope. You have to have hope for your child's life, and this is what my parents did. It wasn't much of a choice – either try the new treatment, or wait until I fell ill with an infection I couldn't fight off," De Silva said. "I am incredibly thankful for the NIH, and the three doctors who pioneered gene therapy and gave me and countless others a chance to experience life. It's difficult to fathom the countless, frustrating hours and sleepless nights that went into this research, and, for every second of it, I am completely grateful. The NIH is America's shining beacon, without a doubt. I have yet to receive more skilled and attentive health care anywhere."

Read the complete CC News story online: <http://go.usa.gov/cAggR>

Upcoming Events

View lectures online: <http://videocast.nih.gov>

Clinical Center Grand Rounds Lecture: Treating Hematologic Malignancies with Chimeric Antigen Receptor T Cells; Human Papilloma Virus-Targeted T cell Therapy for Patients with HPV-Associated Cancers

April 27, 2016, 12 noon – 1:00 p.m.

Lipsett Amphitheater

Presented by James N. Kochenderfer, MD, NCI and Christian S. Hinrichs, MD, NCI.

NIH Take Your Child to Work Day

April 28, 2016, 9:00 a.m. - 4:00 p.m.

Bring your children in grades 1-12 and inspire them to explore career paths in science and public service. Registration is required. For more information, visit: <http://takeyourchildtowork.nih.gov>

NCCIH Annual Stephen E. Straus Distinguished Lecture in the Science of Complementary Health Therapies: Change Your Brain by Transforming Your Mind

May 3, 2016, 10 a.m. – 11:00 a.m.

Masur Auditorium

Presented by Richard J. Davidson, PhD, Waisman Center, University of Wisconsin-Madison.

Clinical Center Grand Rounds Lecture (Nurses Week): Deciphering the Oral Microbiome in Severe Aplastic Anemia Patients: Methods and Results

May 4, 2016, 12 noon – 1:00 p.m.

Lipsett Amphitheater

Presented by Nancy Ames, PhD, CC and Jennifer Barb, PhD, CC.

ZIKA LECTURE *from page 1*

As of March 16, in the U.S. there have been 258 cases of travel-associated Zika and no locally transmitted cases. But, in the U.S. territories, U.S. Virgin Islands, American Samoa and Puerto Rico, travel-associated Zika cases only went up to 3 but locally acquired was up to 283 cases.

Earlier this year, Fauci noted that the Centers for Disease Control and Prevention (CDC) issued an interim travel guidance related to Zika Virus including over 40 countries. And, out of an abundance of caution, CDC recommends pregnant women consider postponing travel to the areas where transmission is ongoing.

He touched on the summer Olympics in Rio de Janeiro in August 2016 and said that the CDC will likely be making recommendations in real time depending on what's going on.

Fauci said that there are multiple candidates in the queue for a future Zika virus vaccine. A Phase I clinical trial will likely begin for the most viable vaccine candidate in September 2016.

View the videocast: <http://go.usa.gov/ctvqA>

HIMD UPDATES *from page 1*

In an effort to continuously streamline communication, sharing and storage of medical records, the department also announced that a new tool within CRIS now allows users to send messages back and forth to each other through Secure Health Messaging. These messages can then be attached to a medical record file. Eventually, Secure Health Messaging will also expand to the Patient Portal, allowing patients to easily communicate with their NIH healthcare team.

Denise Ford, head of the Department of Patient Relations and Recruitment Services, also spoke at a session about the new patient scheduling system. Through this modernization, clinicians are now required to place a medical order

before scheduling a patients' appointment. The new scheduling system is integrated in CRIS, allowing the order to be linked to the appointment and, in real-time, update the CRIS Appointment Tab in the patient record. Previously, the 47 sites that schedule patient appointments used a third party scheduling system (Scheduling.com) in addition to their own scheduling systems. The new system allows for coordinated communication of patient schedules across the care team.

The department, formerly known as the Medical Record Department, has nearly 40 staff members who ensure that medical records are accurately documented in a timely manner, readily accessible and permit prompt retrieval of data.