

- Healthcare advocate, parent of teen with chronic illness, speaks at NIH
- Redesign brings fresh look, added light to NIH's Safra Family Lodge

## Center for Cellular Engineering expands to Southeast Patio



In January, the NIH Clinical Center celebrated the groundbreaking of a new cellular processing facility on the Southeast patio of Building 10 and establishment of the Clinical Center's Center for Cellular Engineering (CCE). The facility marks the most recent expansion for the Department of Transfusion Medicine's growing capacity to support intramural cellular therapy protocols.

Dr. Francis Collins, director of NIH, Dr. Jim Gilman, CEO of the NIH Clinical Center, and ADM Brett Giroir, Assistant Secretary for Health at the U.S. Department of Health and Human Services spoke at the ceremony about the great public health benefit the CCE will provide. From the development of chimeric antigen receptor (CAR) T-Cells used to fight cancer to bringing regenerative stem cell therapy for eye disease closer

to the clinic – excitement filled the Southeast patio during the event.

"This Center allows us to provide safe, innovative therapies and assess their effectiveness in Clinical Center patients," said Dr. Harvey Klein, chief of the Department of Transfusion Medicine. "This increased growth and sophistication of cellular engineering is not just for the patients that come here – it's to improve health for the American public."

In the Clinical Center, cellular processing capabilities serve intramural researchers from nearly all of the institutes that conduct clinical research in Building 10. Thirty-four clinical trial protocols, such as those that involve complex cell and gene therapy and complex hematopoietic stem cell transplants, rely on the CCE and by 2020, 12 more protocols are expected to

be up and running.

In 2000, the Department of Transfusion Medicine Special Services Laboratory had only one small room, and a handful of personnel with specialized cellular engineering capabilities to identify and alter cells for patients suffering from malignant or genetic diseases. Now, in 2018, the Cell Processing Section staffs 11 active rooms for cellular engineering as well as laboratories to develop and characterize novel cellular products. With the increased demand and desire of intramural researchers to investigate cellular therapies, the CCE anticipates providing 15 active rooms by the end of 2019 and 22 active rooms by 2021.

Read more about the event, including testimony from attendees and researchers who rely on CCE capabilities, online: <https://go.usa.gov/xP9bz>

## Virtual reality piloted in an NIEHS study for patients' extended stay

For many patients, the most difficult part of their protocol is not blood draws or testing, but the prolonged stay in a hospital. Dr. Adam Schiffenbauer, a National Institute on Environmental Health Sciences (NIEHS) principal investigator, is working to bring virtual reality to his patients' rooms to help make their stay just a bit easier. A headset, stereo sound, head motion tracking device and light-structured systems are needed for the virtual-reality experience.



Christopher Fortney (left) sets up virtual reality equipment while Dr. Adam Schiffenbauer observes patient Nicholas Rodriguez (right).

## Spices and social skills mix in cooking group for NIMH study participants

People with schizophrenia and related psychoses may struggle with social skills and pre-vocational skills like following directions and working with others. But there is one thing that can bring people together around the table – food. The NIH Clinical Center Rehabilitation Medicine and Nutrition Departments hold a weekly cooking group for these select patients admitted to the hospital for studies related to their psychoses.



Rachel Hingst, with the Rehabilitation Medicine Department, looks over the ingredients of a meal with Megan Schoenfeld, with the Nutrition Department.

# Healthcare advocate, parent of teen with chronic illness, speaks at NIH

Lisa Danielpour, a healthcare advocate and mother of a teen with Crohn's Disease, was the guest speaker at the 2018 NIH Health Information Technology Day at the NIH Clinical Center. She spoke about the Clinical Center's patient portal and how healthcare record-keeping technology has positively impacted her son's healthcare and the research about his illness.

Danielpour told the audience, in October, about her son Josh's journey. In 2014, he was a straight-A student, avid learner and competitive, athletic 13-year-old. But that year, "everything changed". In August 2014, Josh was diagnosed with Crohn's Disease, an inflammatory bowel disease. Over the next year, he would undergo six colonoscopies and endoscopies. Josh did not respond to treatment and became sicker and sicker. "He was in the hospital more than he was out," Danielpour said.

By February 2015, curled up in a ball with abdominal pain and fighting constant bouts of diarrhea, Josh told his parents he needed to go to the hospital. By this point, the inflammation from the disease had spread to his entire digestive tract. The specialists at their home hospital in Cleveland, Rainbow Babies & Children's Hospital, consulted with other gastroenterology experts around the country, but no one had seen a case like his, Danielpour said.

"To watch your child suffer [and] to know there is only so much medical science can do to help is beyond painful. We tried to think of anything we could do to help him and learn everything we could."

Josh was transferred by medical flight from his hospital in Cleveland to Children's Hospital of Philadelphia (CHOP). CHOP then consulted with NIH for help. The Danielpours were familiar with NIH – Josh's father, David, was a senior staff scientist at the NIH National Cancer Institute before moving to Cleveland in 1998.

Dr. Ivan Fuss, a National Institute of Allergy and Infectious Diseases staff clinician working in the NIH Clinical Center, recommended a new medication for Josh, and he slowly started to respond. After



Aaron, Josh, Lisa and David Danielpour at Josh's Bar Mitzvah in 2014.

a combined eight months at CHOP and Rainbow Hospital, Josh finally got to go home. In January 2016, Josh started to come in person to the NIH Clinical Center for treatment and saw Fuss as well as Research Nurse Kim Montgomery-Recht.

"We really appreciate all the care that he got," Danielpour said.

Unfortunately, this was not the end of his medical issues. A liver biopsy showed he was in the early stages of primary sclerosing cholangitis, a long-term progressive liver disease associated with Crohn's Disease. When Josh developed a limp in 2016, NIH specialists diagnosed avascular

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— Lisa Danielpour

necrosis, the death of bone tissue due to a lack of blood supply, in his right hip, most likely a side effect of steroids. Josh quickly had to have surgery elsewhere to mitigate the impact on his femur bone.

Throughout this experience, Danielpour has learned the importance and power of an online medical record.

"The personal health record empowers

the patient with access to information and enhances the patient's safety, communication and experience," she said. "For those with chronic illness or medical complexities, it helps you learn what to track and monitor and be able to do it for yourself."

"For those who are healthy, the personal health record helps to track preventative care. It's important for self-care and self-advocacy, but most of all it's a wonderful and powerful physician and nursing tool to motivate and engage patients and families in their own healthcare," she said. "The more that patients and families are looking at their own information and understanding it, not only are they playing a more active role as we want in patient-centric care, but also, it can save time for the medical professionals because you can focus more on the big picture ... and patients can better think about the questions they have ahead of time before seeing their doctors."

This is particularly powerful at the NIH Clinical Center where many patients and families are coming from locations across the country and around the world. Having easy access to medical records helps patients and families keep track of their own health care and ensure that doctors at home hospitals and NIH are up to date on their care and treatment.

"Josh, I am happy to report, is stable now and what a beautiful word stable is," Danielpour said. "He is doing great in school and getting back to as normal a life as possible."

Josh, who missed most of eighth and ninth grade, is now a 17-year-old high school senior who plans to attend Case Western Reserve University and major in biomedical engineering.

He is learning self-care and self-advocacy, more about his diseases and how to continue to take care of himself, she said. Danielpour thanked the doctors, research nurses and countless staff at the NIH Clinical Center who contributed to Josh's care.

"We're really grateful for the wonderful culture of care and research at NIH. You make all the difference for the patients and families that you see."

Read more online! Scan the barcode or visit [www.cc.nih.gov/about/news/newsletter.html](http://www.cc.nih.gov/about/news/newsletter.html)



- More than 77 gingerbread houses fill the atrium with holiday cheer
- Retired Navy Capt. Pius A. Aiyelawo, Clinical Center COO, speaks at Veterans Day
- Pediatric patients trick-or-treat in hospital

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## Clinical Center News

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## Staff honored for improving patient care and the workplace environment



From left to right, CAPT Richard Decederfelt, CDR Fortin Georges, NIH Clinical Center CEO Dr. Jim Gilman and Clifton Newell on stage at the CEO Awards (not pictured is Kim Lynch). The Clinical Center Pharmacy Department group were awarded for implementing controlled substances ordering system, making NIH the leader of all other government agencies in having first access to available narcotics during nationwide shortages.

In December, Dr. Jim Gilman, CEO of the Clinical Center, proudly presented awards to more than 400 NIH employees for their leadership in helping advance the Clinical Center's priorities of high reliability and quality patient care.

Staff were honored for accomplishments such as:

- handling nation-wide shortages of healthcare supplies and equipment to assure they were procured in a timely manner
- exemplary service provided to

research teams and patients for arranging urgent/emergent ambulance transportation for critically ill patients

- development and implementation of a new automated closed-system device for the manufacture of Chimeric Antigen Receptor (CAR) T cells;
- reducing patient harm by assuring the timely administration of STAT antibiotics using data analytics and rapid cycle improvement techniques.

Staff can view the program and award photos online: <https://go.usa.gov/xEKW9>

## Hospital electronic medical record validated in 2018 as HIMSS Analytics: Stage 7 certification

In 2018, the Health Information and Management Systems Society (HIMSS) Analytics re-certified the Clinical Center's electronic health record, known as Clinical Records and Information System (CRIS), with its highest certification on the Electronic Medical Record Adoption Model, Stage 7. The system is used for all patient care, research and administrative activity. CRIS originally secured Stage 7 in 2015.

The Electronic Medical Record Adoption Model recognizes organizations that work towards achieving a near paperless environment and use an electronic system for reporting scientific findings and analyzing patterns of clinical data to improve quality of

inpatient care, patient safety and care delivery. In addition, awardees must share clinical information via standardized electronic transmission with personnel authorized to treat patients.

Only a small percentage of hospitals out of the approximately 32,000 hospitals in the HIMSS Analytics database have attained a Stage 7 certification. The Clinical Center is the only federal organization to have earned this recognition. The hospital also earned an Outpatient Electronic Medical Record Adoption Model Stage 7 certification for having a completely electronic medical record and data analytics to improve care. Only 3% of health systems reviewed by HIMSS Analytics hold both certifications.

## Pencils down! New electronic performance management tool online in 2019

Starting in 2019, supervisors in the Clinical Center will be putting away their pens and paper and firing up their computers to establish their staffs' annual performance evaluations of federal employees. The electronic performance management appraisal program – ePMAP – will provide greater security, efficiency and accuracy than the paper versions. The ePMAP will be used for performance evaluations being established in 2019 and beyond – current employees must sign in the new ePMAP system no later than January 30, 2019. 2018 PMAPs will be closed out using the old process to avoid any confusion and disruption.

These annual evaluations, known as PMAPs within the Department of Health and Human Services, have a 5-tier rating system for federal employees. The filing process by managers can be time consuming and inconsistent; the lack of centralized filing practices means each department in the hospital manages their files differently.

"This is a really important change that will not only save time and effort for staff and supervisors, but also help ensure accuracy and timely completion of PMAPs" said Dan Lonnerdal, chief of the Office of Administrative Management at the NIH Clinical Center.

In late 2018, the ePMAP was piloted by the hospital's Office of Administrative Management, Nursing, Radiology and the Clinical Research Informatics Departments.

Recognizing the need for confidentiality, the program's developers focused on ensuring the security of employees' data. The ePMAP system is behind the NIH firewall to protect personal information and is certified under Federal Information Security Management Act guidelines.

Previously, a printed copy of an employee's PMAP could easily be forgotten on a desk or in a copier but now, only the employee, his or her supervisor as designated in the NIH Enterprise Directory (NED) and system administrators can see ePMAP records.

The process for logging on to ePMAP is simple. Staff will receive an email from the ePMAP system with sign-in instructions. Once the system is implemented, four years of prior performance evaluations will be saved digitally in the ePMAP system. After four appraisals, the system automatically disposes of the oldest employee performance records although longer retention is allowed if it is required for business use.

The Clinical Center will also help staff resolve any issues through an ePMAP email account – [ccepmap@cc.nih.gov](mailto:ccepmap@cc.nih.gov) – run by subject matter experts to provide rapid responses to questions or issues. Staff are happy to set up in-person training for anyone who needs it, as well. Visit: <https://go.usa.gov/xEKW9> (NIH staff only).

## COOKING *from page 1*

Rachel Hingst, an occupational therapist with the Rehabilitation Medicine Department, conducts the cooking group for four to eight participants in the department's kitchen area. The group focuses on teaching participants the mechanics of preparing meals.

"A lot of the participants struggle with weight gain due to their medications. It can be very discouraging," Hingst said.

This is where the collaboration with Megan Schoenfeld, a dietician with Clinical Center's Nutrition Department, comes into play. Schoenfeld and Hingst work together to develop healthy menus for the classes.

"We focus on increasing vegetables in meals and replacing higher-calorie ingredients with healthier options," Schoenfeld said. They also talk about resources that research participants can access at home like myplate.gov.

Sometimes, this means finding healthy substitutes for foods the research participants already eat. For example, in a recent class, participants learned how to make a healthy pizza. The class used vegetables as toppings, lower-fat ingredients and whole wheat dough and discussed adjusting portion sizes and adding a salad to the meal, Schoenfeld said.

Participants said, "I like learning how to cook and enjoy myself," and "I enjoy cooking with others." Other classes have provided easy to duplicate recipes like sheet-pan meals, nutritionally-balanced meals made on a sheet pan, such as cashew chicken and chicken fajitas.

"We try to find the balance between healthy and indulgent foods," Schoenfeld said.

"It is not practical, and it's not realistic to just tell people they cannot eat certain foods," Hingst added.

Group participants are asked for their input on future class meals. Recipes selected for the classes are easy to follow and do not require hard-to-find or expensive ingredients. It is very important that the participants be able to duplicate the recipes at home, Schoenfeld said. "Quick healthy eating on a budget."

The group has the added bonus of encouraging patients to try new foods, she said.

"I think [our participants] find they actually like foods that they did not think they would," Hingst said.

Hingst and Schoenfeld educate about healthy eating habits during class, but the participants do all the work. They discuss the recipe, decide who in the group will complete the various tasks needed to make the meal and then they make the meal, Hingst said. Afterwards, they all sit down together to share the meal they have made.

One of the intangibles of the class is that it helps improve the attendees' self-image as it helps them to know how to eat healthier and provides them with skill sets they did not previously have, both agreed.

"I learned how to make coffee," commented one participant. "Cooking group challenges me because of the many steps involved," added another.

People living with schizophrenia and related psychoses "often don't have a lot of opportunities to feel successful, so they take a lot of pride in successfully completing these meals," Hingst said.

## Redesign brings fresh look, added light to NIH's Safra Family Lodge



While HGTV didn't make their way on campus in 2018, another four letter group did – the FNIH – and the results are beautiful. New paint, updated wallpaper and an abundance of beautiful upholstery has brought a breath of fresh air to the NIH Clinical Center Edmond J. Safra Family Lodge.

Completed in late 2018, the redesign of the lodge was accomplished through the support of The Foundation for the NIH (FNIH), including FNIH Board Member Mrs. Lily Safra, and The Edmond J.

Safra Philanthropic Foundation, in partnership with the NIH.

After a long day at the hospital, many patients who are stable enough to leave the unit, and their family members, take the shuttle or make the short walk to the lodge – for overnight accommodations. Over the summer of 2018, all 34 guest rooms and public areas, including the library, business center, activity room, lounges and fitness room were updated. Learn more and view before-and-after photos: <https://go.usa.gov/xP9bz>

## NIEHS VR *from page 1*

"NIH scientific groups have been using virtual reality for research purposes to reduce pain and to assist in rehabilitation medicine," Schiffenbauer said. "We're trying to bring it to our patients' room to improve our patients' happiness."

The system must work with the patient's physical limitations, if there are any, and provide a wide array of scenarios or experiences no matter the patient's age.

In August 2018, Schiffenbauer piloted the virtual reality experience with Nicholas Rodriguez, who participated in a study for calcinosis associated with dermatomyositis and juvenile dermatomyositis. Calcinosis, a disease in which calcium salts collect in or under the skin, muscles or tendons, can be painful and cause disabilities and other problems. Rodriguez is receiving a trial drug for this disease, which has no FDA-approved treatments at this time. As part of the study, he receives intravenous infusions for 10 weeks, three times a week.

Rodriguez had several virtual reality experiences – watching whales, painting and interactive music.

"The virtual reality experience allows you to go places and do things you could otherwise not do. It's a useful tool that can bring patients happiness," Rodriguez said.

A number of staff collaborated to make this virtual reality experience possible. Christopher Fortney with the NIH Library arranged for the set up and running the equipment. NIEHS Nurse Practitioner Dr. Rita Volochayev researched virtual reality for meditation and relaxation and contributed her expertise toward patient care.

In the future, with the help of Debbie Gutierrez from the Clinical Center Nursing Department, Schiffenbauer hopes to be able to test the virtual reality with patients for his protocol within a double occupancy room to make sure each patient can use it without disturbing the other by using built-in headphones.