

- Employees deploy after hurricanes hit
- Life without a stomach: a patient's perspective
- 2017 Gingerbread House Contest winners



## Clinical Center

# CEO honors dedicated staff for 2017 accomplishments

Dr. James Gilman hosted the 2017 CEO awards for the Clinical Center Dec. 15 to recognize employees and contractors who by their leadership, achievements and high reliability mindset served as a beacon to their colleagues and brought the hospital closer to achieving its organizational mission and goals.

Approaching his one-year-mark as the first CEO of the Clinical Center, Gilman

was excited to honor awardees, 42 individual award recipients and 300 recipients in group awards.

"I love giving out group awards because I believe healthcare is all about teamwork," he said. "What we do together is so much more powerful than any of us can do ourselves."

Awards recognized improving the accuracy of provider assignment to inpatients,

improving the performance of code blue and rapid response teams, decreasing critical IT vulnerabilities by more than 90%, and developing a new strategy for informed consent when conducting studies of standard of care interventions in emergency settings, among many other initiatives.

Staff can view photos (<https://tinyurl.com/y7y4wlqc>) and download the program (<https://go.usa.gov/xnpB6>).



Clinical Center CEO Dr. James Gilman, left, presented awards for employees dedication to the hospital and patients. Center, awardees are honored for developing a procedure for post operative monitoring of patients with obstructive sleep apnea. Right, Colleen McGowan, Clinical Center Executive Officer, congratulates Dennis Johnson. He, along with fellow colleagues from the Radiology and Imaging Sciences Department, were honored for the development and implementation of an electronic system to prescribe technical procedures for CT scanning.

# New pediatric observation unit enhances patient safety, care

The NIH Clinical Center leadership, staff and patients gathered to celebrate the opening of the new special pediatric observation unit in late November.

The Pediatric Observation Unit is located in 1 NW and will provide additional support for patient safety in pediatric research, said the unit's inaugural chief, Dr. Zena Quezado. Quezado is a seasoned professional in pediatric anesthesia who spent the past seven years at the Children's National Medical Center in Washington, D.C. She is a familiar face in the Clinical Center, serving as a fellow in the Critical Care Medicine Department and later as the chief of anesthesiology.

The unit has monitored beds that will allow for enhanced cardiopulmonary, neurologic and metabolic monitoring of pediatric patients who are in need of closer clinical observation. It is a pediatric research facility that is able to accommodate younger and sicker children, enhancing the hospital's medical and nursing staff's ability to care for more

fragile pediatric patients.

Dr. Deborah Merke, a senior investigator and chief of the Pediatric Service, said, "This new initiative is the culmination of many years of hard work by many people and represents support and recognition that intervening early in life and including children in the groundbreaking research that occurs at the NIH Clinical Center is essential as we strive to enhance health, reduce illness and reduce disability."

The Clinical Center has a notable history for advancing pediatric medicine including discovering the causes of and developing the first treatments for childhood leukemia, developing early treatments for pediatric HIV and the first pediatric gene therapy for children with an inherited disorder that damages their immune system.

About 30-40% of the clinical research protocols enroll children and about 13%



Barbara Jordan, Krista Cato, Dr. Zena Quezado, Dr. Deborah Merke, pediatric patient Hadi and Dr. James Gilman, NIH Clinical Center CEO, cut the ribbon on the new Pediatric Observation Unit Nov. 27.

of patient care activities are for children and adolescents.

"As we expand our resources in pediatrics, we optimize the safety of our current patients and also open the doors to new and exciting possibilities," Merke added.

# Life without a stomach: a patient's perspective on preventative surgery, advancing stomach cancer research

When David Fogel had a stomach, his fast-paced life was focused on expanding Bump 'n Grind, his coffee shop and record store in downtown Silver Spring, and managing a creative agency and two co-working spaces. Incorporated into his busy schedule was raising his two little sons with his wife.

Early in October 2016, a family member who is also a gastroenterologist contacted David's father and said, "We think that 15 years ago, your sister passed away from stomach cancer caused by a gene mutation. Because this gene mutation is hereditary, you guys should probably get tested to see if you also have it." David, and two other members of his family followed the recommendation and together went to a genetic counselor for testing. While the results were negative for David's family members, David's tests were positive for the gene mutation.

He was diagnosed with hereditary diffuse gastric cancer (HDGC) caused by a mutation in his CDH1 gene. Having HDGC does not always mean that a person actually has cancer. But, it can mean, as in David's case, that the risk of getting diffuse gastric, a rare cancer representing approximately 2% of all stomach cancers, increases to almost 80%.

David and his family talked to many doctors and specialists about his options and learned that in its early stages, diffuse gastric cancer has no specific symptoms and does not form a tumor that can be seen with screening. However, by the time that symptoms develop and screening tools can detect a tumor, the cancer is often at a very advanced stage and with a poor survival rate. All of the possibilities that he explored ended with the recommendation that people with the CDH1 gene should have their stomach removed before the cancer can develop.

David's search for options and answers led him to Dr. Jeremy L. Davis, a principal investigator on gastric cancer clinical studies and a surgical oncologist at the National Cancer Institute (NCI). Davis is also the surgeon-in-chief at the NIH Clinical Center and a member of the NIH Foregut Team (<https://go.usa.gov/xnEvQ>), research and clinical experts who work together to provide comprehensive patient care for esophageal,

stomach, pancreas and bile duct diseases.

David shared his emotions, "I felt incredibly fortunate to be able to enroll in a clinical study at the NCI and have the surgery done at the NIH Clinical Center. Working with Dr. Davis and his team was comfortable and reassuring. At the Clinical Center, nothing was pushed on me or rushed and everything was very transparent. This was a very different

***"Hopefully my stomach will help doctors to better understand the CDH1 gene mutation and discover a preventative treatment or cure."***

***- David Fogel***

experience than what I experienced when I started this journey with other hospitals and medical teams. Hopefully my stomach will help doctors to better understand the CDH1 gene mutation and discover a preventative treatment or cure."

It took around five hours for Davis and his team to completely remove David's stomach and attach his esophagus directly to his small intestine. The day after the

surgery, David was up and walking and taking some sips of water to make sure that his reengineered digestive system was in working order.

"I wouldn't say any part of the recovery has been debilitating. However, the challenge is slowing down and changing what and how I eat," David said.

Without a stomach, the process of breaking down food must begin in your mouth, in tiny amounts at a time. The small intestine then completes the job of breaking down food and extracting the nutrients. David used to only eat two large meals each day. Now, he has a watch with an alarm that reminds him to eat every two hours.

"I'm constantly nibbling and trying to make sure that I eat enough calories and protein so that I don't end up losing too much weight", David explained. "My new daily diet currently consists of: two scrambled eggs in the morning, a couple of cheese or peanut butter sandwich crackers, shepherd's pie or chicken pot pie for lunch, a protein shake; salmon or chicken for dinner, maybe peanut butter and apples for dessert, and iron, calcium, and B12 supplements."

He is also learning to be extra careful with reading food labels because he cannot eat anything with sugar listed in the first three ingredients. Sugar causes food to move too quickly through the small intestine and can cause severe symptoms including dizziness, rapid heartbeat, pain, cramping and weakness.

David shared his optimism on his new life without a stomach, "When I look at where I am right now, I thought my life without a stomach would have been a lot more disrupted than it has been. While I don't have the same level of energy that I had pre-surgery, I know that it will return. I'm eating a much better diet and I feel really fortunate to be alive. My aunt who passed away from stomach cancer at the age of 56 did not have this option that was presented to me. While I'm not a religious person, I do believe that my aunt and grandmother have been with me, looking down at me during this entire process: happy, thankful, and cheering me on."



David, seen above with his wife and sons, was featured on NBC Washington, along with his care provider Dr. Jeremy Davis. View the segment: <https://tinyurl.com/y9wlkfsa>

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)



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## Clinical Center News

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Clinical Center

## Upcoming Events

**NIH Clinical Center Grand Rounds: Deep Phenotyping of a Family with Nodding Syndrome from Uganda at the Clinical Center: A Feat in Multi-Institutional Collaboration; Nodding Syndrome is an Autoimmune Encephalopathy Caused by Onchocerca Infection.**

Jan. 24, 2018, 12:00 p.m. — 1:00 p.m.  
*Lipsett Amphitheater*  
Presented by Ariane Soldatos, MD, NINDS/NHGRI and Avindra Nath, MD, NINDS.

**Autotherapies: Enhancing Our Innate Healing Capacity Symposium**

Jan. 25, 2018, 8:00 a.m. — Noon  
*Lipsett Amphitheater*  
Presented by Martha Somerman, PhD, NIDCR; Lawrence Tabak, PhD, NIH; Jeffrey Karp, PhD, Harvard Medical School, Janice Lee, MD, NIDCR; Edward Botchwey, PhD, Georgia Tech and Emory University; Robert Ferris, MD, University of Pittsburgh Medical Center.

**NIH Clinical Center Grand Rounds: Precision Medicine with DNA-targeted Therapies and the Emerging Role of SLFN11**

Jan. 31, 2018, 12:00 p.m. — 1:00 p.m.  
*Lipsett Amphitheater*  
Presented by Yves Pommier, MD, NCI.

**NIH Rare Disease Day**

March 1, 2018, 8:30 a.m. — 4:00 p.m.  
*Masur Auditorium*  
RDD aims to raise awareness about rare diseases, the people they affect and NIH research collaborations to advance new treatments. Attendance is free and open to public. Registration: <https://goo.gl/BJexYA>. To display a poster or exhibit, please include in your registration form. Tours of the CC will be available.

## Training

**Principles of Clinical Pharmacology**

The 2017-2018 Principles of Clinical Pharmacology course is now accepting registrations through Jan. 22, 2018. The free lecture series covers the fundamentals of clinical pharmacology as a translational scientific discipline. Topics include pharmacokinetics, drug metabolism and transport, drug therapy in special populations, assessment of drug effects, drug discovery and development, pharmacogenomics and pharmacotherapy. More details: <https://go.usa.gov/xnEv6> or email [cc-od\\_clinp@mail.cc.nih.gov](mailto:cc-od_clinp@mail.cc.nih.gov)

## Nearly 70 gingerbread houses on display, decorating contest winners announced Dec. 15



Left, is the 1st place Paper Ballot Winner “3 NE Nursing Unit, NIH Clinical Center” and right, is the Facebook Winner “Section on Skeletal Disorders and Mineral Homeostasis, National Institute of Dental and Craniofacial Research.”

The Clinical Center’s 14th Annual NIH Gingerbread House Decorating Contest drew 69 entries and countless smiles. Created by NIH staff, the entries – 14 more than last year – ranged from movie themes such as Moana, Beauty and the Beast and Harry Potter to medical-related

messages about ongoing research and diversity in research.

The houses were judged by employees, patients and visitors with paper ballots and on Facebook. View all of the images on the Clinical Center Facebook (<https://tinyurl.com/ycnhw766>).

## C.A.R.E. Channel provides relaxing imagery, music

Being a world class research hospital means continuously enhancing our world class environment of care. That now extends to offering specially designed, relaxing television programming called The C.A.R.E. Channel.

The channel’s name is an acronym for “Continuous Ambient Relaxation Environment.” View it for free on channel 08 anyplace the Clinical Center cable system is operable.

Running 24/7, it features nature imagery during the daytime and transitions to a moving star-filled sky during the overnight, accompanied by original instrumental music designed to be soothing and relaxing.

“When a project involves improving our patients’ experience, it’s never a hard sell to get Clinical Center staff excited to team up and make it happen,” said John Pollack, chief of the Department of Spiritual Care.

The C.A.R.E. Channel is brought to the Clinical Center through a collaboration between the Departments of Spiritual Care and Nursing. The programming runs 84 hours before repeating itself, fitting for extended stays common to the Clinical Center.

The channel is a tool that for some pa-



The C.A.R.E. Channel provides a healing environment to patients and their care providers. Images can be seen on hospital TVs or downloaded from [www.healinghealth.com](http://www.healinghealth.com).

tients may help reduce anxiety, assist with restfulness and offer a positive focal point when in discomfort.

The relaxing images may help calm nerves in clinics and waiting rooms. Outpatients and caregivers may wish to tune in as they wind down in the Safra Lodge from a hectic appointment slate. Or inpatients may find it a welcome alternative if they don’t wish to or are unable to follow news and plot-driven shows. The possibilities are many — whether to add serenity or just drown out hospital noise.

Questions about the Clinical Center’s broadcasting of the C.A.R.E. Channel? Email John Pollack at [john.pollack@nih.gov](mailto:john.pollack@nih.gov)

# From the Clinical Center to a disaster zone

## Public Health Service professionals help after hurricanes hit in 2017

When a life-threatening storm is bearing down, most people wouldn't think of the NIH Clinical Center. But employees who work in the hospital were among the many responders helping Americans devastated by hurricanes in 2017.

The National Oceanic and Atmospheric Administration predicted that 2017 would be an active hurricane season, and storms hit many parts of the continental United States and Caribbean territories with Hurricane Harvey landing in Houston, Hurricane Irma hitting Florida and the Caribbean, followed by Hurricane Maria whose destructive power left Puerto Rico without power.

Soon after the first storm made landfall, officers of the U.S. Public Health Service who work in the Clinical Center were activated to provide support. Overseen by the Surgeon General, the U.S. Public Health Service Commissioned Corps is a diverse team of more than 6,500 public health professionals. They fill essential public health leadership and clinical service roles with the nation's federal government agencies, including the NIH.

Daniel Goldstein, a physician assistant and commander in the U.S. Public Health Service, works in the Clinical Center for the National Heart Lung and Blood Institute (NHLBI). Goldstein has seen the impact of extreme weather events before, having been deployed to help in the recovery of New Orleans after Hurricane Katrina hit in 2005.

This time he was assigned to a new mission in the U.S. Virgin Islands. He travelled through all three of the islands that make up the territory, but spent most of his time between the east and west parts of St. John, supporting an urgent care center and providing medical care at temporary shelters. The treatment he provided was critical as the area's hospital was destroyed.

The Virgin Islands had planned ahead, flying out their most critically ill patients before the storms hit, so relief efforts focused on urgent care medical services, particularly treatment of fractures, infections, and medication refills.

Adapting to the situation required that we "be flexible to the mission and expect the unexpected," said Goldstein.

Despite their hardships, he said the residents of the Virgin Islands have a "close community" and it was great to see "people looking out for each other" even in such a time of turmoil.

Cmdr. Ulgen Fideli, also a U.S. Public Health Service physician assistant with NHLBI in the Clinical Center, was deployed to Florida to help people who had kidney failure, and required dialysis treatment.

Fideli knew a lot about kidney disease as her father had received dialysis treatment for years before passing away earlier this

year. When Fideli saw the news coverage of the hurricanes, she said "I knew I had to do something."

Fideli traveled to Atlanta and from there he was deployed to Miami. The patients she saw weren't from Florida, however. They were evacuees from the U.S. Virgin Islands.

These were full care patients, a sick population who had chronic diseases and mobility issues, said Fideli. Not only did they have health issues, but they had gone through multiple displacements from their homes to temporary spaces in Puerto Rico and finally to a shelter in Miami. Along the way many lost their bags and medications. According to Fideli, the travel and uncertainty was "taking a toll."

Despite the challenges, there were some uplifting moments. "We would see the same people every day and developed a sense of camaraderie," she said. The security guards at the shelter introduced the staff to Cuban coffee, served in tiny but potent cups.

The day after Fideli's deployment ended, she received word that the residents of the shelter had been moved again, this time to Federal Emergency Management Agency housing in Atlanta.

Seeing so many vulnerable people going through so much hardship was really "humbling," reflected Fideli. "It puts everything in perspective when you come back."

Lt. Melanie Webb, a nurse who works in the NIH Clinical Center's Office of Patient Recruitment, was deployed to Ponce in the southern part of Puerto Rico about two hours from the capital of San Juan. Flying to Ponce, Webb saw the extent of the island's destruction out of the plane's window.

Webb worked in an 80-bed field medical station based in a repurposed basketball stadium, the most stable building in the community, despite its leaky roof.

The patients they served would typically have received home care but they were displaced because of the storm. Due to the overwhelming damage to the community, the care Webb and others provided often extended not just to the patient but to their whole family.

On a regular basis, Webb and her colleagues would conduct "strike missions" where they would travel by military vehicles to bring medical assistance to communities isolated by the damage. They helped treat minor wounds, replenish supplies of medications and, when needed, transported people in medical crisis back to the field hospital.

For Webb, the destruction of homes and infrastructure was truly stunning.

"Usually we treat patients and send them back to the community," said Webb. "But there was no community to send them back to."



Cmdr. Daniel Goldstein treats a patient in the U.S. Virgin Islands.



Cmdr. Ulgen Fideli provided health care for evacuees from the U.S. Virgin Islands in Miami, Florida.



Lt. Melanie Webb (center) was stationed in Puerto Rico and traveled by military vehicles to bring medical assistance to communities isolated by the damage.