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## Volunteers photograph pediatric patients with life-threatening diseases

It has been said, "A picture is worth a thousand words." To some families at the NIH Clinical Center, a picture is worth a lot more.

Since 2015, the Clinical Center has invited the non-profit group Flashes of Hope to photograph pediatric patients who are treated at the hospital. The photo sessions in Building 10 began when one of the Clinical Center pediatric nurses was talking to colleagues about her experience with Flashes of Hope at her previous job at a hospital in Florida. Soon after, the first photo session was arranged in August 2015.

Flashes of Hope was started in 2001 in Cleveland, by Allison and Kip Clarke. The Clarkes' 18-month-old son, who was battling cancer, had befriended another ill child while undergoing treatment.

"During that time, you meet a lot of other sick kids and families because you're at the hospital all the time. My son and I became friends with a boy who passed away. I was thinking how nice it would have been to have [had] a photograph of him, one that captured his special spirit. In

an instant, the whole idea for Flashes of Hope was there," said Clarke in an interview on ladieswholaunch.com.

The photo sessions take place in the Clinical Center Pediatric Clinic multiple times a year, and the non-profit tries to create an environment that is unique to each child. Each sitting is different, with solo portraits or pictures with family, friends or even a favorite caregiver. All of the photographers are volunteers, and the photo packages are provided free of charge.

After each session, the family is presented with an 8 x 12 mounted photo, 4 x 6 photos from the sitting and a personalized weblink where the photos can be downloaded by the family. Fifty-three Clinical Center patients have participated in photo sessions since the partnership's inception.

Melissa de Araujo Vieira, a 15-year-



Melissa de Araujo Vieira, poses with her mother and father, during a Flashes of Hope photo shoot. Her pink hat, which she brought with her from Brazil, is her favorite accessory.

old patient from Brazil participating in a severe aplastic anemia trial in the NIH Clinical Center, said that her photo shoot was "very cool."

"What they do is very beautiful because it distracts people from what's happening," she said.

PHOTOS page 3

## New York first responder faces his own emergency

### *Unexplained weight loss leads to antibody treatments at the NIH Clinical Center*

Most people feel a sense of relief when they have lost some weight. For Sean Muranelli, age 36, each step onto the scale was a worrying reminder that his life was at risk.

Muranelli, a nine-year veteran of the New York City Fire Department, first knew something was wrong when he felt a lump on his neck while taking a shower. Unnerved, he went to see his doctor who had the lump analyzed. His diagnosis: metastatic adenocarcinoma, a cancer of the duodenum — the first part of the small intestine that connects to the stomach. According to the National Center for Biotechnology Information, this rare cancer represents 0.3% of all gastrointestinal tract tumors. The five year survival rate of duodenal cancer is less than 30%.

Muranelli worked with his doctors in New York to treat his cancer, but, un-

fortunately, the chemotherapy failed. Meanwhile, the number of lumps grew from one to eight. And, as the weeks progressed, he eventually lost 55 pounds from his 180 pound frame.

"My body was going haywire," said Muranelli.

Weight loss is only one of the symptoms of adenocarcinoma. Other signs can include pain in the belly, weakness, fatigue and anemia (low red blood cell counts) and swollen lymph nodes which can lead to lumps on the neck. As the weeks passed, Muranelli found himself getting weaker and weaker as the cancer progressed.

With stark ramifications facing him, Muranelli began to search for an alternative treatment that could address his cancer. He began calling researchers throughout New York in the hopes of find-

ing an effective treatment. Unfortunately, none of the medical facilities were able to help him.

He began to expand his search throughout the East Coast, calling at least "fifty different places." Finally, after a call to Johns Hopkins University to inquire about a clinical trial, he was referred to the NIH.

Muranelli kept his expectations low after his unsuccessful treatment and more rejections than he cared to remember. But, he knew his time was running out.

In November 2015, Muranelli came to the Clinical Center for assessment and medical testing. His tumor was studied, and, since it showed specific genetic markers that matched the criteria researchers were looking for, he was enrolled in a clinical trial (<http://go.usa.gov/xYSpB>).

FIREFIGHTER TREATMENT page 3

# Calm waters, colorful fish continue to dazzle patients and their families

In between medical exams and doctors' appointments, patients and their guests can take a break from biomedical research by simply walking by one of the seven aquariums in the NIH Clinical Center – transporting them to life on a coral reef or a tropical Amazon flooded forest.

Since 2007, Joseph Farmer, a contract employee, has cared for the aquariums, which hold a combined total of 615 gallons of saltwater and 405 gallons of freshwater.

"I hope they inspire curiosity and help patients, staff and visitor relax," he said. "I've just added a full spectrum lamp to the Admissions aquarium, and I'll be introducing some live coral at some point soon! In the coming months I will also be updating and restoring some of the information signage on the first floor aquariums - a few of the fish species have changed."

The outpatient aquariums include a tropical Pacific marine tank in Admissions, a tropical freshwater Amazon flooded forest biotope tank in Phlebotomy, a tropical Pa-

cific marine living coral reef in Radiology, tropical freshwater African rift valley cichlids tanks in Pediatrics and the 8th floor Infectious Diseases Clinic, a tropical Pacific marine tank in the 13th Oncology/Dermatology Clinic and a tropical freshwater tank in the Outpatient Surgery waiting area.

"The fish will relax and emerge from the rocks more if viewers don't approach too quickly and simply watch them," Farmer said. "Many fish, particularly tropical marine reef fish, are curious of larger organisms - so, don't be surprised if they come out and watch you as well."

Polina, a 7-year-old patient participating in a Eunice Kennedy Shriver National Institute of Child Health and Human Development trial, gazed at the fish near admissions in June. She said watching the fish here reminds her



Pediatric patient Polina, above, watches the fish near Admissions in the Clinical Center. For more photos, visit CC News online: <http://go.usa.gov/xqyNF>

of home overseas, where she has her own aquarium. While the clownfish was her favorite, seeing so many different fish in the CC made her happy, Polina said.

There's an estimated 120 fish and several invertebrate species combined, including shrimp and starfish, and a dozen coral colonies.

## NIH StoryCorps audio stories now available

The NIH, in partnership with StoryCorps, has released 23 audio stories of those within the NIH community. The stories, posted online, join six stories already released in 2015. StoryCorps, a national oral history project, provided the recording opportunity in the Clinical Center and at Vanderbilt University Medical Center in 2014 and 2015.



Laura McNay, from the National Institute of Allergy and Infectious Diseases, participated with Patrick Faley, a Liberian Ebola survivor.

The collection includes stories from patients, loved ones, researchers, doctors, NIH staff and grantees and others. They explore many facets of medical research: from the joy of saving lives to the pain of losing someone; and from the stigma associated with disease to the bonds that form between patients and caregivers.

Hear the stories: <http://go.usa.gov/xCXzR>.



Arthur Cain, seen above, is one of 20 employees who staff the data center 24-hours-a-day, seven-days-a-week.

As the weather heats up outside, the Data Center three levels down in the Clinical Center basement stays a comfortable 68 degrees. The servers, seen above, run the clinical applications that allow care providers to quickly pull up an x-ray scan, put notes in a patient's medical record, view test results, etc.

With redundant cooling, networking and power options, it's rare that staff will ever experience an interruption in the patient care network – an emergency generator can kick on in 13 seconds! Within the center lies almost 20 miles of wire – enough to circle the perimeter of the NIH campus more than seven times!

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)



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.

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## FIREFIGHTER *from page 1*



Sean Muranelli (third from left) gathers in the NIH Clinical Center with his care team (from left to right) Dr. Tim Greten, Donna Mabry, Dr. Austin Duffy, Melissa Walker and Suzanne Fioravanti.

The trial uses an antibody called MK3475 to fight diseases. He received his first treatment of the therapy on the same day that he arrived at NIH.

MK3475, also known as pembrolizumab, is an antibody that activates T-cells – a type of white blood cell that circulates around the body scanning for cellular abnormalities and infections. The therapy is intended to eliminate cancer tumor cells.

In the two months before his arrival at the Clinical Center, Muranelli was on powerful medications to address his pain.

Throughout his life, Muranelli had suffered broken bones and had needed stitches before, but these injuries were “nothing compared to the pain” in his stomach.

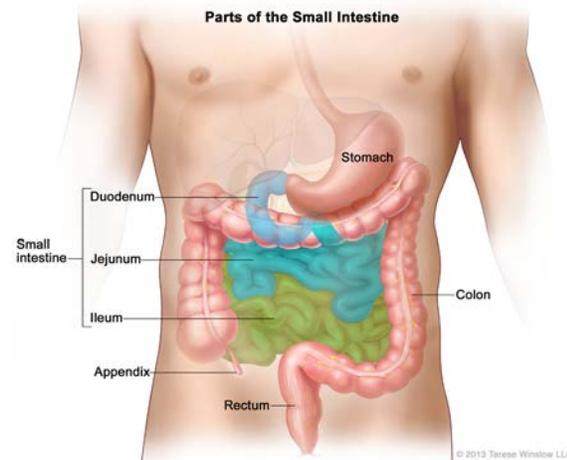
He knew that he was headed in the right

direction when, within one week of his first antibody infusion, he no longer needed the pain medication.

After a month of treatment, he began to gain strength. Soon, Muranelli was able to drive himself the three-and-a-half hours from New York to Maryland and is now almost back to his pre-diagnosis weight. An avid scuba diver, Muranelli was even able to return to the ocean sport, much to the surprise of his doctors.

Dr. Tim Greten, head of the Gastrointestinal Malignancy Section for the National Cancer Institute’s Center for Cancer Research Medical Oncology Branch, was a part of Muranelli’s health care team.

He described the firefighter’s dramatic turnaround after treatment as “one of the



The small intestine connects the stomach and the colon. It includes the duodenum, jejunum and ileum. Photo courtesy of the National Cancer Institute. Illustrator: Terese Winslow

best I have ever seen.”

What’s even more promising is that these results are in line with the research being conducted at the Clinical Center. Greten emphasized that recoveries are “quite common for patients with his disease and [these] specific...genetic markers in the tumor.”

While his journey is far from over, Muranelli has made dramatic progress over the last six months and is upbeat about his experience at NIH.

“They just care; they really do,” said Muranelli about his experience with the staff working at the Clinical Center. “They’re finding cures and saving lives.”

## PHOTOS *from page 1*

“It’s not easy to receive all these medications and the bone marrow transplant. At the time that we had the photos done my hair was starting to fall out because of chemotherapy so I think it was good to have these last photos of me with my old hair. The photos makes you feel even a little bit important. It makes you feel like a model. You just feel like you’re normal.”

Melissa’s mom, Noemia Rocha De Araujo Vieira, said that she’s glad they captured that moment in time “because it’s important to keep in mind what you had, and how you are now. And that she knows that she is still beautiful.” Melissa’s father, Mauro Cesar Vieira, added that the photo shoot was “very important not only for the patients but for everybody. Even the parents can feel better seeing the smile on her face. I feel very happy.”

Melissa’s family sent photos back to their relatives in Brazil and, according to Noemia, they helped show that, “We are here and in treatment but we are ok. We are enjoying our time here and doing what we need to do and know that it’s the best

way to find what we are looking for.”

Earlene Hollerith, mom of 6-year-old patient Leah Hollerith who is also being treated for severe aplastic anemia, participated in Flashes of Hope and thought it was a great experience.

“This was a fun thing to do. It was really exciting for Leah. It just made her feel very special that the attention was on her and we were getting these pictures to bring home.” Hollerith said. “She was usually in pajamas and it was hard to get her change. The photo shoot was a reason for her to get out of bed and actually put on one of her dresses that she loves and do her hair. This was before the transplant because she had pigtails and she hadn’t gone through conditioning yet. To have a family picture together where she’s happy and goofy is awesome. She was able to be a normal 6-year-old.”

Dr. Lori Wiener, co-director of Behavioral Health Core and director of Psychosocial Support and the Research Program for the Pediatric Oncology Branch at the National Cancer Institute’s Center for Cancer Research, coordinates the Flashes of Hope

program visits to the Clinical Center. Karen Post, the Washington, D.C. chapter president of Flashes of Hope, manages the program in the local area with collaborations at the Clinical Center, Children’s National Medical Center and Georgetown Hospital.

This program “does several things for the children: it gives the kids a chance to ham it up, not think about the fact that they’re sick and focus on fun. It’s also a gift for the families. The photographers capture images of the kids so they can see themselves as beautiful and strong. The pictures capture the courage of kids and what they’ve been through,” said Post.

While Flashes of Hope is noted for the pictures its photographers produce, Post emphasized that the organization also raises money for treatment and research into pediatric cancer.

The number of participating patients has grown exponentially from August 2015, with 18 people at the most recent one-day photo shoot. Clinical Center patients and families interested in participating in the program contact Wiener at [wienel@mail.nih.gov](mailto:wienel@mail.nih.gov).

## Lab Safety at the NIH



**1**

**BIOSAFETY LEVEL** **2**

**3** **4**

**5**

Material	Cell or Tissue	Why?	Room	Cell Phone	Home Phone
Entry or Access					
Emergencies					
Emergencies					

Many labs in the NIH Clinical Center have a sign posted on the door to warn of potential hazards and the proper personal protective equipment necessary to go inside. Before entering, understand the precautions and follow the action items to protect your health and others.

### 1. Biohazard Symbol

Before entering a lab space, keep an eye out for the biohazard symbol. The symbol warns employees and other visitors about biological hazards and the precautions needed to protect those who enter. Biohazards can include medical waste, microorganisms, viruses or toxins that can affect human health.

### 2. Biosafety Level

The Biosafety Level (BSL) describes the containment level needed for work in a lab. Precautions increase as BSL increases. The CC has BSL 1 and 2 labs.

### 3. Biohazardous Agents

Take note of the biohazardous agents that are listed on the sign. In NIH labs, the most common biohazards present are human blood and/or body fluids. Their presence would designate BSL 2.

### 4. Procedures and Precautions for Entry

All procedures on the sign, including the donning of personal protective equipment (PPE), must be followed. PPE is worn to protect the main routes of microbe exposure: skin, inhalation, eyes, nose, mouth and ingestion.

### 5. Contact Info

The Principal Investigator of the study or the Laboratory Manager should be the contact on the sign. At least one phone number listed should be a 24-hour emergency contact number.

## Clinical fellows network with NIH senior staff



Dr. John I. Gallin, Clinical Center director (second from left), talks to fellows from the Hematology-Oncology Fellowship Training Program supported by the National Cancer Institute and the National Heart, Lung, and Blood Institute.

The NIH Clinical Center welcomed 82 incoming clinical fellows from across the country at a reception held on July 12 hosted by the Office of Clinical Research Training and Medical Education. The fellows networked with Drs. Francis S. Collins and John I. Gallin in addition to institute directors, intramural scientific and clinical directors, training program directors, NIH principal investigators and Clinical Center administrative staff.

Clinical fellows develop competence as medical, surgical or dental specialists and collaborate with internationally recog-

nized mentors to conduct cutting-edge, patient-oriented research as they engage in conducting a variety of investigational protocols at the Clinical Center.

The Clinical Center sponsors 17 medical/surgical specialty or subspecialty training programs authorized by the Accreditation Council for Graduate Medical Education. Additionally, the NIH supports numerous one-of-a-kind clinical or translational research fellowship training programs within its constituent institutes.

Learn about graduate medical education at NIH: [www.cc.nih.gov/training](http://www.cc.nih.gov/training)

## Jose Galvez named chief of BTRIS, NIH bioinformatics system

In July, the Clinical Center welcomed Dr. Jose Galvez as the new chief of the Biomedical Translational Research Information System (BTRIS). Prior to joining the Clinical Center team, Galvez served as program director of Clinical and Translational Informatics with NIH's Center for Biomedical Informatics and Information Technology.

BTRIS is a resource available to the NIH intramural community that brings together clinical research data from the Clinical Center and other NIH Institutes and Centers. In addition to labs and medication data, users of the system can run protocol-specific reports on demographics, diagnoses, clinical documents, PDF's such as signed consents, vital signs and radiology reports with images.

As chief, Galvez holds a dual appointment with the National Library of Medicine



(NLM). Galvez provides guidance for staff conducting biomedical informatics research and, with NLM, leads an intramural training program in biomedical informatics for staff and fellows. Galvez will act as a conduit between technical and scientific staff.

Dr. Jon McKeeby has served as acting chief since 2015, following the departure of Dr. James Cimino.