

### U.S. Navy Captain Pius Aiyelawo joins Clinical Center as chief operating officer



Pius Aiyelawo, Clinical Center chief operating officer, (left) was sworn into the Senior Executive Service, by Dr. Lawrence Tabak, NIH principal deputy director.

In April, retired U.S. Navy Captain Pius Aiyelawo joined the Clinical Center as the chief operating officer. Aiyelawo is the first COO to oversee clinical areas in addition to the administrative side.

"Pius's tremendous healthcare leadership experience is matched only by a positive energy and spirit that will

inspire both patients and staff," said Dr. Jim Gilman, Clinical Center CEO.

Aiyelawo has held senior leadership positions in hospitals and large medical research programs throughout a distinguished military career spanning over 27 years. Read more in the news release: <https://go.usa.gov/xQbTM>

### Frosting cookies and making cards, patients share Valentine's Day with First Lady Melania Trump



First Lady Melania Trump celebrated Valentine's Day with pediatric patients at The Children's Inn at NIH. View the live stream videocast of the First Lady's visit and the full story at CC News online: <https://go.usa.gov/xQaew>

### Patient with rare disease receives surprise visit from bone marrow donor

What would you say to the person who saved your life? A young man at the NIH Clinical Center faced this very question early in 2018 when he met the person who donated bone marrow to treat his life-threatening illness.

Jackson Taylor has been a patient at the Clinical Center since 2010, when he was just 10-years-old. At that time, he came to participate in a trial for patients with immunodeficiency diseases.

Over the course of several years, researchers at the NIH kept a close eye on Taylor's condition. His immune system did not function properly – he often had severe and frequent infections and illnesses. The care team eventually identified a defect in a gene called magnesium transporter 1 or MAGT1. In 2014, the research team made an even larger scientific discovery – they identified and named a new rare disease that affected Taylor and a handful of other patients. The disease is an X-linked immunodeficiency with magnesium defect, Epstein-Barr virus infection, and neoplasia – known as XMEN.

This previously unrecognized disease brought Taylor back in 2016 to enroll in a National Cancer Institute (NCI) bone marrow transplant trial.

"When Jackson was found to have rapidly expanding lymphatic tissues following exposure to Epstein-Barr virus, the need for bone marrow transplant became urgent," added Dr. Gulbu Uzel, an immunologist and staff clinician with the National Institute of Allergy and Infectious Diseases (NIAID).

While most people have Epstein-Barr virus already in their body, they'll never see side effects because their immune system keeps it under control. But for patients like Taylor, whose immune system is not working properly, Epstein-Barr virus would likely lead to cancers of the immune system.

"A bone marrow transplant is a potential cure for immunodeficiency diseases," said Dr. Jennifer Kanakry, one of Taylor's care providers from the NCI. During a transplant, a patient receives healthy blood-forming cells (stem cells) to replace their own stem cells.

Taylor turned to the NIH's Unrelated Donor Stem Cell Transplant Program. In 2017, nearly 30 unrelated donor transplants took place in Building 10, which was about 40% of all transplants done at the NIH that year.

Jennifer Wilder, primary coordinator for the program, works with patients' clinical research teams, the Clinical Center's Department of Transfusion Medicine and Be The Match – the manager of the largest marrow registry in the world.

# Staff, need to access electronic health records? Use the online request form!

The Clinical Research Information System (CRIS) – NIH’s electronic health record – touches virtually everyone at the Clinical Center in one way or another, including staff from 17 NIH Institutes who work in Building 10. The Department of Clinical Research Informatics, the team that manage the Clinical Center’s IT systems, including CRIS, recently updated the form staff use to request access to this important system.

When a student, trainee or other staff (who are not medical prescribers) join the NIH, often they need to request access to CRIS as part of their job. Whether it is to document patient care, retrieve data or analyze trends, NIH staff need to access clinical and research information to assist in their work and help achieve the mission of the NIH to improve the health of the nation. The NIH carefully evaluates CRIS access requests to ensure safeguards are in place that protect patient’s medical information.

These are the recent updates to the electronic CRIS Account Request Form (also known as eCARF):

- The employee’s supervisor should fill out and electronically sign the electronic CRIS Account Request Form (<https://cris.cc.nih.gov/accounts/pdf/CARF.pdf>) using their PIV card and click ‘Submit Form’ (applicant signature not required).
- Once ‘Submit Form’ is selected, it will be automatically forwarded to a new email address of the CRIS Security team: [crisaccessrequests@cc.nih.gov](mailto:crisaccessrequests@cc.nih.gov)
- The electronic CRIS Account Request Form specifies access type based on user roles. Select the employee’s role based on their NIH credentialing status, job function and need to know.

The form should be submitted prior to taking CRIS training, with the exception of credentialed prescribers (M.D., P.A., N.P., D.O., Dentists, Audiologists). Register online for CRIS training: <https://training.cit.nih.gov/>. View more details (<https://cris.cc.nih.gov/accounts/index.html>) or watch the CRIS video (<https://youtu.be/WxqHan1xCTo>).

## DONOR *from page 1*

She coordinates donor details, plans for the marrow harvest and schedules the patient’s infusion of cells.

Taylor’s transplant followed the usual pattern of the many research collaborations across the NIH: he was cared for by the NCI’s Experimental Transplantation and Immunology Branch with involvement from experts at the NIAID and the Clinical Center.

In September 2016, Wilder found a match for Taylor. Sean McLaughlin, a 22-year old from New England, was willing to make a bone marrow donation and his blood type, among other factors, matched Taylor’s needs. McLaughlin traveled to D.C. to donate his marrow Dec. 21, 2016 and it was infused into Taylor a few hours later.

“Going through a transplant is a process,” said Kanakry. After his marrow graft was given that December day, “there is a long process of preventing graft versus host disease, preventing infection, waiting for the blood counts to come back up from zero and slowly building up an entirely new, healthy immune system.”

The transplant, delivered by IV, may have taken only a few hours, but the story didn’t end there.

According to the Be The Match bone marrow registry rules, unrelated donor transplants are anonymous to the NIH care providers and the patient for at least one year following the transplant. So Taylor and McLaughlin corresponded anonymously over the next year. The first letter they wrote was on the day of the transplant.

“I think in total we wrote about eight letters back and forth to each other,” recounted Taylor. “Even though words on paper weren’t fully able to express my emotions, it was extremely helpful to express my gratitude for my donor’s sacrifice.”

McLaughlin remembered, “I couldn’t have been happier each time he sent a letter telling me how well he was doing. It made me realize that everything I did was worth it. It actually worked!”

On Jan. 5, 2018, they were finally able to meet face to face. Taylor was at the Clinical Center for his one-year transplant follow-up visit. But to his surprise, Wilder had worked with Taylor’s transplant team, his social worker and his family to arrange for him to finally meet McLaughlin.

“I loved bringing the patient and donor together, and seeing the family’s reaction was



A year after his bone marrow transplant, Jackson Taylor (right) meets his donor Sean McLaughlin (left).

priceless,” said Wilder. “It’s also incredibly important to highlight things like this for our staff – the research teams as well as the Clinical Center staff who care for patients every day. I am really pleased that we could share a success story with them, and also highlight the donor in a way that made his sacrifice and gesture real to everyone.”

The visit made a real impact.

“Meeting Sean, my bone marrow donor, was crazy largely due to the fact that I didn’t know he was going to meet me in the hospital. When we came face to face, it was like meeting a long-lost brother I never knew I had. The amount of emotions was overwhelming, I wasn’t sure what to say. Spending the day together and getting to know him was amazing,” said Taylor.

“Knowing that there were two people in that room who had never met, but share the same DNA was a profound and amazing feeling,” added McLaughlin.

Taylor’s experiences haven’t ended with meeting McLaughlin. A Canadian citizen, Taylor is now a volunteer for the Canadian Blood Services, the main organization that coordinates blood donations and recruits bone marrow donors in Canada. He plans to work on events that educate and inspire people to donate blood and register for bone marrow donation. “It really does save lives,” he said.

As for McLaughlin, he found donating marrow to be incredibly powerful.

“For many patients, a bone marrow donation is the last resort or only option,” he said. He encouraged others to join a donor registry. “Knowing that you are the only reason someone is alive is remarkable.”

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)



- Health & Human Services Secretary, Alex Azar, meets with patients, NIH staff in March
- National Eye Institute turns 50
- Dr. Jerome Adams makes first NIH visit as 20th U.S. Surgeon General

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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# Poolesville High School students develop device for Project SEARCH graduate to increase productivity

Thanks to the bright minds of three local high school students, NIH Clinical Center employee Ricky Day has been able to use a new device that has helped him more than double his productivity in the Office of Administrative Management.

Day, who graduated from NIH Project SEARCH in 2011, is in charge of processing patient taxi voucher receipts and invoices. By entering the receipt amounts into an Excel spreadsheet, he is able to compare the charged amount to the travel time – checking for possible discrepancies or overcharges. As part of this, Day has to take documents in and out of a manila envelope. The task of placing the large stack of papers back into the envelope is especially challenging due to his limited dexterity.

“After being introduced

to Ricky, we were inspired by his positive attitude and determination to complete his tasks independently, regardless of how difficult they may be,” said Alex Carbonell. He, along with his classmates Dhruv Maniktala and Ashwini Thirukkonda, are involved in the Science, Mathematics, and Computer Science program at Poolesville High School. As a part of the program, they were required to find an opportunity to apply their knowledge from the course in the community.

“Despite our limited experience in the engineering field, we wanted to help Ricky become more confident, independent and productive. With this in mind, we set out to build an assistive technology for him,” Maniktala said.

To solve the problem, the

students designed a specialized tray that could hold and align the documents. After placing them in the tray, Day can slide an envelope onto the device, surrounding the paper. Finally, using the handles, Day can tilt the device to allow the paper to slip into the envelope.

Traveling back and forth from school to the NIH over several months, the students brought updated prototypes and tweaked it according to feedback from Day.

“As we’ve worked with Ricky, we’ve seen just how hardworking and optimistic he is. Ricky’s also a problem-solver in his own right, and his ideas and suggestions have driven our design process,” Thirukkonda said. “It’s also been amazing to see just how much our simple, and inexpensive device has



Ricky Day, front, holds the prototype device designed for him by the three students from Poolesville High School.

more than doubled his productivity, which will impact the Clinical Center and its patients. Still, the best thing would have to be seeing Ricky’s face light up after he’s used a new prototype [of the device], and knowing that our work made that happen.”

## Let’s move with heart: NIH staff celebrate American Heart Month in February



NIH staff filled the Clinical Center atrium Feb. 2 — known as Wear Red Day — to celebrate American Heart Month. Coordinated by the National Heart, Lung, and Blood Institute (NHLBI), attendees line danced for 30 minutes at the event to raise awareness of heart disease, which is the number one killer of both men and women in America. Research shows that being physically active can help lower the risk of heart disease and stroke. At the event, Dr. Gary Gibbons, NHLBI director, invited everyone to move more often. “You can change the way you live, how you eat, how you become more active!” Attendees were encouraged to record a short video demonstrating their favorite way to move, and share it on Twitter and Instagram, using #MoveWithHeart. View videos from staff in the Clinical Center: [www.movewithheartpledge.com](http://www.movewithheartpledge.com)

## Catalog of patient library resources now accessible online

The Clinical Center patient library catalog recently went digital – NIH patients, their family members and caregivers can now go online from any computer, tablet or mobile device to browse and reserve more than 7,000 available items. Previously, the catalog was only accessible to those who traveled to the 7th floor to conduct a search. Now users can review materials at home and hold them for when they arrive. If they’re already in the hospital, guests can use their bedside TV/Tablet.

The Patient Library offers books, audio books, music, DVDs and XBOX 360 games. They subscribe to over 30 magazines and have newspapers available, too. Laptops, tablets and musical instruments are on hand for check out. The library recently added the three-part Discovery series *First in Human*, which aired in August 2017, to their tablets. The series captures the real-life experiences of doctors, researchers, staff, patients and their caregivers at the Clinical Center. Ask a librarian to access the show, or, inpatients can call 301-451-7603 and staff can make arrangements to bring a tablet to the bedside.

Visit the catalog: <https://go.usa.gov/xQrnT>

# Personnel updates

## Laboratory Medicine



After a distinguished 35-year-career at the Clinical Center, Dr. Thomas Fleisher retired as Chief

of the Department of Laboratory Medicine at the end of 2017. Fleisher was in charge of diagnostic testing for inpatient and outpatients that involved chemistry, hematology and microbiology testing. His department also provides phlebotomy services. He served as department head since 1998.

"[He] has been one of the principle reasons why the Clinical Center is the superb facility that it is," said longtime colleague, Dr. Henry Masur, Chief of the Critical Care Medicine Department. "He has been an unsung hero of the intramural program's success."

Effective January 2018, Dr. Karen Frank assumed the responsibilities of Acting Chief of the department.

## Nursing



Dr. Gwenyth Wallen was named Chief Nurse of the Clinical Center Nursing Department in December 2017. Wal-

len has served as the interim chief nurse since late 2016. In this role, she is the hospital's senior nursing executive responsible for nursing practice, standards, policies and professional development of the more than 600 nurses practicing in the Clinical Center.

She provides national and global leadership within the clinical research enterprise. Wallen remains focused on developing this specialized nursing role and disseminating information, education and innovations on safety and quality nursing care delivery and clinical research practice. Wallen is a newly Tenured Senior Investigator and Chief of Nursing Research and Translational Science.

## Surgery



In December, Dr. Jeremy Davis was named Surgeon-in-Chief at the Clinical Center. Davis oversees all surgical activi-

ties, provides strategic planning for surgical care and works to improve surgical quality and safety protocols throughout the hospital. Each year at the Clinical Center, more than 2,200 operations are performed by over 40 senior surgical staff.

Davis will work with Clinical Center staff, including those in the Department of Perioperative Medicine, to ensure that NIH continues to provide the highest level surgical care to patients. During his first year, he will focus on centralizing surgical outcomes data, improving perioperative efficiency and providing risk-assessment for clinical research-related procedures. He is also a Surgical Oncologist in the National Cancer Institute.

## Clinical Research Training & Medical Education



Dr. Thomas Burklow has joined the NIH to lead the Medical Research

Scholars Program, a year-long program that competitively selects about 40 medical, dental and veterinary students seeking future careers in biomedical research to join laboratories on the Bethesda campus to engage in basic, clinical or translational research.

Prior to NIH, Burklow served as a senior attending pediatric cardiologist at Walter Reed National Military Medical Center where he also served as Chief of Pediatrics. In addition to his duties with the Medical Research Scholars Program, he will continue to use his expertise and serve as a pediatric cardiologist for the Clinical Center's youngest patients.

## Starbucks marketplace cafe opens



The Clinical Center Starbucks Marketplace opened Feb. 2. The cafe, which sits where the former Au Bon Pain was located, offers pastries, muffins and cookies as well as hot and cold beverages. Patients, staff and visitors can enjoy hot meals and additional snacking options. For more information, contact John Crawford, an NIH food services program manager, at 301-402-8180.

## Frasca, architect and designer of the north part of Building 10, dies

Robert Frasca, a founding design partner responsible for creating the north side of Building 10, known as the Mark O. Hatfield Clinical Research Center (CRC), died Jan. 3. Frasca, 84, worked for Zimmer Gunsul Frasca Architects, the firm selected from an international design competition in 1996 to design the CRC. The 870,000-square-foot addition, which opened in 2005, has 200 inpatient beds and 93 day-hospital stations.

To Frasca, working at the Clinical Center was more than just a job.

"He loved scientists and [doctors] and felt they were doing God's work and he was only providing the cathedrals for it all to happen," Frasca's wife, Jeanne Giordano, said recently to John Gallin, NIH's associate director for clinical research and chief scientific officer of the Clinical Center.

Gallin, who was the Director of the hospital during renova-

tion, added "[Frasca] quickly grasped our mission. Aside from [his] great design skills, he had a remarkable ability to listen and respond to our stakeholders. He grasped how patients and their families react to a serious illness. He understood the stress care providers and scientists face. With good humor, optimism, inclusiveness and sensitivity [he] became a friend of the NIH.

In 1997, Frasca spoke before an audience of Clinical Center researchers and staff about the importance of their input when designing the new facilities.

"We really believe that a good science building can contribute to good science. In designing this building, it is a partnership. We literally learn from one another. The more



Harold Varmus, Robert Frasca, Mark Hatfield and John Gallin at the groundbreaking of the hospital's new addition.

emotional investment you have in the building, the better building it's going to be," Frasca said.

Frasca's portfolio includes Doernbecher Children's Hospital in Portland, Ore.; the Memorial Sloan Kettering Cancer Center's Mortimer B. Zuckerman Research Center in New York; and the Dana-Farber Cancer Institute's Yawkey Center for Cancer Care in Boston.