March 2017

Clinical Center news

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NIH...Turning Discovery Into Health®

Gilman assumes post of NIH Clinical Center chief executive officer

Decorated general with extensive management experience hits the ground running

Dr. Francis Collins (left), director of the National Institutes of Health, swore in the NIH Clinical Center's first chief executive officer, Dr. James K. Gilman, Jan. 9.

Dr. James K. Gilman, a retired United States Army major general and cardiologist, took the helm of the Clinical Center on Jan. 9, and was quick to make an impression on staff with his affable, positive demeanor and confident, efficient and yet consensus-oriented leadership style.

Gilman hit the ground running by participating in a Clinical Center Hospital Research Board meeting in his first week, followed soon thereafter with three "Meet the CEO" meetings in Masur Auditorium (at times to accommodate all shifts) and touring several departments. He also plans to conduct regular town halls. Gilman's approach early on is biased toward listening first, and he emphasizes the importance of valuing staff at all levels, especially those on the front lines.

Gilman's priorities for the Clinical Center are clear. In a nutshell:

"My focus is setting a high bar for patient safety and quality of care including the development of new hospital operation policies," Gilman asserted. A regular at the morning patient safety huddle in the Medical Board Room (see related content on page 7), he is committed to ensuring that the Clinical Center follows the principles of high reliability organizations, an area in which he has much experience.

On March 22, Gilman will join Dr. Peter Pronovost, senior vice president of Patient Safety and Quality at Johns Hopkins

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Patient perseveres in battle with Chronic Granulomatous Disease

Clinical Center patient Llasmin Canseco (left) with one of her care providers, Celina Mon temayor.

At just six months old, Llasmin Canseco was diagnosed with Chronic Granulomatous Disease (CGD), a rare inherited disorder that weakens the immune system. The portion of Canseco's white blood cells called granulocytes fail to produce microbe-killing hydrogen peroxide, leaving her with chronic inflammation and defenseless against frequent bacterial and fungal infections.

There are five genetic types of CGD, four of which present with very similar medical problems. CGD is estimated to occur in one in 200,000 to 250,000 people worldwide though the genetic type of CGD affecting Llasmin (P67) occurs in just 5% of CGD patients. Llasmin's CGD was carefully managed by antibiotics and other medications throughout her life, allowing her to reach young adulthood. However, in 2016 she acquired a fungal pneumonia that progressed to infect and partially destroy her chest bones leaving her doctors scrambling to find a treatment before it turned deadly. High doses of multiple antibiotics and repeated surgical treatments failed to eliminate or slow spread of the infection. Llasmin needed help fast.

In March 2016, at age 26, she enrolled in an NIH clinical trial that would attempt to give her a brand new immune system and a second chance at life.

"I tried having a normal life, but I have always had to take care of myself because I had Chronic Granulomatous Disease," she said.

At home in California, Llasmin enjoys competitive sports, like tennis and basketball, and is hoping to pursue a career in accounting.

"Even though I tried not to get ill, I still got sick. Throughout my life I had many infections and was hospitalized often."

Just as the 2016 New Year approached, Llasmin's health condition took a turn for the worse.

"I had a critical fungal infection in my sternum and lungs that was not getting any better with anti-fungal medications. The infection was worse every day, and the [San Diego] doctors' major concern was that the infection could spread more and reach my heart."

In desperate need of another treatment option, her medical care team found an NIH blood stem cell clinical trial, Haploidentical Transplant for People with Chronic Granulomatous Disease Using Post Transplant Cyclophosphamide, led by Dr. Harry Malech and Dr. Elizabeth Kang from the National Institute of Allergy and Infectious Diseases.

The trial, which took place at the NIH Clinical Center, transplanted hematopoietic stem cells collected from Llasmin's healthy mother to Llasmin in an attempt to replace her defective immune system with a healthy immune system derived from her mother's blood stem cells. This clinical trial is designed to allow transplants from a parent or other close relative who may be only a half match with respect to tissue typing (HLA pattern). Most standard transplants use donors who match more closely. This trial expands the use of transplanta-

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Medicine and director of the Johns Hopkins Armstrong Institute for Patient Safety and Quality, to present a special Grand Rounds focusing on patient safety. Gilman will speak on "Macro Medical Errors and the Just Culture," and Pronovost will speak on, "Working Toward High Reliability."

Once the federal hiring freeze lifts, Gilman plans to round out his leadership team, including hiring a COO who would oversee both clinical and operational functions.

Before his appointment to the NIH, Gilman was executive director of Johns Hopkins Military and Veterans Institute in Baltimore, Md., a position he assumed following his retirement from the Army in 2013.

Gilman is a highly decorated leader from his outstanding, decades-long service in the Army, with rich experience commanding numerous hospital systems, and who had oversight of all medical research and development for the Army while commanding the U.S. Army Medical Research and Materiel Command in his final assignment.

Gilman hails from tiny Hymera, Ind., and after graduating from Rose-Hulman Institute of Technology with a degree in Biological Engineering in 1974 he went to Indiana University School of Medicine and received his MD in 1978.

He graduated from the Command and General Staff College and the Army War College. He is board certified in both Internal Medicine and Cardiovascular Diseases and is a fellow of the American College of Cardiology and the American College of Physicians.

Well-travelled and an avid reader – recently completing Ron Chernow's tome "Alexander Hamilton"– he admits the tasks ahead, coupled with his new commute, may cut into some of his personal hobbies, but he doggedly finds time to safeguard his own health through regular exercise.

Gilman and his wife Jeffri are the parents of three adult daughters. They also have one grandchild who is in kindergarten this year.

With the arrival of Gilman, Dr. John I. Gallin transitioned his attention full time to new roles as the NIH associate director for Clinical Research and chief scientific officer of the Clinical Center.

Clinical Center's new steam turbine reduces energy use, saves money

Donald Edwards (left), chief of the NIH Clinical Center's Facilities Branch, Greg Leifer (center), with the Energy Management Branch, and Michael McClain (right), the facility manager for Building 10, gather at the Clinical Center's new steam turbine recently installed in the basement of the hospital. The new equipment, which provides heat to the hospital by converting steam to mechanical energy, will reduce power consumption by using it more efficiently, thereby saving costs. This modern and easier-to-operate equipment replaces the old turbine installed during the building's construction in the 1950s. The new turbine will provide an estimated 2.4 million kilowatt hours of electricity, equivalent to enough electricity to power 200 average-size homes per year. This upgrade is anticipated to save approximately $200,000 per year.

Management Intern Program unlocks new administrative-management career paths

While under the hiring freeze, the NIH Management Intern (MI) Program, a highly competitive, two-year career-development program for current NIH employees, is not currently recruiting. Interested parties are encouraged to take the time in this interval to confer with colleagues and learn more about this prestigious program to determine if it's right for them in the future.

MIs come from a variety of job backgrounds, including both scientific and administrative fields. Recent MIs have joined the program from positions as diverse as intramural program specialist, police officer, contract specialist, high voltage electrician and extramural support assistant.

MIs rotate through different administrative career fields to gain invaluable insight into the NIH while contributing to the work of NIH through targeted assignments and challenging projects. After two years and upon completion of the program, MIs transition into an administrative-management career in one of many areas throughout NIH.

To contact MI program staff or current MIs, or to hear about future program dates, go to https://trainingcenter.nih.gov/intern/mi/.

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

- Local students donate cards and puzzles to pediatric patients
- CC staff recognized at NIH Director's Awards

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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NIH Clinical Center

Oncology care plan for cancer survivors discussed in Malaysia, Brazil

Dr. Leighton Chan (second from left), chief of the NIH Clinical Center's Department of Rehabilitation Medicine, presented on cancer rehabilitation at the Global Cancer Rehabilitation Initiative in Brazil. Photo courtesy of Sao Paulo State Government.

By the year 2026, the American Cancer Society projects that the number of U.S. cancer survivors may exceed 20 million. As survivors travel home after treatment, they are faced with the opportunity to consider what's next in their lives, but many also face physical and psychological side effects of disease and treatment.

Dr. Leighton Chan, chief of the NIH Clinical Center's Department of Rehabilitation Medicine, along with other collaborators, published a paper in November in the Archives of Physical Medicine and Rehabilitation, highlighting the growing need in the U.S. healthcare system to meet the challenges of cancer survivors and to better alleviate or mitigate the functional impairment they may experience.

A lot of treatments around cancer, including surgery, chemotherapy and radiation, can have profound impacts on a patient such as fatigue, pain, depression and lymphedema (swelling in the arms or legs). While most of these symptoms can be treated with the help of a cancer rehabilitation professional, currently, there are not many specialists around the country who are incorporated in the oncology care plan, aside from places like Sloan Kettering, M.D. Anderson, and at the NIH Clinical Center, according to Chan.

"We've been doing cancer rehabilitation here in the Clinical Center and in this department for years. Every day, my staff sees first-hand the challenges our patients face when confronted with the long term complications of cancer treatment. Pain, swelling, fatigue, nerve damage – we have to manage it all. Cancer rehabilitation, then, is a natural fit for our mission; it's a stubborn, challenging area with lots of area for improvement," he said. "[But, across the U.S. and the world] it's an underdeveloped branch of rehabilitation, and something we think will really take off in the future."

Chan's department, and collaborators from the National Cancer Institute and the Eunice Kennedy Shriver National Institute on Child Health and Human Development's National Center for Medical Rehabilitation Research, convened a meeting in June 2015 at NIH to elevate the state of the science in cancer rehabilitation. Following the two-day gathering of 200 cancer care and rehabilitation experts, Chan and others compiled the paper, which provides recommendations "to stimulate action among healthcare providers, policy-making bodies, research institutions, professional societies and associations and patient advocacy organizations toward initiating advancements in the field."

The paper suggests individual providers should focus on the following:

1. Providing rehabilitation screening and assessment as part of a comprehensive cancer care plan starting at the time of the cancer diagnosis
2. Assessing functional status throughout the course of treatment – before, during and after intervention
3. Considering 'pre-habilitation,' where possible, to help patients achieve better outcomes"[With this paper,] we started this national ball rolling," Chan said. And quickly, the interest in cancer rehabilitation went international.

Chan was asked to present on cancer rehabilitation at international meetings in Malaysia and Brazil in late 2016. And, he's been invited to go to China and Argentina to continue to educate healthcare providers about the importance of integration of rehabilitation medicine in oncology and early assessments by rehabilitation specialists. The Clinical Center Rehabilitation Medicine Department, along with other multidisciplinary groups, plan on creating a set of standards for physicians and therapists by spring 2017.

"If we can create a set of guidelines, then we can help create new programs throughout the United States and the world. That, to me, would be a wonderful success," said Chan who was just awarded the American Physical Therapy Association Debbra Flomenhoft Humanitarian Award for his efforts to focus attention on this underserved area.

In addition to the guidelines, continued education is needed for oncologists, patients, the research community and those involved in the financing of the services, such as the Centers for Medicare & Medicaid Services. But Chan feels hopeful that the growing interest in this area will eventually impact care and policy, and that an increasing number of cancer survivors will be able to live a more functional and fulfilling life after battling, and overcoming, disease.

"[Survivors] have a right to certain expectations around the quality of [their] life and maximizing their ability to do the things they want to do – whether that's going back to work or re-engaging in their hobbies," Chan said. "In general, the oncology community is focused on mortality and disease-free survival as the primary outcome measures. But, we also know that someone's ability to function after a treatment is equally critical."

Quezado heads new CC pediatric observation unit

Dr. Zena Quezado has joined the Clinical Center pediatrics team as the first chief of Pediatric Anesthesia and Critical Care. She will head up a new special pediatric observation unit, located in 1 NW, which will provide additional support for patient safety in pediatric research.

Quezado, previously a fellow in the Critical Care Medicine Department and later chief of Anesthesiology at the Clinical Center, spent the past seven years at the Children's National Medical Center in Washington, D.C. She is a seasoned professional in pediatric anesthesia with close to 20 years of experience. "This is a very exciting opportunity for me and being back at the Clinical Center is almost like coming home," said Quezado.

The pediatric unit will include four beds where children who require closer observation will be able to have cardiovascular and respiratory monitoring. Children who may need intensive care will continue to be treated in the Clinical Center ICU or be transferred to outside pediatric hospitals.

"We're thrilled to have Dr. Quezado return to the NIH to lead this exciting new program to ensure a safe environment going forward for children who are volunteering to help us with our research," said Dr. John I. Gallin, NIH Associate Director for Clinical Research and Chief Scientific Officer for the Clinical Center, who led the effort for the new unit and to bring Quezado to the hospital.

Quezado will split her time between the unit and her own research lab where she studies the pathobiology of pain and concomitant behavior changes associated with developmental disabilities.

CC collaborates with WRNMMC, USUHS

The National Institutes of Health Intramural Research Program, the Walter Reed National Military Medical Center (WRNMMC) and the Uniformed Services University of the Health Sciences (USUHS) have launched a partnership to share cutting edge medical care facilities and other resources while improving patient care, support collaborative research and expand training opportunities for personnel.

This agreement will expand access of NIH Clinical Center patients to specialty consultants, opportunities for military healthcare beneficiaries to participate in clinical trials at the CC; expand opportunities for military and CC medical staff to maintain clinical competency and to enhance the "combat" readiness of the military work force; and will enhance training collaborations and expanded access to a broader scope of patients for clinical fellows from both institutions.

WRNMMC is one of the nation's largest and most renowned military medical centers and is comprised of nearly 8,500 staff members. WRNMMC serves U.S. active duty military, military families, veterans and national leaders. The USUHS is the nation's federal health professions academy which place an emphasis on military health care, leadership, readiness and public health. USUHS offers graduate degrees in medicine, clinical psychology, biomedical sciences and public health.

The three neighboring federal facilities, located across 500 acres in Bethesda, Md., will capitalize on each other's strengths, enable patients to smoothly transfer to and from NIH and WRNMMC and take advantage of the clinical expertise of each institution.

"This is a unique opportunity to capitalize on opportunities for learning and practice for personnel, employees and trainees to develop the best and brightest health professionals and leaders of the future," said Dr. Frederick P. Ognibene, deputy director for Educational Affairs and Strategic Partnerships at the Clinical Center.

This agreement builds on previous cooperation between the Clinical Center and Walter Reed. Since 2012, the two institutions have collaborated on educational resources for staff and critical care fellows in the Critical Care Medicine Department at the Clinical Center.

NIH Continuing Medical Education activity provider upgrades record-keeping

Continuing Medical Education (CME) activities at the Clinical Center are moving online. This change affects those who attend or have recently attended NIH CME activity provided by Johns Hopkins School of Medicine.

The Johns Hopkins School of Medicine recently upgraded its CME record keeping to an online only system called CloudCME. With the new CloudCME record keeping system, attendees no longer have to sign in or manually complete a CME Self-Report Credit form to obtain CME for attending. Participants will also no longer have to wait until the end of the academic year to receive transcripts or certificates for proof of CME credits earned.

To verify the CME provider for an activity, contact that CME activity's coordinator for more information.

Johns Hopkins School of Medicine provided CME attendees can receive credit for attending the activity instantly by sending a text message from their mobile phones to the Hopkins CME phone number: 443-541-5052. This new CME record-keeping system makes it easier for the CME attendees to submit attendance and allows them online access to their CME transcripts/certificates on the Johns Hopkins CloudCME website: https://hopkinscme.cloud-cme.com/aph.aspx

NIH CME activities play an important role for many physicians and health care professionals in the NIH intramural program.

For instructions on how to use the new CloudCME record keeping system, attendees should contact the coordinator of that CME activity. General questions on NIH CME activities or the Johns Hopkins School of Medicine CME system, should be sent to the Office of Medical Education and Clinical Research Training's Daniel McAnally at daniel.mcanally@nih.gov.

New, upgraded FollowMyHealth patient portal now available

To improve patient engagement and satisfaction, the new FollowMyHealth® patient portal was introduced Jan. 10. The new patient portal offers Clinical Center patients access to maintenance of personal health records, secure health messaging, educational materials and accessibility through mobile application. NIH staff may now communicate with patients using the Secure Health Messaging (SHM) application within CRIS or the SHM website and patients will receive messages through the FollowMyHealth® portal.

The ability to view and schedule appointments will be added in future upgrades. Patients can only sign up for the FollowMyHealth® portal by email invitation. Invitations have already been emailed to NIH Clinical Center patients who had an account in the original patient portal inviting them to create FollowMyHealth® accounts. Invitations are also emailed on a daily basis to patients who have appointments and/or admissions at the NIH Clinical Center.

Patients may request an email invitation by contacting the Health Information Management Department's Patient Portal Support Team (1-855-644-6445) or visiting the portal website: https://www.cc.nih.gov/followmyhealth/. Through the upgraded patient portal, patients will continue to have access to selected documents and results from their electronic medical records.

The original patient portal was retired Feb. 10. For additional information, please contact the Patient Portal Support Team at 1-855-644-6445.

Clinical trials at NIH Clinical Center in need of participants

- Researchers at NIH Clinical Center are recruiting healthy adults, 18-50, to undergo an initial assessment to determine if they will qualify for future malaria studies. These future studies may involve evaluation experimental medications, vaccines and vaccine strategies to prevent malaria. Compensation is provided for participation. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 16-I-0039. http://go.usa.gov/xkyM2

- NICHD seeks adolescent girls above average weight, 12 to 17, to join a research testing whether attention training program on a smartphone will influence teens' eating habits. Compensation will be provided. Parents/guardians must give permission for children to participate. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 17-CH-0014.

- NIAID study seeks healthy adult volunteers, 18-64, for research to better understand the effects of glucocorticoids on the body. These medications are commonly used to treat conditions that cause inflammation on the skin and in the body like lupus, asthma and eczema. This research may help find better treatments for people with conditions that cause inflammation. Participants will receive one intravenous dose of a glucocorticoid, and a glucocorticoid cream will be applied to a small area of the skin. Blood and skin samples will be collected. Two outpatient visits at the NIH Clinical Center. Compensation is provided. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 16-I-0126.

- NICHD seeks healthy, children, 8 to 17, to join a research study of growth and health behaviors. Compensation will be provided. Parents/guardians must give permission for children to participate. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 15-CH-0096.

- NIDCR researchers at NIH are conducting a study identifying the conditions of craniofacial abnormalities in an effort to develop treatments specific to the type of abnormality. The purpose of this study is to learn about abnormal development of the face, head and neck and to determine their genetic variants. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 16-D-0040.

- NIDCR is seeking people with dry mouth due to radiation therapy for head and neck cancer. Researchers are testing if an investigational gene therapy using "AAv2hAQP1" increases saliva in patients who have received radiation therapy for head and neck cancer. Travel to and from the Clinical Center (within the U.S.) will be provided. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 15-D-0129. https://go.usa.gov/x8yXE.

Clinical Center staff recognized for outstanding achievements

Dr. John I. Gallin, then director of the NIH Clinical Center, speaks to staff at the 2016 Clinical Center Director's Annual Address Awards Ceremony on Dec. 16.

At the Clinical Center Director's Annual Address and Awards Ceremony on Dec. 16, Dr. John I. Gallin, then director of the Clinical Center, honored staff from various departments throughout the hospital.

"This is one of my favorite annual events, because it gives us a chance to recognize all of the hard work and dedication that is integral to our success," Gallin said. "This year, we have faced many challenges and uncertainty and responded with strength and opportunity. We reacted to change in positive ways, investing even more in our hospital and our mission. I am very proud of the accomplishments that we have made during this year of transition."

He recognized Clinical Center staff who are NIH leaders on the front lines of patient care and safety as well as clinical research and innovation. Highlights included recognition for excellence in customer service, patient support, mentoring, scientific advancements, medical records management, improving quality of work life and training.

Gallin also thanked staff for the medical advances made during his tenure as director for the Clinical Center and said he was looking forward to his new roles as NIH associate director for clinical research and chief scientific officer of the Clinical Center.

Read full article online: https://go.usa.gov/xXCVN.

Read the program online: https://go.usa.gov/x97Qm (NIH only). View photos here: https://www.flickr.com/gp/clinicalcenternih/1x25f0 from the ceremony (NIH only).

Sawyers honored as 2017 Distinguished Clinical Research Scholar and Educator in Residence, presents Grand Rounds lecture

Dr. Charles L. Sawyers, a Howard Hughes Medical Institute investigator, the Marie-Josée and Henry Kravis Chair in Human Oncology and Pathogenesis, and chairman, Human Oncology and Pathogenesis Program, at the Memorial Sloan Kettering Cancer Center, was recognized as the 2017 Distinguished Clinical Research Scholar and Educator in Research - the fifth to be honored.

As part of the award, Sawyers a world-renowned cancer physician-scientist who studies mechanisms of cancer drug resistance with the goal of developing novel therapies, presented the Clinical Center Grand Rounds lecture Feb. 8, "The Changing Landscape of Cancer Drug Resistance."

Sawyers, who co-discovered the antiandrogen drug enzalutamide approved by the US Food and Drug Administration in 2012 for treatment of advanced prostate cancer, discussed the different mechanisms of drug resistance and the history of the research around drug resistance.

Following the lecture, Dr. James K. Gilman, chief executive officer of the NIH Clinical Center, presented a certificate of appreciation to Sawyers.

View the videocast: https://go.usa.gov/xXazp.

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tion by allowing the use of less closely matched donors, but the trial reduces the risks of the severe complications often associated with mismatched donor transplants by using a novel conditioning (chemotherapy and radiation) regimen.

Although usually a parent is only half-matched, Llasmin's mother was much more closely matched than expected. This factor, along with the conditioning regimen, may have contributed to the successful outcome of this transplant.

"By the time she came here, she literally had a hole in her chest," said Dr. Celina Montemayor, with the NIH Clinical Center Department of Transfusion Medicine. "An eight centimeter infection had eaten its way through the sternum, the breast bone surrounding the heart and big blood vessels. It looked like Swiss cheese."

In no shape to immediately start conditioning for the stem cell transplant, Llasmin's doctors turned to Montemayor and her colleagues in DTM and the NIH Donor Center at Fisher's Lane in Rockville to provide healthy donor granulocyte transfusions (white blood cells that fight bacterial and fungal infection) to help stabilize the uncontrolled infection to have a fighting chance for success with the stem cell transplant.

To battle the fungus that was eating away at her chest, Llasmin received 11 transfusions of granulocytes. Llasmin's mom and dad, who were her caregivers throughout her time at NIH, nicknamed the granulocytes her 'soldiers.' But the real heroes, they said, were the members of the D.C., Maryland and Virginia communities who came to the NIH Donor Center at Fishers Lane in Rockville to donate these critical white blood cells.

"It took a lot of selfless donors to contribute to this miracle, up to two per week, to get her through this," Montemayor said.

Within 24 hours of coming out of the arm of a donor, the cells were going back into Llasmin to fight the fungal infection. Donors have to come in the day before their donation for medication to increase the amount of white blood cells in the circulatory system.

The donated white blood cells are only viable for 24 hours so they are immediately put to use in the NIH Clinical Center.

"Granulocytes have made a difference in my life because those infusions were like a window of hope for my family and me. It prevented the infection from spreading more in my body, and I am thankful for that," Llasmin said.

Granulocytes have been used at the NIH and a few other centers for patients with refractory infections, but they carry the risk of alloimmunization, development of an immune reaction to foreign antibodies, that can increase the risk of rejection of a subsequent bone marrow transplant. Patients can develop severe reactions after repeated granulocyte infusions limiting their overall or repeated use.

Kang and colleagues have been using the drug sirolimus to prevent alloimmunization from occurring and have been successful in transplanting patients treated with granuloctyes and sirolimus prior to their actual transplant. Thus they felt comfortable starting the granulocyte transfusions under the cover of the sirolimus soon after Llasmin's arrival at the NIH. These granulocytes were then continued during the transplant period until the graft took over and started producing normal neutrophils, about two weeks after getting her mother's stem cells.

While the road to recovery included a mild case of graft versus host disease, caused by the donor stem cells attacking Llasmin, this was easily managed and Llasmin's body is now able to produce powerful white blood cells to protect her from infections people commonly face in day-to-day life.

At her most recent visit, nine months after the transplant, her new stem cell graft is stable, her infection appears to be cured and she even has evidence of significant regrowth and healing of her chest bone. Her transplant doctors are cautious about not claiming a cure for her CGD until her bone marrow graft is stable for at least two years, but she appears to be on her way to that outcome.

Patients with CGD are followed for at least five years after their transplant at the NIH.

"It was not easy, but with the help of my parents and family, the care of the doctors and nurses, the support of the recreational and rehabilitation therapist, and with the help of many others, I made it through," Llasmin said. "Transplant has made a great difference in my life because my body will now be able to combat infections on its own, and I will be able to live a more pleasant and healthy life."

Learn more about CGD: https://go.usa.gov/xXUS4.

Donate granulocytes, or other types of blood, to patients at NIH: https://clinicalcenter.nih.gov/blooddonor/.

Clinical Center staff starts each day focused on patient safety

Representatives from Clinical Center departments and NIH Institutes convene daily at 8:40 a.m. in the Medical Board Room to report on concerns from the previous 24 hours and to look ahead to any potential safety or quality issues expected in the next 24 hours. The daily huddles were established last year to bring staff representing direct care providers as well as hospital leaders together to provide awareness and real time understanding about potential or existing safety, quality and service issues.

Upcoming Events

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

Clinical Center Grand Rounds Lecture
Macro Medical Errors and the Just Culture; Working Toward High Reliability
March 22, 2017, Noon – 1:00 p.m.
Masur Auditorium
Presented by James K. Gilman, MD, CC and Peter Provonost, MD, PhD, Johns Hopkins Medicine.

NIH Director's Wednesday Afternoon Lecture Series
The Split Personality of Human O-GlcNAc transferase
April 18, 2017, 3:00 p.m. – 4:00 p.m.
Masur Auditorium
Presented by Suzanne Walker, Ph.D., Harvard University.

NIH "Take Your Child to Work Day"
April 27, 2017, 9:00 a.m. – 4:00 p.m.
Bring children grades 1-12. Email questions to Take-Your-Child-To-Work@nih.gov or visit http://takeyourchildtowork.nih.gov/Pages/default.aspx

OP Phlebotomy hours extended

To better serve patients, the Outpatient Phlebotomy Services' hours will be extended starting April 3.

Outpatient Phlebotomy Hours of Operation:
- Monday – Thursday 6:30a.m. to 5:15 p.m.
- Friday 6:30 a.m. to 4:15 p.m.

Closed weekends and holidays.

After Hours Blood Drawing Service:
- Blood drawing service can be obtained at 5SW Day Hospital after Outpatient Phlebotomy closes.

Maryland Terps attend Rare Disease Day at NIH

Top: Donna Gregory, Recreational Therapy chief, posed with athletes at the Clinical Center North entrance. Bottom left and right: Athletes inspired patients at the pediatric unit's playroom.

Football players from the University of Maryland visited patients Feb. 27 during Rare Disease Day at NIH to inspire those battling uncommon illnesses. The Recreational Therapy Section of the Rehabilitation Medicine Department facilitated the athletes' visit. The collegiate athletes are part of the national nonprofit organization Uplifting Athletes, which supports outreach, research and education about rare diseases. "Our objective here is to inspire [patients] and to really give back... [T]hey look at the world with hope and happiness," said Maryland football player Adam Greene after visiting patients at the Clinical Center.

The goal of Rare Disease Day, which typically takes place annually on or near the last day of February, is to raise awareness about rare diseases and their impact on patients' lives. Rare Disease Day at NIH is sponsored by the National Center for Advancing Translational Sciences and the NIH Clinical Center. Nearly 1,000 people participated in this year's Rare Disease Day in person and by webcast.

Watch video of the athletes' visit: goo.gl/gHnTIX [Disclaimer]: https://clinicalcenter.nih.gov/disclaimers.html.

More information: http://www.upliftingathletes.org [Disclaimer]: https://clinicalcenter.nih.gov/disclaimers.html.

NIH Rare Disease Day events, organized and sponsored by NCATS and the Clinical Center, promote research, educate public and empower patients. Videocast: https://go.usa.gov/xXCTK.

Generous contributions come from the Clinical Center for the Combined Federal Campaign

Clinical Center employees contributed $138,202 to non-profit organizations locally and around the world that make a positive difference as part of the 2016 Combined Federal Campaign (CFC). The 10 core team coordinators and 71 keyworkers for the CFC campaign at the Clinical Center, worked together to reach out and raise awareness to all hospital staff. The CFC campaign ran from Sept. 28 – Dec. 31, 2016. Clinical Center fundraising activities included the annual Baking It Possible Clinical Center Bake Sale, which raised over $2,700, and the Dollars for Change fundraiser, which raised over $900.

This year, entries from the 2016 CFC NIH Director's Art Challenge "The Beauty of Science" were displayed in the Clinical Center's hallways to help raise awareness about the CFC.

Overall, the NIH raised more than $2.4 million, exceeding its goal by seven percent. Working together, the NIH and the Clinical Center helped "Show Some Love."