

Renovated Pharmacy begins phased opening

Improvements move facility from “outdated to outstanding”



Cutting the ribbon at the May 18, 2022, Pharmacy opening ceremony were (left to right) Dr. Richard DeCederfelt, acting Pharmacy chief at the Clinical Center; Dr. James Gilman, Clinical Center CEO, Dr. Lawrence Tabak, acting director of the National Institutes of Health, Dr. Alfred Johnson, deputy director for management at NIH and Dr. Marilyn Farinre, Clinical Center Pharmacy operations chief. In the background are Dr. Tara Schwetz, acting principal deputy director for management of NIH and Dr. Michael Gottesman, deputy director for management for Intramural Research at NIH.

Who says you can't come home again?

After years of construction and operating out of temporary locations, the Clinical Center's Pharmacy reopened in a renovated space in the Southeast wing on the first floor of the hospital.

The 10,000 square foot facility incorporates the Pharmacy's outpatient, unit-dose and intravenous admixture unit (IVAU) operations into a single location. The outpatient section opened in early May 2022, followed by the unit-dose section opening in the new space at the end of May and the IVAU coming online in the Fall.

"The NIH invested extensive thought and resources into planning and building a Pharmacy that supports our three pillars of patient safety, clinical quality and world-class research," said Dr. James Gilman, CEO of the hospital.

"I especially want to thank the Pharmacy staff - both those who actively contributed to this project and those who ensured safe

continuity of operations for our valued patients during construction," added Gilman.

The impact on the patient experience was minimal. Patients meet with a facilitator during the check-in process, continue to check in at a kiosk and the waiting area in front of the travel office remains the same.

A new outpatient medication pick-up area features three transaction windows with several features to help with patient privacy: frosted glass dividers and acoustic wall coverings and sound absorbing ceiling panels.

"Our goal was to move from outdated to outstanding, and I think we've hit the mark," said Capt. Rick DeCederfelt, acting chief of the Pharmacy Department.

Behind the scenes, there will be a number of new procedures that will be invisible to patients but will improve the patient experience and safety. A new system will automate the storage and retrieval of

Development of the Pharmacy has been guided by four key principles:

- **Safety** of patients and staff;
- **Efficiency** to save time, money and eliminate errors;
- **Positive staff impact** by creating a workplace with high morale, excitement and engagement, and
- **Regulatory compliance** to ensure that the Clinical Center's Pharmacy meets or exceeds any regulations governing its facility or operations.

prescriptions making pick-up faster, more accurate and more efficient.

"We've invested in long term sustainability of the sterile environment and focused on excellence by creating in-house standards exceeding regulations and industry best practices to support and conduct clinical research by providing safe, high-quality care - one patient, and one medication, at a time," added DeCederfelt.

This is a new and complex system, and well worth the investment.

-Donovan Kuehn with contributions from Esther Jeon, Christina Martin, Nadia Guirguis, Falguni Kanthan and Marilyn Farinre



"I have personally witnessed the evolution of the Pharmacy's role in supporting clinical research... and would like to express our sincere appreciation to NIH leadership for demonstrating their confidence in the Pharmacy by investing in the resources necessary to create a one-of-a-kind facility." From the opening remarks of Capt. Rick DeCederfelt, acting chief of the Pharmacy Department.

One month, many stories

Clinical Center staff reflect on their heritage

May is Asian American, Native Hawaiian and Pacific Islander (AANHPI) Heritage Month and this year's theme of "We are not a monolith" highlighted the diversity of languages, cultures and customs of many countries and regions among the AANHPI community.

As of 2021, the AANHPI population make up 19.4% of the NIH total workforce and 18% of the Clinical Center workforce.



Annie Cichocki

When Cichocki thinks about AANHPI month, her traditions, family and history stand out. Cichocki was born on the island of Mindanao in the southern Philippines and identifies as an Asian Pacific Islander from Southeast Asia.

While growing up, Cichocki was taught

to bear with injustice and to work harder than her non-Asian peers to prove her worth and that she belonged. She believes this is partly due to her upbringing. She was raised to prioritize hard work rather than speaking up to be recognized or promoted.

"It's particularly harder for me as a female immigrant. I feel that I always must prove myself above my peers. Asian Americans are perceived as smart, hardworking, easy-to-manage employees. The problem with that perception is that we're seen as good workers, but not great leaders."

To better understand AANHPI experiences in the U.S., Cichocki recommends reading *Pan de Sal Saves the Day* by Norma Olizon-Chikiamco and Mark Salvatus – a book about a Filipino girl who learns to appreciate her own unique gifts in a story about building self-confidence.



Mike Delostrinos

Mike Delostrinos is a management analyst working in the Office of Hospital Administrative Support. He currently works directly with the hospital's employees helping them navigate the Integrated Time and Attendance System timekeeping system

and leave sharing programs such as Voluntary Leave Transfer Program and Leave Bank.

Delostrinos identifies as a Filipino American and celebrating his Filipino heritage consists of food and quality family time.

"My family is very traditional where we celebrate a lot of the religious celebrations

together. We tend to focus a lot on family and strive to have meals together at least once a week," he said. Delostrinos viewed this month as an opportunity to gain understanding, learn about different cultures and values and to respect the different activities people embrace.

"My heritage has shaped me by being family and service oriented, where putting others before yourself is essential.

"We take this month to acknowledge some of the accomplishments that others have done or simply educate yourself on some of the cultural aspects."



Thomas Burklow

Dr. Thomas Burklow is the acting director of the Clinical Center's Office of Clinical Research Training and Medical Education. He also serves as the director for the Medical Research Scholars Program and

coordinator for undergraduate medical student electives at the hospital. Burklow also chairs the Clinical Center's simulation training project team.

Burklow was born in South Korea to a Korean mother and a Caucasian father.

"Growing up in America, there were very, very few Asians in my own community. Consequently, I was raised culturally 'white'," said Burklow.

Over time and as an adult, he realized how his deeply ingrained values and belief systems came from his mother and how they were shaped by her Korean heritage.

"I now have a greater identity with and appreciation for my Korean roots, and understand better why I hold harmony, family, tradition and fortitude as being essential in life. But at the same time, I firmly embrace uniquely American values of independence, equality and optimism. It is a cliché, but America really is a melting pot, and we become a better country when we can show appreciation for, and even integration of, the values that everyone brings to the table."

-Janice Duran



Esther Jeon

Dr. Jihyun "Esther" Jeon is a Pharmacy project manager and process improvement officer for the Pharmacy Department in the NIH Clinical Center.

When Jeon thinks about her Korean heritage, food, family and culture come to mind. As a first-generation

immigrant from South Korea, her daily life is surrounded by Korean culture.

"As all generations gather around to make Kimchi (fermented cabbage) together, I am reminded of my roots and pride in my culture," said Jeon.

Jeon believes building social relationships in the Asian American community is vital to her identity. Sharing information and supporting others who are experiencing similar circumstances can help navigate her path.

"I participate in the activities of the NIH chapter of Korean American Women in Science and Engineering. We exchange the personal, academic and work-life among members to strengthen the network."

Jeon hopes that one day we can acknowledge that we are all different and there is nothing wrong with that.

"I am blessed to live and work in a multi-cultural community, including a sizeable group of Asian Americans, where diversity and inclusion are valued."

Annie Cichocki is the chief of the Clinical Center's Nutrition Department. She manages a full range of both clinical and research services, including the daily operations of the metabolic kitchen and the NIH Dietetic Internship Program, in addition to ongoing food service delivery and managing quality assurance and performance improvement programs.

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Editor: Donovan Kuehn | Layout: Justin Baker
Contributors: Debbie Accame, Robert Burlison, Janice Duran, Cindy Fisher, Maria Maslennikov, Daniel Silber, Esther Jeon, Christina Martin, Nadia Guirguis, Falguni Kanthan, Marilyn Farinre

National Institutes of Health Clinical Center
10 Center Drive, Room 6-2551
Bethesda, MD 20892-1504

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Contact: Donovan Kuehn
donovan.kuehn@nih.gov



Meeting the language needs of patients

In-person, remote and written translations facilitate communication

"සායනික මධ්‍යස්ථානය වන සාදරයෙන් පිළිගනිමු" would elicit a raised eyebrow from most people, but for some Clinical Center patients they are welcome words after a long trip to Bethesda, Md. The phrase is in Sinhala, one of the two official languages of Sri Lanka, and it roughly translates as "Welcome to the Clinical Center."

According to the Centers for Medicare & Medicaid Services, more than 25 million people in the United States have limited English proficiency (LEP). These limits can make it more difficult to seek treatment in the medical system. Language barriers have been associated with lower quality of care, poor clinical outcomes, longer hospital stays and higher rates of hospital readmissions.

To help avoid those negative outcomes and provide safe and patient-centered care, the Clinical Center provides access to in-person language interpretation, remote interpretation and translated written materials.

These resources are provided to patients regardless of whether they are onsite, participating in a virtual telehealth appointment or talking to a member of the Clinical Center's staff over the phone.

The Language Interpreters Program is a part of the Social Work Department and is focused on providing professional medical interpreters to ensure quality, precision, and accuracy of interpreting. The services are provided at no cost for patients with LEP and can be requested in CRIS (the medical documentation system at the Clinical Center) with a minimum of 24 hours' notice. The Clinical Center also hosts a cross-departmental Language Access Committee to assess how it serves patients and visitors with limited English proficiency.

In March of 2020, the Language Interpreters Program transitioned most of its services to a virtual telehealth model and re-deployed its five full-time equivalent Spanish Certified Medical Interpreters to meet demand both virtually and onsite. Telephone and local interpreter contracts also supplement services.

Onsite services have continued for high-risk procedures, emergency situations and complicated informed consent encounters. The demand for robust linguistic services continually grows.



"Meeting the linguistic and cultural needs of our LEP patients is a matter of patient safety, commitment to the participation of diverse populations in research and represents a core value of the Language Interpreters Program," said Brenda J. Robles, a Certified Medical Interpreter and Manager of the Language Interpreters Program at the NIH Clinical Center.

While separate from language interpretation, the hospital also provides sign language interpretation for the hearing impaired through the Office of Research Services as another feature of its approach to patient-centered care.

In 2021, Spanish accounted for 80% of the oral linguistic services provided by the hospital and 98% of the translation requests for written patient education materials.

Language requests are tied to the language needs of patients enrolled in studies that treat patients in the Clinical Center. That can mean changes on a year-to-year basis depending on where patients may be coming from.

In 2021, two languages made it onto the most requested list for the first time: Sinhala and Dari, a variety of Persian spoken in Afghanistan. In previous years Hebrew, Portuguese, Mongolian and Amharic have been in demand.

While there's no way to predict which languages will be in demand from year to year, the Clinical Center is committed to capturing data trends to prepare for and to serve its patients with unmatched medical care, cutting-edge research and a commitment to understanding and communicating with all who walk through its doors.

-Donovan Kuehn



Hospital CEO maps out diversity and equity action plan

“Passion has to be transformed into concrete action”

Almost 2,000 federal staff work in the Clinical Center, and it's important how they feel about their workplace. At his April Town Hall, Clinical Center CEO Dr. James Gilman discussed some of the positives, challenges and opportunities ahead for the workforce.

To understand any issue, it always helps to get to the facts of the matter. To do this, Dr. Gilman walked through the hospital's workforce numbers, broken down by race/ethnicity.

Overall, the numbers indicate a diverse workforce in the Clinical Center. But hidden in those stats are some issues of equity.

“One of the insights that came from the demographic data is, like much of the NIH, we have an under-representation problem in terms of Hispanic/Latino staff members. We have far fewer than the racial and ethnic mix in the area where we live and work would suggest,” said Gilman.

Another issue is diversity decreases – particularly for the Black/African American population – as one looks at the senior General Schedule level and scientific/medical positions. The General Schedule (GS) classification and pay system covers the majority of civilian white-collar federal employees in professional, technical, administrative and clerical positions.

“There may be good diversity amongst Clinical Center staff, but there's not equal representation because there isn't equal representation at all levels,” stated Gilman.

“[H]aving more diverse leadership and more diverse representation related to our core business, which is biomedical science –

Clinical Center Diversity, Equity, Inclusion and Accessibility Commitments

Diversity

The Clinical Center will strive to ensure representation of all underrepresented groups at all levels and in all common job series at the hospital.

Equity

The Clinical Center will develop and utilize transparent processes for hiring, advancement, awards, rewards, incentives, training, travel, educational opportunities and workplace flexibilities.

Inclusion

The Clinical Center will assure the development of programs designed to enable those from underrepresented groups to compete on a more equal basis with those from overrepresented majorities.

Accessibility

The Clinical Center will continue to instill a culture of acceptance of individual differences, including those physical, emotional and mental conditions that may require accommodation(s) in order for the staff member to perform at their best.

including those who take care of patients in the Clinical Center – that would make our workplace better and that would make us a better place to do our core mission of clinical research.”

Dr. Gilman also shared the data collected when the Clinical Center conducted its Diversity, Equity, Inclusion and Accessibility (DEIA) Engagement Survey staff survey in the Fall of 2021. The survey was completely anonymous and was administered by an outside third party called Snowbird Consulting.

Over 700 members of the Clinical Center staff shared their thoughts out of 1,800 potential participants.

The survey results indicated high levels of engagement among staff and high levels of inclusion, although the results varied based on the racial background of the people who completed the survey.

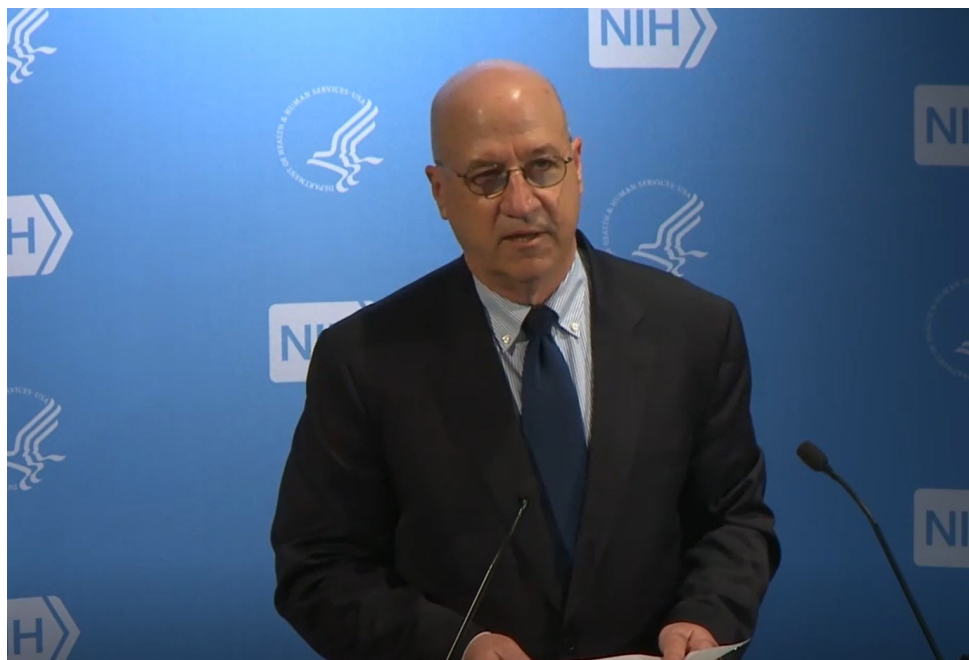
One additional insight was that 16% of all survey respondents disclosed having a disability, compared to seven percent reported to the NIH's Office of Equity, Diversity and Inclusion (EDI). Dr. Gilman drilled down on this discrepancy.

“There are a lot of people who feel that they have some sort of disability...and when questioned about why they failed to disclose it they felt that it had a career impact: that their assignments would not have been as good, that their opportunities for promotion and advancement or receiving an award would not be as good if they had disclosed [their disability],” said Gilman.

He stated that there are protections for staff with disabilities and that there is an opportunity to strengthen the education of the hospital's supervisors to help ensure that they accommodate and not penalize staff with disabilities.

“There's a lot of work that's been going on. A lot of work and a lot of passion. And that passion has to be transformed into concrete action - things we can actually do in order to make a difference,” said Gilman.

After sharing the data, Gilman mapped out a plan of action, which includes:



Dr. James Gilman addresses the Clinical Center Town Hall

- Addressing hiring gaps in senior positions
- Creating a written policy for hiring and advancement in the Clinical Center that hospital leadership will ensure is shared widely and followed across the organization
- The Clinical Center will work with EDI and the Office of Human Resources to ensure both applicants and selectees for senior positions are diverse
- Expanding the DEIA awards and recognition program for the Clinical Center
- Providing cash awards to all staff of a department/office that meets diversity criteria
- Engaging, recruiting and hiring from Minority Serving Institutions and Historically Black Colleges and Universities
- Making equity a foundational consideration in recognition, retention and development programs at the NIH Clinical Center

“We are not going to solve this today, this week, next week, month or year – but it is a good start. And it will be a journey – we are committed to stay on it,” said Gilman.

The Clinical Center depends on a diverse workplace that embraces a culture of teamwork and collaboration. For more information on the Clinical Center’s Diversity, Equity, Inclusion and Accessibility committee and hospital equity initiatives, please visit <https://intranet.cc.nih.gov/deia> (Staff only)

Demographic	Percentage of Medical Officers	Percentage of CC Workforce overall
White/ Caucasian American	65.2%	40%
Asian American	25%	18%
Black/ African American	5.3%	36%
Hispanic/ Latino American	3%	4%

-Donovan Kuehn

Sharing music with the hearing-impaired

Dr. Charles Limb presents first in-person Grand Rounds lecture since 2020

In May, Dr. Charles J. Limb was recognized as the 2022 Distinguished Clinical Research Scholar and Educator in Research (DCRSER). As the 2022 NIH Clinical Center’s DCRSER honoree, Dr. Limb gave a “Great Teachers Lecture,” a special session of the weekly Clinical Center Grand Rounds program. Titled *Music for Deaf Ears: Cochlear Implant-Mediated Perception of Music*, this was a subject Dr. Limb cares about passionately.

Limb is a professor in the Department of Otolaryngology – Head and Neck Surgery at the University of California, San Francisco, the Director of the Douglas Grant Cochlear Implant Center in San Francisco and the Medical Director of Cochlear Implantation at UCSF Benioff Children’s Hospital in Oakland, California.

Following the lecture, Dr. Richard Childs, a Rear Admiral in the United States Public Health Service Commissioned Corps and



Dr. Charles J. Limb receives recognition from Dr. Richard Childs

a Senior Investigator at the Laboratory of Transplantation Immunotherapy in the National Heart, Lung, and Blood Institute’s Division of Intramural Research, presented a certificate of appreciation to Limb.

Limb is a scientist and musician who has conducted pioneering research using neuroimaging. His research examines the

hearing and language function of the brain in the creation and perception of music by musicians and listeners with normal or impaired hearing, including those with cochlear implants (CIs). He is known for involving musicians and music in presenting these discoveries to broad scientific and lay audiences.

Limb published a first-author paper in 2008 of a study at the NIH Clinical Center that examined “improvisation in professional jazz pianists using functional MRI,” which has been cited over 830 times. As an independent investigator, Dr. Limb continued this line of research and in 2014, published a paper that examined the interactive nature of improvisation between two musicians.

Full story online at www.cc.nih.gov/ccnews

-Debbie Accame

Clinical Center cGMP Sterility Lab is first of its kind in an academic hospital

Lab fulfills hospital need; moved into new space in May

The Department of Laboratory Medicine's (DLM) Sterility Lab performs behind-the-scenes operations normally taken for granted at the NIH Clinical Center. So when the lab received a CEO award last December for Innovation, the 12 front-line bench technologists and three managers were very excited, according to Dr. Anna Lau, the chief of the Sterility Testing Service, who led the lab's establishment.

The award recognized the outstanding inter-disciplinary collaboration that established the cGMP Sterility Lab to "support the NIH cGMP program for Investigational New Drugs discoveries and patient care innovation."

Current Good Manufacturing Practices (cGMP) are a set of Food and Drug Administration (FDA) regulations designed to ensure that a medication is safe and has the ingredients and strength it claims to have. There are stringent requirements for the methods, facilities and controls used in manufacturing, processing and packaging of a medication.

NIH Leadership identified the cGMP Sterility Lab as a critical need at the NIH in 2015/2016, following two high-profile product contamination events, FDA inspections of multiple facilities and the Red Team report.

Since 2018, the Sterility Lab staff worked many additional hours, not only supporting the 13 different manufacturing facilities on the NIH campus, but also building new microbiology lab practices needed to meet cGMP compliance. They created a new lab from scratch, including hiring and training personnel, establishing practices, creating documents and implementing new systems.

There was even construction of a brand-new physical cGMP lab that they moved into in early May 2022. During construction, they operated in a temporary lab in Building 10, while creating the foundations for improved cGMP practices.

"Every team member in the Sterility Lab stepped up 200% to not only complete the high-volume daily work duties, but to take

on additional projects and tasks to prepare for the new lab. We take great pride in our work and the services that we offer to NIH to support patient care," Dr. Lau said.

Staff who contributed to this effort spanned the hospital, including DLM, Hospital Engineering and Facility Services, the Office of Research Support and Compliance and the Office of Research Facilities.

Everyone played a role in helping to coordinate activities for the new lab, including project management, validation and commissioning activities and establishing cleaning and gowning programs.

This is a unique lab for an academic hospital. There are manufacturers and private companies that specialize in cGMP microbiology, but none exist within a hospital or academic setting.



The Sterility Lab Team is very excited to be in their new, qualified cGMP lab.

This core lab performs the testing of all investigational drugs in clinical trials at NIH. There are 13 manufacturing facilities on campus, with eight at the Clinical Center, four at the National Cancer Institute, one

at the National Institute for Mental Health and numerous more new cGMP facilities under development at the NIH. All of these departments focus on making novel medications that go from "bench to bedside."

In addition to product testing, the lab must constantly monitor and test environmental cultures to ensure that manufacturing spaces are operating under a state of control. Everything must remain clean to maintain the safety, quality and integrity of the products.

Dr. Lau noted, "Having our on-site laboratory provides on-site expertise and helps expedite the process of getting new products into development, investigation and trials."

The Sterility Lab also managed to roll out new document management systems to ensure cGMP compliance, including the MasterControl document management system and the REES Environmental Monitoring System.

This required focused organization and coordination for project management across multiple teams, according to Dr. Lau.

James Gebo, the Sterility Lab's quality assurance manager, was one of the few staff who had previous experience in a cGMP environment. Lau noted, "This could not have been possible without James, who spearheaded the construction project and was instrumental in helping us develop our cGMP program."

Amanda East, the Sterility Lab's operations manager, also played a critical role in getting the lab to a state of readiness. East said the team is excited to have this qualified space that meets all the cGMP standards. "This is great for us and for all of NIH," she said.

-Debbie Accame

Building for all

Short term disruptions ahead of improvements at NIH



Cranes and fresh asphalt are appearing around the National Institutes of Health Clinical Center as the NIH prepares for a bout of construction on campus.

From now until 2028, the NIH campus will be in flux with street and lane closures accommodating construction crews as roads and facilities are improved.

Some of the changes include traffic adjustments to help vehicles flow on and off campus; modified traffic light timing on highway MD 187; a new, dedicated roadway for Safra Family Lodge and Building 60; closures of Convent and Center Drives to general campus traffic and reduced access to parking in some parts of the campus.

The NIH Office of Research Services and the Office of Facilities will be revising and updating signage to clearly communicate these changes as they're implemented.

Be up to date before you get to campus, visit www.traffic.nih.gov to see the latest developments and to help you navigate as things change.

Hospital unveils “Wellness on Wheels”

Cart provides support for pediatric patients and their families

Last year, the average hospital stay at the NIH Clinical Center was 9.4 days and some stay for far longer. No matter how well prepared you are, that’s a long time to be away from the comforts of home. Now the hospital has a partner who wants to bring a little extra support to pediatric patients and their families while they receive treatment.

At the beginning of May, the Clinical Center and the Mattie Miracle Cancer Foundation unveiled a “Wellness on Wheels” cart at the hospital. The cart provides free snacks, blankets and other comfort items to families who are caring for a child with cancer and other serious illnesses.

Currently, there are around 1,600 clinical research studies in progress at the NIH Clinical Center. Of those research protocols, 35% include children and 14 NIH Institutes admit children as a part of their research and treatment. In 2021, pediatric patients accounted for about 10% of the Clinical Center’s patient activity with that number expected to grow in coming years.

Attendees were addressed by Dr. James



Staff and patient at the unveiling of the Wellness on Wheels cart.

Gilman, the Clinical Center’s CEO, Wiener, Dr. Victoria Sardi-Brown, co-founder and president of the Mattie Miracle Foundation and Peter J. Brown, co-founder and CEO of MMCF.

The Wellness on Wheels was revealed at a special ceremony in the hospital’s seventh floor atrium. Luciano Javier Perez Vela, a pediatric patient being cared for by the Clinical Center Pediatric Service, was the guest of honor who unveiled the cart for the gathered staff and guests. He quickly went

to explore what the cart had to offer and pulled out some items he thought would comfort his mother.

The Wellness on Wheels initiative was facilitated through the efforts of Dr. Lori Wiener, the co-director of Behavioral Health Core and director of the Psychosocial Support and Research Program for the National Cancer Institute’s Pediatric Oncology Branch, staff in the Office of Administrative Management and the hospital’s Pediatric Service.

“We have launched significant research and operational changes to strengthen and expand our ability to care for pediatric patients,” said Dr. James Gilman, CEO of the Clinical Center, to the assembled crowd.

“Whereas our mission is to conduct the research necessary to improve human health, we understand that feeling cared for counts. It counts tremendously. Patients often come to the CC when they have no other options. We will not add to their burden by failing to assist them in every way possible,” added Gilman.

-Donovan Kuehn

Surgery nurses receive “TrueNorth” award

Recognized for lifelong learning; advocating for patient safety

The NIH Clinical Center Perioperative Nursing staff were honored with a TrueNorth award by the Competency & Credentialing Institute (CCI), a non-profit credentialing body focused on improving patient outcomes.

The TrueNorth Award recognizes organizations that use certification as a “true north” to guide their perioperative nursing staff to be lifelong learners, models of competent practice and advocates for excellence and patient safety. The NIH Clinical Center was the only perioperative facility selected for the 2022 award.

Operating Room Nurse Manager Myra Henley led the credentialing effort and accepted the award on behalf of the OR nurses.

Acting Chief Nurse Officer Dr. Barbara Jordan emphasized that the Clinical Center’s Nursing Department (CCND) strongly supports specialty certification with financial support for certification exams and renewals as well as specialty certification preparation.

“We are very proud of clinical research nurses in perioperative services and their commitment to excellence in patient care and nursing practice with outstanding patient outcomes.



CC staff accept the award: (left to right) Elizabeth Custis, RN, Dennis Washington, RN, Jessica Turner, RN, Dr. James Gilman, NIH Clinical Center Chief Executive Officer, Myra Henley, OR Nurse Manager, CCND Chief Executive Officer, Dr. Barbara Jordan, Acting Chief Nurse Officer, Karen Holcomb, RN, and Celeste Klutsey, RN

They are most deserving of the TrueNorth Award,” said Jordan.

Henley noted that in 2018, the unit set a goal to increase the certification rate for perioperative nursing staff to at least 50%. By 2021, 62.5% of the perioperative nurses were certified.

The nurses were very proud of their accomplishments and overjoyed and honored to be selected as the recipients of the award.

“Receiving this award is such an honor and is important to the NIH CC and CCND because it displays that we are committed to our nurses’ lifelong learning, through the support of higher education and the seeking of certification, to enable this group to continue to provide quality and safe care supporting the mission and vision of the NIH,” remarked Henley.

“What makes this group so special and well-deserving is our nurses not only prioritize their growth and development; they also display their leadership by becoming peer-champions and supporting fellow staff members in achieving their certification,” added Henley.

Henley shared an African proverb at the end of her remarks that she felt reflected her feelings about this group, teamwork and their commitment to achieve the TrueNorth award: “If you want to go fast, go alone. If you want to go far, go together.”

-Debbie Accame

“I felt like someone was looking out for me”

Advancing rare disease research through partnership

Often, it's the parents of children with rare and poorly understood conditions who become prime movers in helping advance research and treatments for their kids and other families in similar situations. One way some organize and multiply their efforts is by creating a nonprofit research foundation dedicated to this mission, or by getting involved with one that already exists.

Through these efforts, parents can raise and distribute funding for research grants, produce vetted information and educational materials and create public awareness campaigns. But another vital aim of these rare disease foundations is creating working alliances in academia, industry and government to optimize partnerships in the United States and even abroad.

On Feb. 28, the virtually held NIH Rare Disease Day called attention to these often behind-the-scenes activities. One of the sessions - Our Journey With NIH: How One Rare Disease Organization Forged a Transformational Research Partnership – focused on the perspectives of a pediatric patient, a parent, a medical researcher and a nonprofit leader.

The rare disease discussed was juvenile myositis (JM), a serious autoimmune condition where the body's immune system attacks its own cells and tissues. Affecting under 5000 young people in the U.S., key features of JM include muscle weakness, fatigue and skin rashes.

The Cure JM Foundation was created in 2003 by a small group of parents and grandparents to address the fact that little was understood about this rare condition - and with an express aim of finding improved treatments and supporting patients and families affected by JM.

“Where does one start from virtual ground zero?” asked James Minow, Cure JM's Executive Director. “We knew we had to recruit other families and get them involved. We sought to bring the best medical and research expertise on board and finally, we had to establish partnerships with institutions like NIH to leverage the enormous research capacities they have. These efforts helped us get started.”

NIH Gets involved

NIH's Dr. Lisa Rider, Head of the Environmental Autoimmunity Group in the Clinical Research Branch of the National Institute of Environmental Health Sciences, has produced a significant body of research on JM and other systemic autoimmune diseases.

Her group has conducted a number of natural history and treatment studies of JM and related conditions and new studies are currently being designed. Dr. Rider credits

Cure JM for providing numerous patient referrals for this research.

“Our partnership with Cure JM has been instrumental in expanding our focus on JM research,” stated Rider.

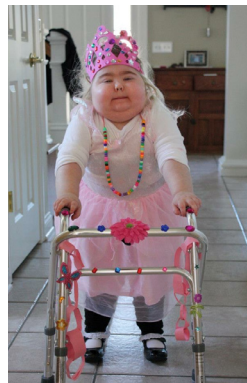
“They have helped support training for some of our research fellows, and also funded several key collaborations in our work, including support for an international myositis genetics consortium, studies of treatment responses in patients with JM, and work to develop new response criteria for myositis.”

Rider spoke further about additional links between Cure JM, NIH and jointly-conducted external research studies with George Washington University, which have helped hone the training of pediatric rheumatology fellows, residents, medical students and visiting faculty in providing clinical care to JM patients.

The value of this alliance with NIH was publicly acknowledged at Rare Disease Day, when Cure JM expressed their thanks to the several NIH Institutes involved in “finding better treatments and cures for patients and families who are living with JM”.

A Parent's Perspective and a Patient's Experience

Kristine Alderfer, recently elected as President



Katherine Alderfer at age 5

of Cure JM's Board of Directors, spoke about her initial experiences to help her daughter Katherine, who was diagnosed with the condition at age 4.

“A rare disease foundation needs to focus on being part of the process that brings forth better treatments, and many rare diseases don't have approved treatments. For Cure JM, it made sense to partner with major research institutions and especially NIH. Cure JM learned that NIH was already conducting basic myositis research and was able to help direct investigations specific to JM,” said Alderfer.

Kristine's daughter Katherine spared no detail in describing her daily experiences with JM – the appearance of a skin rash, being unable to climb stairs, choking on food and mood problems.

“My muscles were being destroyed and I was failing more every day,” recalled Katherine. Once a diagnosis of JM was made, her family did more research and

found a children's hospital in Indianapolis where she started infusions to stop further muscle deterioration.

“This was the start of 12 years of hospital stays and more treatments trying to figure out what worked best,” Katherine added.

It was at this point Katherine's family connected with Dr. Rider at NIH through a study on twins and siblings that are discordant for autoimmune disease. “I am thankful for this and so glad that Cure JM supports research in the NIH studies I have been part of. Participating in research studies is something rare disease patients have to do if we are going to find cures for so many of these diseases. When we take part in research we are building our own future.”

Katherine further observed that some JM patients respond better to existing treatments and further research is needed to help those JM patients who are not as fortunate. “I had heard that no two kids with JM are exactly the same, but the doctors and researchers at NIH already knew this.” She also feels good that while she is being helped, this same work is helping others like her. “When I came to NIH I felt like someone was looking out for me.”

Kristine Alderfer's advice on finding help at NIH and other large research facilities is to start with internet research. A starting point is the Genetic and Rare Diseases (GARD) information center. She also urges parents to make full use of the NIH RePORTER, a valuable portal to aggregated information on the spectrum of NIH research.

“You enter the disease to find researchers studying the disease and which ICs are funding research for them. You can find published studies, even if they were not associated with NIH, and connect with those groups.”

The NIH Clinical Center's Office of Patient Recruitment (OPR) can help with clinical trial participation – it's just a matter of contacting one of their information specialists to start the process.

Dr. Rider added “A rare disease foundation adds the dimension of bringing in families and finding strength in numbers and dedication to a cause. Cure JM has been very successful in engaging families and that translates into accelerated research participation. Seeing Katherine's outcome, and how she's doing with JM, has been so heartening to see through the years.”

You can watch the 2022 Rare Disease Day panel discussions, rare diseases stories and more at <https://videocast.nih.gov/watch=44155>

-Robert Bureson