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These complex patients were being screened out; now they're being screened in

New NIMH Autoimmune Brain Disorders Program highlights patient inclusion and interdisciplinary collaboration

Typical teenagers can appear to be riding an emotional roller-coaster - happy one day, sad the next. But something is different this time. They start to get easily confused and sometimes paranoid. They can't focus or sleep and start to act out in inappropriate ways. For parents of kids with autoimmune brain diseases, this reality is all too familiar.

Autoimmune brain diseases, including autoimmune encephalitis and central nervous system (CNS) vasculitis, refers to a group of conditions that occur when the body's immune system mistakenly attacks healthy brain cells. According to the Genetic and Rare Diseases Information Center, which is supported by the National Center for Advancing Translational Sciences, this can cause various neurologic and/or psychiatric symptoms such as impaired memory and cognition, abnormal movements, seizures, problems with balance, speech or vision and psychiatric symptoms like psychosis, aggression, panic attacks, compulsive behaviors, euphoria or fear.

Symptoms may vary and can progress over time, jeopardizing the safety of those affected and sometimes progressing to a loss of consciousness or coma.

Many patients with autoimmune brain disorders may be perceived as "too sick" for a traditional psychiatry inpatient unit and "too psychiatrically complex" for a general pediatric unit. In the past, many studies excluded this group of patients from research leaving them very few options for care or to find out more about their illness.



Staff from across several units - Pediatrics, Pediatric Psychiatry and the Neurology Department - collaborated to bring this project to life

Now, a new team within the Clinical Center will be able to serve pediatric patients with this condition. The National Institute of Mental Health (NIMH) Autoimmune Brain Disorders Program officially launched in the 1SW unit, under the leadership of Medical Director Dr. Gena Mooneyham, a pediatrician and child psychiatrist by training.

This effort required months of interdisciplinary planning, which blossomed out of a collaboration between Dr. Avindra Nath, the Clinical Director



Dr. Gena Mooneyham, Medical Director of the Autoimmune Brain Disorders Program at the National Institute of Mental Health

for National Institute of Neurological Disorders and Stroke and Dr. Maryland Pao, the Clinical Director for NIMH. Since then, it has extended across all aspects of the day-to-day patient care and the development of their translational research portfolio.

Nurse Educators Myra Woolery, Rosa Roseau and Chris Gagnon worked together with Nurse Manager Andrew Nyabwari and

Clinical Nurse Manager Tom Houston, to develop and implement a new interdisciplinary curriculum for the nursing team. This joint collaboration proved invaluable with the unit's launch, according to Dr. Mooneyham.

Patients do not ordinarily have the ability to receive intravenous infusions or oxygen support in designated behavioral health spaces and they often need to be transferred out to a general pediatric unit. However, unit staff received extensive training on the safe administration of IV infusions and oxygen support and use a simulation learning space on the unit to facilitate ongoing training. The wall panels house oxygen and suction equipment behind a safety panel and all other equipment was intentionally selected so that it could be "brought in" and "taken out" as needed, different from the standard inpatient room.

According to Houston, the staff greatly appreciated the willingness of team members to share their expertise as they learned the necessary skills to take care of these patients.

"This whole effort would not have been possible without the extraordinary leadership and guidance of Dr. Mooneyham. She has been an advocate for us every step of the way, either through providing education herself or by bringing in former nursing colleagues for virtual group discussions who have been through a similar transition," said Houston.

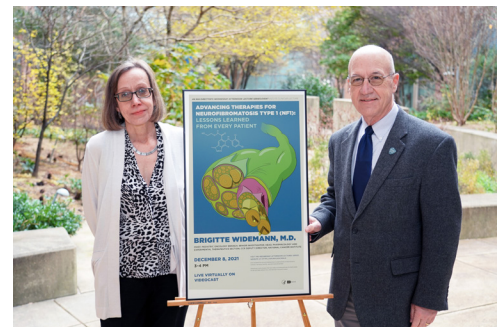
Dr. Gena Bergvall, an Advanced Practice Nurse - Clinical Nurse Specialist and Nurse Practitioner for Neuroscience Nursing, was also instrumental in the curriculum development and directly involved in the first patient admitted in July 2021 as a joint initiative with the Neurology unit.

NIH researcher recounts pursuing a treatment for childhood tumors

Astute Clinician Lecture describes 30-year search for a solution

In December 2021, Dr. Brigitte Widemann, Chief of the Pediatric Branch for the National Cancer Institute, presented the Astute Clinician Lecture, *Advancing Therapies for Neurofibromatosis Type 1 (NF1): Lessons Learned from Every Patient*.

Neurofibromatosis type 1 is a rare genetic condition people are born with and causes tumors to grow along the nerves. It most commonly occurs in children and can lead to the development of plexiform neurofibromatosis (PN) which can then progress to become a variety of tumors affecting the nervous system, as well as endocrine and gastrointestinal functions.



NIH Clinical Center CEO, Dr. James Gilman recognizes Dr. Brigitte Widemann, presenter of the 2021 NIH Astute Clinicians lecture

Symptoms tend to develop gradually over many years and can vary from person to person. PN are slow growing but over time can occur on the face (including around the eye), neck, arms, legs, back, chest, abdomen and internal organs. They can become large and disfiguring and create significant physical and emotional distress for young patients.

Large tumors can cause a nerve to become thick and misshapen, which can affect the structure of nearby bone, skin and muscle and can cause severe pain, mobility problems, vision and hearing loss and high blood pressure. Most plexiform neurofibromas are not cancerous, but can develop into aggressive cancers.

Apart from complete surgeries, which were not guaranteed to resolve the condition, there were no effective therapies.

Widemann's research team hoped to change that. They measured growth and size of PNs by determining three-dimensional tumor mass, finding that younger pediatric patients showed the most rapid growth. Researchers also found that once started, tumor growth did not reverse or decrease in the slightest.

Hospital receives outstanding nursing quality award

The National Institutes of Health Clinical Center was among six medical centers recognized with the NDNQI (National Database of Nursing Quality Indicators) Award for Outstanding Nursing Quality for "elevating nursing excellence, and in turn, improving patient outcomes."

The award was presented by the technology firm Press Ganey, which works with more than 41,000 health care facilities focused on improving the overall safety, quality and experience of care. According to Press Ganey, the NDNQI Award for Outstanding Nursing Quality honors the best-performing academic medical centers, teaching hospitals, community hospitals, pediatric hospitals, psychiatric hospitals and international hospitals, based on an assessment of 17 areas of nursing measures.



Image of NDNQI Award

Since the award was due to hard work throughout the hospital, it is circulating on a tour throughout the Clinical Center's units and specialty areas so all staff have a chance to celebrate the achievement and take a photo with it.

The NDNQI was established by the American Nurses Association in 1998 and is a voluntary database of unit-specific quality indicators that are directly related to nursing care. These data connect the impact of nurse staffing ratios, direct patient care and quality outcomes.

The national database focuses on specific quality measures for hospitals and medical centers and includes six criteria focused on nursing staff:

- Nursing hours per patient day
- Registered Nurse education/certification
- Nursing staff skill mix
- Nurse turnover rates
- Nursing care hours in emergency departments, perioperative units and perinatal units
- Skill mix in emergency departments, perioperative units and perinatal units

"We are honored to be recognized for the commitment and dedication to patient safety and excellent patient care demonstrated every day by our clinical research nurses and interprofessional colleagues. This is a significant achievement for Clinical Center and IC staff members," said Dr. Barbara Jordan acting chief nursing officer for the hospital.

"Now more than ever, it is important to acknowledge and celebrate the strength and resiliency of these dynamic health systems across the nation who, despite facing enormous challenges, have continued to provide their communities with safe and exceptional care," said Patrick T. Ryan, the chairman and chief executive officer of Press Ganey.

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Early clinical trials did not reverse or halt progression of PN tumors when compared to existing natural history data. However, later studies using the medication selumetinib showed positive responses leading to reduced tumor size, lessened disfigurement and lower reported pain levels for many patients. Some pediatric patients participated in multiple trials, offering a basis for comparison.

In 2020, 30 years after the discovery of the NF1 gene, Widemann's pioneering research on NF1 resulted in the first U.S. Food and Drug Administration approved medical therapy, the MEK inhibitor selumetinib, for children with NF1 and inoperable, symptomatic plexiform neurofibromas.

Selumetinib has since been approved in other countries and a study of selumetinib for PN in adults is now underway.

"It was really a marathon, not a sprint," Widemann noted, remarking on the time and breadth of study required to arrive at an approved drug therapy for PN. Widemann also mentioned the launch of a new NF1 natural history study and cited current and proposed cooperative studies inside NIH and with external researchers, with each one having the potential to enrich the broad scope of NF1 studies. She viewed this as a continuation of the progression of research that began 30 years ago.

The Astute Clinician Lecture was established in 1998 through a gift from the late Dr. Robert W. Miller and his wife, Haruko, to recognize U.S. scientists who have observed unusual clinical occurrences and, by investigating them, have opened an important new avenue of research.

View the lecture on NIH Videocast at <https://videocast.nih.gov/watch=43814>.

- Robert Bureson and Mickey Hanlon

New Pharmacy opening in 2022



New Pharmacy opens later this year

Clinical Center CEO, Dr. James Gilman, tours the new permanent pharmacy facilities under construction in the hospital. Expected to open in 2022, the new Clinical Center Pharmacy will be home to Outpatient, Unit-Dose and IVAU (Intravenous Admixture Unit) operations, with state-of-the-art automation to support the efficient and accurate delivery of medication preparation and dispensing services and with streamlined processes to improve our patients' safety and healthcare experience.

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Bergvall explained, "As nurses and health care practitioners, we sometimes rely on the comfort of our specialty and may not see beyond the patient's primary diagnosis. This collaboration is an example of when nurses went beyond their specialties (behavioral health and neuroscience) to develop a holistic plan of care, truly customized to the patient's needs."

"Dr. Mooneyham respected the nurses' feedback and utilized a shared knowledge and decision approach as measured by consistent and efficient daily patient rounds. This shared mutual respect empowered the nursing teams to participate in decision-making," she added.

Mooneyham emphasized that the nursing collaboration between Pediatrics, Neurosciences and Behavioral Health has been a critical component to their success. It highlights the inclusion of a patient population that was previously excluded, as well as interdisciplinary collaboration.

"It has been a joy and privilege to get to see everyone coming together across specialties."

- Debbie Accame

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Editor: Donovan Kuehn | Layout: Justin Baker
Contributors: Debbie Accame, Robert Bureson, Janice Duran, Cindy Fisher, Mickey Hanlon, Maria Maslennikov, Daniel Silber

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



Clinical Center

UDP brings hope to patients with perplexing conditions

Patient talks about her decade in the Undiagnosed Disease Program

Imagine visiting your doctor and having them tell you they have never seen symptoms like yours in their entire medical career. For thousands of Americans, this is their everyday reality.

The NIH Undiagnosed Diseases Program (UDP) focuses on the most challenging medical cases referred to the Clinical Center. The initiative originated in 2008 from the National Human Genome Research Institute, the NIH Office of Rare Diseases Research and the NIH Clinical Center to study previously unknown or otherwise puzzling conditions that resist diagnosis, are considered undiagnosed and some qualify for further study.

With the express goal of providing answers for patients with mysterious conditions and a general aim to learn more about these medical mysteries, UDP gathers teams of experts in many specialties from across NIH to work on these cases. Clinicians often use advanced DNA and genomic sequencing analyses to uncover clues about the illnesses.



Louise Bengé, participant in the NIH Undiagnosed Diseases Program for the past decade

One participant, Louise Bengé, has been enrolled in the program for a full decade, making a continuing series of visit to the Clinical Center for initial evaluation, ongoing study and follow-up. She recently spoke with Clinical Center News about her experience.

This interview has been edited for length and clarity.

What were you experiencing that led you to the Undiagnosed Disease Program at the Clinical Center?

Louise Bengé: My legs had started bothering me while I was in my 20s – the calves of my legs became hard as rock and it was difficult to walk. I saw several specialists, and one said “you have the legs of a 60-year old woman” – my own mother was 60 at the time and getting around better than I was. I had seen one specialist who thought surgery might be an option but then decided against it. Some doctors I saw just thought I needed to walk more!

But the family physician got really involved and referred me to the local hospital to get an ultrasound. These results alarmed the ultrasound specialist, who immediately contacted my doctor who then became even more concerned. She was the one who then contacted NIH on my behalf. I was accepted into this program along with all my sisters and brothers who were experiencing the same problem. This shared condition was of special interest to NIH.

There was bloodwork, various types of scans, heart testing and evaluation and more. Our return visits were set for every six months and then it went to an annual visit.

What happened when you first arrived and NIH and what followed that initial visit?

Bengé: I first went with one of my sisters. We thought we'd be there for three days but it lasted 10 days! We went through a battery of tests- it seemed like every test imaginable. There was bloodwork, various types of scans, heart testing and evaluation and more. Our return visits were set for every six months and then it went to an annual visit. We started out staying in the Clinical Center, but later moved to the Family Lodge.

What was learned through the UDP about your condition?

Bengé: They suspected right away there was a genetic component in this. My parents had been told they were very distant fifth cousins, but the Undiagnosed Diseases Program found they were actually third cousins. So we have a genetic abnormality that results in having insufficient adenosine to keep blood arteries from hardening and calcifying.

Where do things stand now with your participation in UDP?

Bengé: We all still come up once a year for testing and examination as they continue to study what might decrease or halt this condition. I feel lucky to be in this program interested in following our family's journey with this genetically-linked condition.

In 2012, building on the early successes of the UDP, NIH extended the program into a network of seven academic medical centers around the United States, known as the Undiagnosed Diseases Network (UDN). In 2018, the network expanded again to incorporate 12 sites around the country.

Do you know someone who might be one of the estimated 25 million Americans who suffer from a rare disorder? The UDN is currently accepting participant applications.

To learn more visit <https://undiagnosed.hms.harvard.edu/apply/>, email UDN@hms.harvard.edu or call 1-844-RING UDN (746-4836) (toll-free from USA, Canada and Mexico) or 1-617-432-2344 from all other countries.

- Robert Burleson

Concert unites Clinical Center patient and staff in music

As the sweet sounds of the ballad “Hallelujah” wafted through the NIH Clinical Center’s atrium, there were some damp eyes and all were reminded just how amazing this place is.

A Thanksgiving-week concert featured 13-year old Caesar Santos on violin, NIH Director Dr. Francis Collins on guitar and National Cancer Institute Post-baccalaureate fellow Robert Masi on piano. The pieces ranged from classical to spiritual.

Santos’ musical talents emerged early; he began playing the violin when he was two years old. He almost lost his life to sickle cell disease and after suffering multiple strokes beginning at age four, had to relearn how to play the violin each time. But he defines resilience, and in September Santos received a bone marrow transplant from his sister at NIH in a clinical trial in the Cellular and Molecular Therapeutics Laboratory led by Dr. John Tisdale of the National Heart, Lung, and Blood Institute.

Santos is now on the road to recovery and is happy to show off the pink color that has returned to his hands and lips as the donor bone



Caesar Santos

marrow is taking root and his sickle cell disease is fading away. Through his music, Santos and his family wanted to thank the hospital staff for all the help they have received during these challenging times.

Read the full story online at www.cc.nih.gov/ccnews

- Debbie Accame

Clinical Center staff take home 2021 NIH Director's awards

150 staff recognized for outstanding contributions

The pandemic isn't over, but some of the hard work in getting us closer to that goal has been recognized by the NIH Director. Dr. Francis Collins announced the winners of the 2021 Director's awards and Clinical Center staff featured prominently.

There were 150 people recognized in group awards, with an additional five individual award winners in four different categories.

Among the groups recognized were the NIH Asymptomatic Testing Team who planned and implemented a site in the NIH Clinical Center to screen for SARS-CoV-2 infection in asymptomatic staff. As a result of the efficiency of the testing site, the hospital was able to expand testing to include the rest of the NIH campus with no increase in staffing levels and served as a model to other NIH sites and federal agencies.

The NIH COVID-19 Vaccine Clinic Team was acknowledged for superior efforts to plan and operationalize a COVID-19 Vaccine Clinic in the NIH Clinical Center to enable administration of vaccine doses for NIH staff. The efficient design and operations of the clinic ensured the NIH successfully administered all available doses with no waste, little or no wait times for staff and streamlined reporting.

The Critical Care COVID-19 Transport Team was recognized for developing air and ground transport procedures for Critical Care COVID-19 patients coming to the NIH Clinical Center.

Early in the process when ground transport was not available to pick up a patient at the helipad, the ICU Urgent Transport Team and the NIH Fire Department responded to bring patients to the ICU.

The Clinical Center Nursing Executive Team was acknowledged for their leadership in the planning and execution of efforts to support the National Institutes of Health during the COVID-19 pandemic. As the COVID-19 pandemic reached community level spread, keeping the occupants of Building 10 safe became a priority. In March 2020, nursing staff volunteers and USPHS Commissioned Corps Officers set up symptom screening areas and 100% masking was incorporated to keep people safe in the hospital.

The Personal Protective Equipment (PPE) Supply Chain Group received a shout out for outstanding service in the planning and distribution of PPE, ensuring safety and health during the 2020 national COVID-19 pandemic. During this critical time, this team established and improved processes to monitor, allocate, and inventory proper PPE usage across the NIH campus.

The DLM COVID-19 Sample Accessioning Team was recognized for exceptional performance and demonstration of technical abilities as health technicians (phlebotomists) at the NIH Clinical Center. Since the rapid launch of COVID-19 testing platforms in early 2020 the Accessioning Team processes thousands of COVID-19 test samples per week.

The Patient Support Services Department Customer Service and Support Team was acknowledged for exceptional customer service and support provided to patients, research teams and Clinical Center departments during the pandemic.

Staff excelled in customer service, willingly took on additional responsibilities and worked extra hours to support the NIH Clinical Center during this difficult year.

The NIH Clinical Center Medical Supply Technician Team was recognized for its high-quality customer service focused on PPE for the safety of NIH staff and patients throughout the COVID-19 pandemic. This dynamic, dedicated and collaborative group of individuals displayed highly specialized skills and expertise while working together to maintain sufficient levels of PPE in support of the hospital, NIH Institutes and Centers and many other stakeholders throughout the pandemic. Their efforts solidified the NIH Clinical Center's ability to support staff, patients and visitors during the pandemic.

A complete staff listing of the Clinical Center awards can be seen at <https://directorsawards.hr.nih.gov/2021/awards/ic/cc>.

For the full list of all NIH Director's awards visit <https://directorsawards.hr.nih.gov/>

Diversity, Equity, Inclusion and Accessibility at the Clinical Center

The NIH Clinical Center has developed a comprehensive program to combat racism and reduce disparities across the workforce which will be implemented in early 2022.

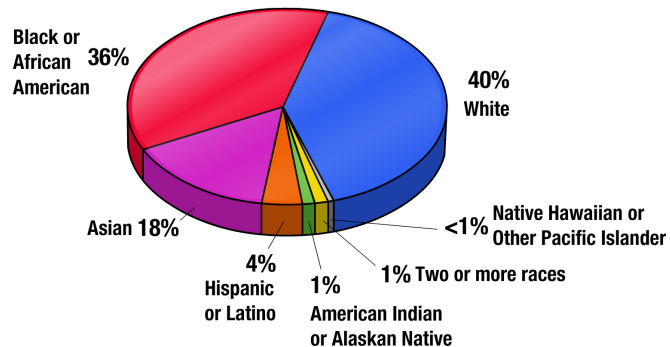
This program includes a Diversity, Equity, Inclusion and Accessibility (DEIA) committee, with a mission to create, promote and sustain an organizational culture that advances DEIA in all levels of the Clinical Center. While this program is new, the concepts are not. The hospital depends on a diverse workplace that embraces a culture of teamwork and collaboration. Senior leadership has highlighted the need to focus on and elevate the organization's DEIA values, particularly related to structural racism and inclusion.

The vision of the Clinical Center's program is to highlight and ensure that the hospital is proactive in reducing disparities across its workforce, especially in leadership positions. As it currently stands, NIH's total workforce is not representative of the nation's overall demographic makeup and the equity gap is even greater when looking at career levels within the demographics.

The DEIA program aims to highlight and ensure that the CC is proactive in reducing disparities across the workforce, beyond hiring initiatives. The Clinical Center is actively making efforts to ensure it continues to provide a safe, inclusive, diverse and accessible environment for all staff.

NIH also offers great resources for accessibility such as the NIH Reasonable Accommodation Program in the EDI Office, a central interpreting program that enables employees who are Deaf and Hard of Hearing to request interpreters and Communication Access Real-time Translation (CART) services.

2021 Race/ethnicity data for the NIH Clinical Center



Source: <https://intranet.cc.nih.gov/deia>

Source: CC demographic data provided by NIH Office of Equity Diversity and Inclusion (EDI) and includes full-time equivalent federal employees only (Comm Corps are excluded). Data as of 3/27/21.

Furthermore, EDI implemented a Race, Accessibility, Culture and Equity (R.A.C.E) working group that looks to positively influence individual, institutional and structural change on these issues at NIH. However, these examples do not mean the work is done. Success will be reached when all staff at the Clinical Center feel welcomed, respected and valued.

"This will be a shared responsibility for all of us, so wide-spread understanding and on-going support will be essential to the overall success and sustainment of what will be a very long-term effort.

However, one thing we know for certain is, the time to act is now and we are doing exactly that," said Ila Flannigan, the deputy executive officer of the Clinical Center.

For more staff information on DEIA, please visit <https://intranet.cc.nih.gov/deia> (staff only)

Read the full story online at www.cc.nih.gov/ccnews

- Janice Duran