

Art project in the Clinical Center focuses on overdose crisis

Exhibit provides a link between art and medicine

One of the most painful and difficult experiences for a parent is the loss of a child, no matter their age. How does one even move forward after such a devastating loss?

For Theresa Clower, her son Devin's death at the age of 32 from a fentanyl drug overdose left her bereft and grieving. She describes him as a vibrant, smart person, who was close to his family and a joy to be around. Now Devin's and other portraits are on display in the Clinical Center through January 2023.

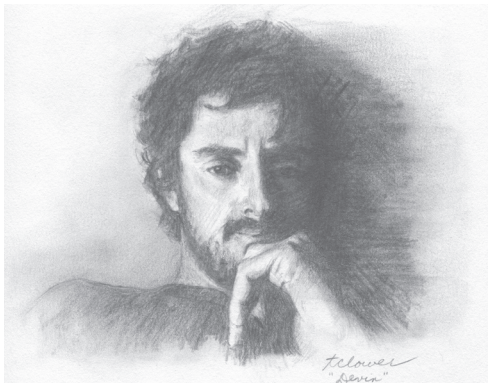
Fentanyl is a powerful synthetic opioid that is similar to morphine, but 50 to 100 times more potent. According to the National Institute on Drug Abuse (NIDA), opioids, including illicitly manufactured fentanyl, are now the most common drugs involved in drug overdose deaths in the United States.

Due to its potency and low cost, fentanyl is being mixed with other drugs, such as cocaine, methamphetamine and marijuana. This is especially risky when people taking drugs don't realize they might contain fentanyl as a cheap but dangerous additive. This can make the drugs stronger than their bodies are accustomed to and more likely to cause overdoses.

After Devin's death, Clower started drawing his portrait based on a photograph she had. She chose to draw in graphite pencil because she felt "it demonstrated lightness and darkness, which I think we all have inside us."

As she drew, she began to process her sorrow. She experienced how immobilizing grief can be and realized she could not live in that mindset forever. She describes herself as generally an optimistic person who has always been able to see the potential in all situations. So she made a decision to "move into hope" - to take the pain and give it purpose. She wanted to draw more portraits of others who had died from drug overdoses. She was still mourning but taking "small bites out of grief."

At first, it was difficult to get people to open up, due to the stigma toward addiction. Clower notes that people with addiction continue to be blamed for their disease, which prevents 90% of those with



Portrait commemorating a man who died of a drug overdose

substance use disorders from seeking help. It was hard to find friends and families who were willing to share their stories and struggles. However, as the project grew, she found more support.

Clower did not set out to create a national non-profit organization, INTO LIGHT Project but as she learned more, she began to see a vacuum in understanding the individuals who lose their lives to drugs. They come from all socioeconomic, educational and ethnic backgrounds.

In the following years, the number of exhibits grew, and ranged from Florida to California. PBS also interviewed Clower for their series "Growing Bolder."

Clower eventually connected with Dr. Nora Volkow, the director of the National Institute on Drug Abuse (NIDA). In 2021, Dr. Volkow participated in a video shown at an exhibit opening in Florida.

At that exhibit, Dr. Volkow expressed how science can help address the overdose crisis by developing treatments and preventing overdoses from occurring.

"Here at NIH, we work to advance science on drug use and addiction, and apply that knowledge to improve health for people and communities," Volkow said. "But science is only part of the picture. Communities also need to offer emotional support and help to encourage treatment and sustain recovery." Full story online at www.cc.nih.gov/ccnews

- Debbie Accame

Clinical Center launches new wellness initiative

Program will gauge staff well-being in the future



The NIH Clinical Center Leadership want you to be okay. That's not just a sweet idea – it's backed by a new wellness initiative.

The new program, called the Clinical Center Wellness Committee, seeks to elevate awareness of existing well-being opportunities and to leverage those programs more effectively. Hospital leadership also wants to find better ways to serve staff who work outside of the standard work day (9 am-5 pm) and to address long-term wellness opportunities.

"Addressing stress and burnout increases compassion and empathy, improves physical and mental health, and helps care providers reconnect with the joy and meaning of practice" said Dr. Ann Berger, Chief of the Pain & Palliative Care Department, Wellness Committee co-chair.

The benefits of improving employee wellness are plentiful. On a personal level, care providers can focus on the fulfillment of providing treatment to those in need. On an organizational level, there can be less staff turnover, an improved work environment, fewer medical errors, increased patient satisfaction and less energy spent on corrective actions.

The Clinical Center already has some resources for employee well-being in place. Among them is an Accreditation Council for Graduate Medical Education Wellness

Healthcare Simulation Week at the Clinical Center



Hospital staff in a simulated patient room.

The NIH Clinical Center held its Healthcare Simulation Week from September 12 through 16. Hosted by the hospital's Healthcare Simulation Program, the week showcased how state-of-the-art simulation can support training and education for clinical and administrative professionals.

Activities during the week highlighted resources, training aids and equipment available to healthcare professionals that can assist in improving team communication, patient safety and clinical outcomes.

The week also featured speakers including Dr. Joseph Lopreiato, Capt. (ret), US Navy, an associate dean for Simulation Education at the Uniformed Services University of the Health Sciences and former president of the Society for Simulation in Healthcare. Lopreiato spoke on the evidence supporting simulation-based education.

Additional presenters included Dr. Nitin Seam, associate chief of Critical Care Medicine, who spoke on simulation-based education for High-Risk Low-Volume care, and Dr. Mabel Gomez-Mejia, medical simulation facilitator, who presented on the NIH Clinical Center's simulation program activities and initiatives.

"This is only the beginning," said Ronald W. Gillis, healthcare simulation tech with the NIH Clinical Center Nursing Department. "We envision continued interest in the simulation program and its need to expand while leading the way for a higher degree of patient care within the NIH Clinical Center."

The week offered NIH and Clinical Center staff the opportunity to explore a scenario in the simulation suite. Employees from

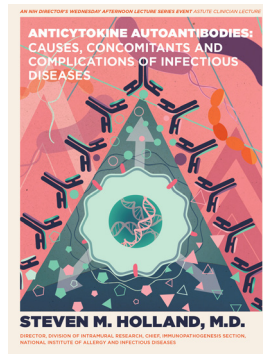
different disciplines and experience-levels participated in the activity.

"Many nurse residents are familiar with simulation, as a considerable amount of their clinical practicum hours in their BSN/MSN programs were done via simulation (in the sim lab and virtually) due to the impact of the pandemic on practicum site availability. Participating in this week's activity sets expectations high of what to expect when attending professional development offerings at the Clinical Center, and I look forward to exploring future partnerships with the CC Simulation Program to optimize learning outcomes," said Melanie Mudd, Clinical Research Nursing Residency program coordinator.

By creating a realistic healthcare environment, Healthcare Simulation Week provided learning tools that taught new skills, refreshed old ones and improved the delivery of safe and effective patient care.

- Yvonne Hylton

Holland presents 2022 Astute Clinician Lecture



Dr. Steven Holland, an NIH Distinguished Investigator, NIAID Scientific Director and Chief of the Immunopathogenesis Section, gave the Astute Clinician Lecture as a part of the NIH Director's Wednesday

Afternoon Lecture Series on November 2 via NIH Videocast. He presented "Anticytokine Autoantibodies: Causes, Concomitants and Complications of Infectious Diseases." Holland's lecture marked the 25th anniversary milestone for the Astute Clinician Lecture Series.

Watch the lecture at <https://videocast.nih.gov/watch=45960>. Continuing Medical Education credits will be available.

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Committee and Code Lavender - a rapid response program to help caregivers after a stressful situation, such as the loss of a patient. The Clinical Center also has mindfulness and meditation programs, yoga and debriefing sessions for staff with morally distressing situations.

"The committee will help foster an overall workplace culture of wellness, which is beneficial in variety of ways. Thanks to some great initiatives that were already underway and the goodwill of so many individuals dedicated to making wellness a priority, I believe this new committee is well-positioned to take staff wellness to an even greater level," said Dr. James Gilman, Clinical Center CEO.

In the immediate future, there will be an informational and planning session where the current wellness programs will be inventoried, and the leaders of these programs will be invited to join the hospital's new Wellness Committee. This committee will expand and include representatives from the National Institute of Mental Health, the Occupational Medical Service, the NIH Recreation & Welfare Association, Clinical Center Communications, as well as other stakeholders broadly across the hospital.

"Burnout is multifactorial. It's not limited to an individual or individual work groups. It affects an entire organization, and therefore, needs an organizational response. And, ultimately, in taking better care of ourselves and our colleagues we are more prepared to meet the day-to-day challenges we encounter," said John Pollack, MDiv, Chief of the Spiritual Care Department and Wellness Committee co-chair.

Within the next year, the Wellness Committee will develop metrics to document program use, measure the progress of improvements and implement at least one educational opportunity for the staff of the hospital. Informational materials to promote the programs are also under development.

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

- Dan Silber

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

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

Hospital staff share their experiences for Hispanic Heritage Month

Family, mentors and role models play a key role in success

September 15th through October 15th marks Hispanic Heritage Month, a celebration of the people and culture that contribute to the nation's cultural mosaic. The CC News reached out to Clinical Center staff to find out what the month means to them and learn about their experiences.

By its nature, Hispanic is a broad definition that encompasses many different experiences and backgrounds.

Juan Carlos Fierro Pineda was born and raised in Chihuahua, Mexico, and after finishing Medical School, he practiced for a few years in Mexico.

"From caring for Indigenous people living in poverty in remote areas of Chihuahua with nothing other than a stethoscope, to working in the ER department amid the Mexican narco war - these experiences shaped me professionally and provided me with a better understanding of our Latinx communities in the U.S. and the healthcare disparities amongst them," said Fierro Pineda.

Rosa Garay Lopez, who works as a certified medical interpreter in the Clinical Center's Social Work Department, cited her Puerto Rican heritage as a part of her desire to overcome obstacles.

"My Puerto Rican heritage is me being loud, speaking really fast, and me not sitting around just waiting for things to happen," said Garay Lopez.

Maritza Frazer-Sinclair, a Program Specialist in the Health Information Management Division of the Department of Clinical Research Informatics, traces her roots back to Puerto Rico and New York, and calls herself "Nuyorican."

"How my heritage shaped me, it gave me the need to assist others as I have seen my parents, aunts and uncles do. The desire to assist even in the smallest way and always in the background," said Frazer-Sinclair.

Jose Maldonado, an Administrative Officer for the Office of Administrative Management, said that his heritage helped shape the person he is today by hearing stories from his parents of "how my ancestors and generational family members took pride in themselves and their work."

The importance and influence of family was a recurring theme among those interviewed. Norma Street, a Perioperative Information System Application Administrator in the Department of Clinical Research Informatics, discussed the importance of family traditions as she grew up in Puerto Rico.

"My parents were very intentional about promoting traditions because as they said it fostered unity. And they were right!

Traditional food was always made at home, there were always family/friends in the

As she pursued her career at NIH she decided to further her education.

"I decided to go back to school to obtain a Master's in Healthcare Administration. I graduated a month before my oldest daughter graduated from college too. It was special! This education opened up doors for me to explore job opportunities," said Dorfeo-Connor.

Staff also discussed the importance of mentors and role models, citing their co-workers and family members as important factors in the development and progression of their personal lives and careers. Key attributes like patience, graciousness, determination, support and guidance came up again and again.

"I believe that in every stage of my journey at the Clinical Center I have been lucky enough to have a role model and mentor that has dedicated time and guided me through my goals in that moment. Throughout my time at NIH I have been lucky enough to have different leaders, colleagues and even patients that have inspired me to keep learning and progressing to be the best version of myself," said Maria Fagoaga, a clinical analyst who specializes in lab informatics for the Department of Clinical Research Informatics.

(Editor's Note: if you are looking for a mentor or to provide mentorship, the NIH has a mentoring program which can be reached at nihmentoring@nih.gov)

Valerie Velez Toro, a certified medical interpreter in the Clinical Center's Social Work Department, summed up her experiences at the hospital and the rewards that come with it.

"Every day, I work with Hispanic patients who come from different countries and backgrounds. This reminds me of how rich our Hispanic heritage is. I invite everybody to broaden their horizons and learn more about the Hispanic experience in the United States. You would be surprised at the beautiful things we have to share."

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

- Donovan Kuehn

5 things to know about Hispanic Heritage Month

Each year, Americans observe National Hispanic Heritage Month from September 15 to October 15, by celebrating the histories, cultures and contributions of American citizens whose ancestors came from Spain, Mexico, the Caribbean and Central and South America.

1. The observation started in 1968 as Hispanic Heritage Week under President Lyndon Johnson and was expanded by President Ronald Reagan in 1988 to cover a 30-day period starting on September 15.
2. September 15 is significant because it is the anniversary of independence for the Latin American nations Costa Rica, El Salvador, Guatemala, Honduras and Nicaragua.
3. Roughly 13% of people five years and older in the United States speak Spanish.
4. At about 62.6 million people, the Hispanic population of the United States makes up roughly one out of five (18.9) people of the nation.
5. According to the 2020 Census, 11.8% of Maryland's population is identified as Hispanic or Latino.

Learn more:
www.hispanicheritagemonth.gov

kitchen and laughter and loud music drowned [out] conversations! So, my world included many traditions that I continue to cultivate today with my own eclectic family here in Maryland" said Street.

Meanwhile, Brenda Robles, manager of the Language Interpreter Program in the Social Work Department, talked about her family's investment in education.

"My family is committed to education. We make it a priority to be present at the milestone of each other's lives, especially graduation events," said Robles.

Education also played an important role for Marina Dorfeo-Connor, a Hospital Administrative Officer with the Office of Administrative Management. She recounted her challenges with learning English and receiving recognition for her degree that she earned overseas.

Gubbi honored as Distinguished Clinical Teacher

Award winner lauded for “patience” and “sincerity”



Headshot of Dr. Gubbi

Dr. Sriram Gubbi was presented the NIH 2022 Distinguished Clinical Teacher Award (DCTA). The award is the highest honor bestowed on an NIH senior investigator, staff clinician

or tenure-track investigator. As this year's awardee, Gubbi will deliver the John Laws Memorial Lecture next year.

According to his nominators, Gubbi exemplifies the ideal qualities of a mentor, teacher, clinician and researcher. He is highly involved with the endocrine fellowship training program where he supervises and teaches fellows in clinics and conferences.

Gubbi is a staff clinician/assistant research physician in the Genetics and Endocrinology Section of the National Institute of Diabetes and Digestive and Kidney Diseases' Metabolic Diseases Branch. He is currently the lead associate investigator in natural history protocols on functional thyroid disorders and thyroid cancers.

Dr. Marja Brolinson, a clinical fellow at the National Institute of Child Health and Human Development and co-chair of the Clinical Fellows committee, praised Gubbi's interactions.

"With the utmost patience and sincerity, he always goes above and beyond to teach the fellows however many times it takes to solidify our knowledge - making difficult concepts easier and forming us into better clinicians," said Dr. Marja Brolinson in her introductory remarks.

Last year's DCTA winner, Dr. Jonathan Hernandez, a surgical oncologist with the Surgical Oncology Program in the National Cancer Institute, presented a lecture entitled *The Development of Implementation of Ex Vivo Human Tumor Systems for Translational Science*.

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

- Donovan Kuehn

Diagnosis to treatment: three siblings from Sweden return to the Clinical Center

Researchers study their rare genetic disorder

The Flysjo family from Sweden are a recent example of the reach and influence of the Clinical Center's rare disease research and how this research impacts the lives of people worldwide.

Their journey started with concern about developmental problems in their two-year old son, Hampus. They eventually found the cause: GM1 Gangliosidosis, an exceedingly rare and ultimately fatal inherited neurodegenerative disorder. A devastating diagnosis, this news was compounded by learning their younger twin daughters, Isabella, and Julia, also had GM1.

After receiving the diagnosis, parents Niclas and Jessica Flysjo quickly shifted from shock to action. They learned of NIH's National Institute of Human Genome Research

Institute (NHGRI) first-in-human gene therapy study for GM1. All three children were admitted to the study, but yet another challenge arose: the COVID-19 pandemic. In an attempt to slow the spread of the virus, the U.S. government decided to close

its border to foreign travelers. Determined to do what they could for their children, the Flysjo family arrived on one of the last flights into the United States before cross-Atlantic travel was paused.

Once at NIH, the Flysjo children received experimental intravenous injections aimed at making their bodies produce an enzyme needed to slow or even halt their neurodegenerative condition. They recovered at The Children's Inn for six-months and then returned to Sweden.

In the midst of the diagnosis, travel and treatment in a foreign land, the NIH campus provided a respite for the family.

"We were struck by how beautiful the building and surroundings are and we much appreciated how all of the staff took such good care of us.

To be greeted with a smile and a friendly 'Hello!' can really make a difference when you're having an otherwise difficult day," said Niclas.

Experimental treatments require periodic re-evaluation - for this study, the family has returned to the Clinical Center twice a year, with future visits planned annually for the next three years.

"We are pleased to learn there are no unexpected developments, but the best news is the treatment has considerably slowed down the disease progression. MRIs show promise and we've observed that the children are learning new skills, but more importantly not losing any acquired skills," added Niclas.

"For these return visits, it's more than just brain MRIs - there

are many other studies, including sleep studies, X-ray studies, ultrasounds and physical therapy. We do try explain to them what is about to happen before they go for a procedure although we know their understanding is limited because of



Hampus enjoying a family trip.

their age and condition."

"Back in Sweden, we continually work towards having the children retain the progress they have made," he summarized.

On every visit, the Flysjos have noticed the competence and professionalism of everyone they interact with - doctors, nurses, technicians and related support staff.

"For all the questions we have had about this disease and the treatment we are receiving, everyone has been able to answer these questions in a way we can understand. We feel we are in very good hands at NIH - really the best place possible for receiving treatment and at the same time helping to add to what is known about GM1."

The family will return to the Clinical Center in April 2023 for ongoing evaluation of this experimental therapy.

- Robert Bursleson