

Family Advisory Committee Newsletter

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Moseley Institute Update: A Team Effort Designed to Care



By Mary Newman, MSN, RN, CPON, NE-BC

On March 2, 2023, Nemours Children's Health and Nemours Children's Hospital, Delaware announced the Lisa Dean Moseley Foundation Institute for Cancer and Blood Disorders after receiving a transformative gift of \$78 million from the Lisa Dean Moseley Foundation. With a gift of this magnitude, a team came together to imagine how we could transform our ability to improve care delivery to our patients with cancer and blood disorders by building a state-of-the-art, patient- and family-centric, Inpatient Unit with Outpatient Services and a Day Hospital. In other words, two unique spaces that also work together for patients.

Guided by the Nemours Construction Project Management Team, Facility Planning, and the Planning and Design teams, we interviewed experts in pediatric health design to select an architecture firm and construction management companies that would design and build these spaces. We needed building experts who could integrate comprehensive care with an innovative approach and focus on wellness during a time of illness.

Due to the size of the projects (and an aggressive timeline), we brought in HDR Architects to design both spaces, and Turner Construction for the Inpatient 5 West unit, and HSC Construction for the Outpatient Services and Day Hospital. It was a relief to know that these companies are among the best, with experience designing some of our nation's leading health care institutions.

Over the next few months, "The Moseley Team" came together, consisting of nurses, physicians, social workers, psychologists, therapy services, pharmacy, parent advisors, hospital administrators, and many more. During the schematic design phase of these projects, HDR facilitated a two-day, Immersive Design Event (IDE) with The Moseley Team and the Construction Project Management Team, Facility Planning, and the Planning and Design teams. This multidisciplinary workshop stimulated conversation around innovation, integration and enhanced design outcomes. We also brought parents of patients on the 3 East Inpatient Unit as well as our Family Advisory Committee members to the IDE to engage them as well.

The focus was to design a healing space that propels our children forward to help them feel strong and safe as they move through their journey with us. This meant creating environments that are dynamic, interactive and embody the Nemours Children's philosophy of caring for the whole child, "Well Beyond Medicine."



What's Next for The Moseley Team

The team coined the term "Moseley Mondays" since recurring meetings were focused on different phases of designing the spaces. HDR partnered with Nemours Children's to merge clinical expertise with their experience and best practices in pediatric cancer and blood disorder center design. Considerations such as patient room size, family space, access to daylight and views, staff space, safety and security, interactive amenities, circulation, and line-of-sight were essential to creating a therapeutic space.

The targets for completion are December 2024 and Summer 2025. We will have 19 exam rooms, 18 infusion rooms, a treatment space for sedated procedures and recovery, and apheresis. This includes separate spaces for psychology, social work, nutrition counseling, physical therapy, Child Life therapy, and private consult spaces for discussion and education for our patients and families.

We continue to engage our patients and families, having recently attended a Teen Advisory Council meeting to solicit ideas from our adolescent and young adults. There is a palpable excitement and passion around designing and building these two spaces that will have a positive impact for our patients and families and improve their quality of life.

This work will continue up to and beyond the opening of these new spaces. We hope to create these environments to make it easier for patients and families to navigate their care. We will continue to explore how these spaces will improve how efficiently we work, how effectively we collaborate and communicate, and how we can best support our patients and families during their journey with us.



PARENTS' CORNER

By Patricia and Ed Christine (parents of patient)

Editor's note: This article shares how some hospital therapies can turn into beautiful habits.

Apart from the state-of-the-art medical attention my son was given by the doctors, nurses and staff at Nemours Children's Hospital, Delaware in Wilmington, other crucial parts of my son's time was spent with departments such as Child Life, Physical Therapy, Social Work and Creative Arts.



A range of kind people visiting our room gave us a more positive atmosphere and made the days go by much more quickly. Leaving the confines of the hospital room to have a couple of laughs while playing pool, smiling while petting a dog, visiting the garden, or creating music was also a great way to relax.

One of Nate's favorite outlets was art therapy with Jess Kee. Jess had a natural ability to connect with Nate. Instead of getting the common one-word answers, he spoke to her — and anyone with a teenage boy knows what a feat that is!

Just entering the "Art Therapy" space transformed us from the beeps and alarms of the hospital room to a calming atmosphere where we found solace in creating a piece of art. Jess shared art materials with us and we began to bring in materials of our own for our extended visits. Our art collection continues to grow at home as well. We are so grateful for all of the psychosocial support that we have received. Thank you to all the wonderful staff!

Staff Spotlight



Meghan Davitt, MD

Dr. Davitt completed her undergraduate education at Villanova University with a major in biology and a minor in gender and women's studies. She stayed in Philadelphia and completed her medical school training at Lewis Katz School of Medicine at Temple University. She went on to complete her pediatrics residency at Nemours Children's Hospital, Delaware and Thomas Jefferson University Hospital in Wilmington and Philadelphia, respectively. This is where she grew to love the field of pediatric hematology and oncology. She continued her training by completing a fellowship in pediatric hematology/oncology at Children's Hospital at Montefiore in the Bronx, New York, where her research focused on outcomes in pediatric leukemia. In her spare time, she loves to run, bake and spend time with her family and friends.



Melinda Challenger

Melinda is excited to join Nemours Children's as the associate nurse manager of 3E and the hematology/oncology clinic. Melinda has always held pediatric oncology near and dear to her heart. She was an active member of THON (fundraiser for childhood cancer) during nursing school at Penn State where she helped raise money for patients and families of Hershey Medical Center. After college, she began working at the Children's Hospital of Philadelphia on their oncology and bone marrow transplant floor. She then became a travel nurse and was able to experience beautiful places, meet amazing people, and expand her knowledge as a nurse along the way. During her travel assignments, Melinda worked as a pediatric bone marrow transplant coordinator as well as an adult and pediatric outpatient nurse navigator. Melinda has been to all 50 states (thanks to multiple cross-country drives), with Montana, Hawaii and California being her top three favorites. In her free time, she loves to travel, try new foods, and enjoys spending time with her friends and family.

Diagnosis 101: What is neuroblastoma?



Medically reviewed by: Manisha Makker Bansal, MD

Neuroblastoma is a type of **cancer** that starts in early nerve cells called neuroblasts. Normally, these immature cells grow into working nerve cells. But in neuroblastoma (nur-oh-bla-STOW-muh), they grow uncontrollably and become cancer cells that form a solid tumor.

Often, neuroblastoma starts in the tissue of the adrenal glands. These triangular glands sit on top of the kidneys and make hormones that control heart rate, blood pressure, and other important body functions. Neuroblastoma also can start in other areas of the body with clusters of nerve cells, like in the belly, chest or neck. The cancer can spread through the blood and start growing (metastasize) in other parts of the body, such as the lymph nodes, bones, lung and liver.

Almost all cases of neuroblastoma happen in infants and children younger than 5 years old. The success of treatment depends on many things, including the child's age, how much disease there is, and characteristics of the tumor.

What causes neuroblastoma?

Neuroblastoma happens when neuroblasts grow and divide out of control instead of developing into nerve cells. Experts believe that a defect in the genes of a neuroblast lets it divide like this. Rarely, the tendency to get this type of cancer can be passed from a parent to a child.

How is neuroblastoma diagnosed?

If they suspect neuroblastoma, doctors will order tests to confirm the diagnosis and rule out other causes of symptoms. These tests may include:

- **Urine tests** and blood tests
- Imaging studies (such as X-rays, CT scans, MRIs and ultrasounds)
- A **biopsy** (taking a small tissue sample to check in a lab)
- A **bone marrow aspiration and biopsy**

If the test results show it is neuroblastoma, doctors classify the disease as low-risk, intermediate-risk or high-risk. This is called **staging**. To do this, they consider the child's age, the area affected by the cancer, and the results of tests done on the neuroblastoma cells.

The doctor also will order an **MIBG scan**. In this test, a low-dose radioactive material is attached to a molecule (MIBG), then injected into the child. Neuroblastoma cells will absorb the MIBG. During the scan, doctors can see where the cancer cells are in the body. Doctors also can use this scan to see how well a child responds to treatment because it will show how much cancer is left.

MIBG given with higher-dose radioactive iodine can treat neuroblastoma. After it's injected, it delivers the radiation specifically to the neuroblastoma cells and kills them.

How is neuroblastoma treated?

How doctors treat neuroblastoma depends on its staging and whether the cancer has spread.

Doctors will closely watch a child with **low-risk disease**, and do tests often to make sure the tumor doesn't get bigger. Sometimes, they'll do surgery to remove the tumor.

A child with **intermediate-risk disease** will likely need chemotherapy and may also have surgery. Some may need radiation therapy.

A child with **high-risk disease** needs longer, more aggressive treatments, including surgery to remove the tumor, **radiation therapy**, **chemotherapy**, **stem cell transplants** and **immunotherapy**. Studies are being done to see if MIBG treatment will improve a child's chances of being cured.

More information about neuroblastoma can be found online at:

- **[American Cancer Society](#)**
- **[The Children's Neuroblastoma Cancer Foundation](#)**

Little Heroes, Big Fights

On October 1, 2020, what was supposed to be a quick trip to the ER for a swollen jaw, turned into an 18-month fight against high-risk neuroblastoma.

Greyson was diagnosed during the height of COVID-19, so I was in the ER by myself. I remember seeing three sets of feet walking up to the curtain and them asking me if we could talk in the room next door. I knew in my heart exactly what they were going to tell me, the words no parent ever wants to hear. Over the next few days, we learned what type of cancer we were up against and what we needed to do to get our baby healthy.

Greyson's battle with high-risk neuroblastoma was extremely complicated. During his second SCT (stem cell transplant) he developed TA-TMA (transplant associated-thrombotic microangiopathy) which affected his kidneys leading to chronic kidney disease and other long-term side effects. He spent more time in the hospital than he did at home, but the nurses and doctors became our second family. They made an extremely difficult situation bearable.

Despite everything, Greyson never lost his spunk or fight. There's been no evidence of disease since March 2021, and he has been off treatment since February 2022. He's 6 years old and in kindergarten. He loves spending time with his parents, family and especially his big brother, Mark.



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