

# HOPE



## Mysteries Unlocked

Discovery and innovation enhance care for children with rare diseases





Patient Filicia McEven, 11, left, and Megan Piphus Peace, a puppeteer on Sesame Street, hang out in Seacrest Studio.

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"I have von Hippel-Lindau disease; it doesn't have me. It has taught me to see things through a different lens, to be more empathetic."



**On the cover:**  
Blake Kirby, 10, is one of only 23 known people in the world to have Saul-Wilson syndrome, a very rare genetic disorder. Photo by Donn Jones.

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# HOPE



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### Senior Vice President for Development

Mary Beth Thompson

## Editor

Christina Echegaray

## Contributors

Danny Bonvisutto, Jill Clendening,  
Christina Echegaray, Nancy Humphrey,  
Leigh MacMillan, Jessica Pasley,  
Ray Vaughns Jr.

## Director of Publications

Kathy Whitney

## Photography

Samantha Blondell Photography,  
Chad Davis, Donn Jones, Cayce Long,  
Erin O. Smith, Susan Urmey

## Design and Art Direction

Diana Duren

## Executive Director of Digital Media

Wayne Wood

## Advisory Board Members

The Monroe Carell Advisory Board is an advocacy, fundraising and advising group.

Members educate constituents in the community and do outreach to secure resources to support the mission of

Monroe Carell. Learn more at [VanderbiltHealth.org/advisoryboards](https://VanderbiltHealth.org/advisoryboards).

## Mission Moment



We all look forward to the longer and warmer days of spring and summer, which bring a renewal of sorts to us following the dreariness and darkness of winter. Yet this spring, our community experienced an unthinkable tragedy of the darkest kind. As the trauma center serving our community, our teams became intimately connected to the Covenant School tragedy on that March day, as they sprang into action to care for our community's children. With the stark realization that medical aid wouldn't help, they offered a different kind of healing for the families.

This is what we do every day at Monroe Carell Jr. Children's Hospital at Vanderbilt: support our community with compassion, hope and healing through our actions — whether direct patient care, exemplary teamwork across disciplines, continuous learning together, or in our search for novel approaches.

In this issue of *Hope*, we share with you a few examples of this work with the theme of teamwork and the goal of personalized care — all told through patient stories. Over the last decade plus, we have built a world-class pediatric cancer program with numerous services available in our state only at Monroe Carell. We share several of these programs, highlighting how your generosity helps us deliver improved outcomes.

Another program that brings discovery to the bedside is our Vanderbilt Undiagnosed Diseases Program, managed by our genetics division in Monroe Carell. This program serves infants to adults, with the ability to make a significantly larger impact possible through the Potocsnak Center for Undiagnosed and Rare Disorders at Vanderbilt University Medical Center.

Through our Comprehensive Epilepsy Program, our team individualizes care for children and adolescents with epilepsy to find the right treatments — from nutrition to medications to surgery — in hopes of eliminating or controlling seizure activity and to maximize a child's quality of life.

The common thread through our work is passion for advancing the care of children and collaboration. The supporting teams behind our clinical teams are also essential to the unique work we do. These include but are not limited to our music therapy program; our pharmacy, nutrition and social work teams; and our environmental services and transport teams, each bringing their own expertise to ensure personalized care.

We could not do what we do every day without the support of our community. You stand by us and help make our visions become reality, and for that we are so very grateful. Your incredible support translates to optimism which in turn allows us to offer hope and healing every single day to those we serve.

Sincerely,

Meg Rush, MD, MMHC  
*President*

Steven Webber, MBChB, MRCP  
*Pediatrician-in-Chief, Chair of the Department of Pediatrics and James C. Overall Professor*

Jeffrey Upperman, MD  
*Surgeon-in-Chief and Chair of the Department of Pediatric Surgery*

John W. Brock III, MD  
*Senior Vice President of Pediatric Surgical Services, Monroe Carell Jr. Professor, Surgeon-in-Chief Emeritus*



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to find out how you can make  
a difference.



# good to know

NEWS FROM MONROE CARELL



**Clip In 4 the Cure**, a relay-style, team cycling event held at First Horizon Park on March 25, saw more than 300 riders. This year's event also featured on-field yoga, food trucks, a VIP tent for top fundraisers and sponsors, a Kids Corner with child-sized spin bikes, and other family-friendly activities. Proceeds support cancer initiatives at Vanderbilt-Ingram Cancer Center and Monroe Carell Jr. Children's Hospital at Vanderbilt. 🦋



## Monroe Carell named a Leapfrog Top Hospital



Monroe Carell Jr. Children's Hospital at Vanderbilt was named a Leapfrog Top Hospital for 2022, earning the designation among a select group of children's hospitals across the nation.

Monroe Carell was one of only 12 children's hospitals in the nation and the only one in Tennessee to receive a spot on the 2022 Top Hospital list released in December 2022.

Founded in 2000, The Leapfrog Group is a coalition of public and private purchasers of employee health coverage that works to encourage health care safety, quality and affordability. Leapfrog members provide health benefits to more than 37 million Americans who live in all 50 states.

This is the sixth time that Monroe Carell has made the Top Children's Hospitals list. Leapfrog has published these unranked lists since 2006.

The breakdown of this year's list of 115 Top Hospitals is 12 Top Children's Hospitals; 32 Top General Hospitals; 13 Top Rural Hospitals; and 58 Top Teaching Hospitals.

Children's hospitals selected as a Leapfrog Top Hospital must meet rigorous quality and safety standards. 🦋

## Family's gift will support pediatric cancer research

Lily Hensiek's cancer diagnosis in 2008 has inspired three generations of her family to devote time and financial support to research and training in pediatric cancer. The family recently made a new \$1 million commitment to endow the Lily's Garden Discovery Researcher Fund at Vanderbilt University Medical Center.

The latest gift from Lily's family — Larisa and Phillip Featherstone and Carol and Ron Johnston — supports fellows and early career investigators in pediatric cancer. The family lives in Franklin, Tennessee, and owns a workplace safety consulting firm, Johnston & Associates.

Support for fellows helps to

set trainees on a course for a career of discovery and caring for young people with cancer. Early-career investigators often need interim funding to get to the next level on their research path.

"We are very grateful to the Featherstone and Johnston family for their unwavering generosity," said Debra Friedman, MD, MS, director of the Division of Hematology and Oncology and E. Bronson Ingram Chair in Pediatric Oncology.

"This support helps ensure senior fellows and other early-career investigators have the resources they need to conduct studies on emerging treatment options for young cancer patients."

The gift from the family in honor of Lily, now 22 and a recent

graduate of the University of South Carolina, is a continuation of their past giving to Monroe Carell Jr. Children's Hospital at Vanderbilt, which totals \$3 million. Lily was diagnosed with pre-B cell acute lymphoblastic leukemia when she was in second grade.

Larisa, who chairs the Monroe Carell Advisory Board, said the family's most recent gift helps fill a need not currently being met to support doctors working on innovative ideas.

"I truly believe that these fresh, bright minds that are so passionate are taking cancer research to the next level. We are giving them that initial seed money to help take their ideas even further," she said. 🦋

On hand for a celebration of Lily's Garden initiatives were Debra Friedman, MD, MS, left, and Brianna Smith, MD, MS, (holding the plaque) and, from right, Larisa and Phillip Featherstone with their daughters Lily, Sophie and Sophia, and Carol and Ron Johnston.



# 29%

More than 1 in 4, about 29%, of Tennessee parents are concerned their child has undiagnosed anxiety or depression, according to the 2023 Vanderbilt Child Health Poll. The poll, fielded in the fall of 2022 by researchers at the Vanderbilt Center for Child Health Policy, also found more than 30% of parents polled said their child had been diagnosed with attention deficit hyperactivity disorder, anxiety or depression, a 7% increase since the question was first asked in the annual poll in 2019. The Vanderbilt Child Health Poll is conducted annually to gauge parents' concerns about a wide range of topics. 🦋



Dominic Gamez, 8

## Expandable prosthesis gives young patient more mobility

In January 2022, Dominic Gamez, an active 7-year-old boy who loved playing travel soccer, was diagnosed with an 8-inch tumor involving two-thirds of his femur, extending from the bottom of the femur near the growth plate (at his knee) to the femur shaft.

A biopsy at Monroe Carell Jr. Children's Hospital at Vanderbilt revealed he had osteosarcoma, cancer that originates in the bone-forming cells. Treatment requires a combination of chemotherapy and surgery.

"Osteosarcoma is the most common bone cancer seen in children and is highly malignant," said Scott Borinstein, MD, PhD, professor of Pediatrics in the Division of Pediatric Hematology and Oncology at Vanderbilt University Medical Center and director of the Pediatric Sarcoma Program at Monroe Carell. "Eighty percent of all osteosarcomas occur around the knee, like Dominic's did," he said.

Growth plates are the biologic machines that make new bone so that we can grow. In addition to removing the cancerous bone, necessary for a cure, often surgery to

remove osteosarcoma involves the removal of growth plates.

His family was given three choices: amputate; replace the resected femur with a cadaver bone (allograft); or implant a magnetic expandable prosthesis that can be manipulated to grow incrementally as the child grows.

"Amputation was out of the question," said Dominic's mother, Lessley Gamez. They also ruled out an allograft which must be replaced as the child grows, is more unstable and is more apt to fracture with activity. The family chose the magnetic expandable prosthesis for Dominic, which has been used 17 times at Monroe Carell over the past decade. It requires one surgery to remove the tumor, check the tumor's margins and insert the implant.

"Of all the options, this gives him the best chance to be active, to be Dominic," said Dominic's surgeon, Jennifer Halpern, MD, assistant professor of Orthopaedic Surgery. "The expandable femur replacement/ knee replacement is durable, reliable, and it grows with the child."

After a seven-hour surgery in April 2022 to remove his knee and femur, the prosthesis was implanted. A few weeks later he continued his chemotherapy regimen.

For patients who choose the magnetic expandable prosthesis, advanced imaging helps to plan and build their custom implants. MRI scans help to determine the size of the tumor that needs to be removed. CT scans are used to build custom implants that match the patient's anatomy. The size of the implant also impacts the growth potential of the device. The larger the replacement, the more the implant can be "grown."

Halpern said the magnetic expandable prosthesis is ideal for Dominic because his femur would normally grow more than 4.4 inches over the next eight years.

Within hours of surgery, Dominic took a few steps with his walker, and with the help of physical therapy, he was walking with a walker by the end of June 2022. Dominic, now 8, is doing well and hopes to join a swim team. 🦋

## Rush elected to Children's Hospital Association Board



Meg Rush, MD, MMHC, President of Monroe Carell Jr. Children's Hospital at Vanderbilt, has been elected to the Children's Hospital Association Board of Trustees.

The Children's Hospital Association is a member organization representing more than 220 children's hospitals nationwide. Serving as a voice for its members and champions of children's health, CHA's mission is to advance child health through innovation in the quality, cost and delivery of care in children's hospitals and health systems nationwide.

A member of the Board of Trustees embodies this mission individually as a leader and representative of their respective organization and collectively as fiduciary leaders and stewards of CHA's strategic priorities, initiatives and organizations.

"I am truly honored to be asked to serve in this way and excited to join a very talented group of leaders to advance children's health in our country. The Board of Trustees is an active group of individuals who bring diverse vantage points from their individual hospitals, systems and states but with a shared vision of working together to advance causes important to the health and well-being of our youth," Rush said. 🦋

# STAY SEAT SMART

The Trauma Injury Prevention Program at Monroe Carell Jr. Children's Hospital at Vanderbilt strives to reduce unintentional injuries among children and promote safe behaviors in the community. One area of focus, the Stay Seat Smart Program, funded by General Motors, aims to improve knowledge and correct usage of child safety seats. In Tennessee, an estimated 82% of car seats are improperly installed. From 2019 to 2022, the Trauma Program at Monroe Carell assessed and treated 1,005 children (all age groups) for motor vehicle crash injuries. About 36% of those children were unrestrained or improperly restrained.

## Types of safety systems



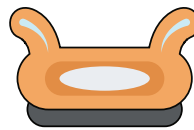
### Rear-facing infant/convertible car seat

Birth - until child reaches highest weight/height the seat allows, in rear seat \*



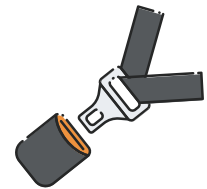
### Forward-facing 5-point harness seats

Ages 1-3 and greater than 20 pounds, in rear seat \*



### Booster seats

Ages 4-8 and less than 4'9" tall, in rear seat



### Safety Belts

Ages 9+ and greater than 4'9", in rear seat. All children under age 13 should ride in the back seat.

*\*Note: Rear-facing is recommended for as long as possible. Children should stay in harness seats until top height or weight limit for car seat before moving to booster.*

## Did you know?

10%

Since 2011, booster seat usage for children ages 4-7 has decreased by 10%.

47%

In the age group of 4-8, about 47% of trauma patients seen at Monroe Carell following a motor vehicle crash were unrestrained or improperly restrained.

71%

Car seat use reduces the risk for injury in a crash by 71% for infants and by 54% for toddlers.

## Resources for parents

A certified child safety technician can check your installation and answer questions. To find a technician or inspection station near you, visit [tntrafficsafety.org/cps-fitting-stations](https://tntrafficsafety.org/cps-fitting-stations). Free virtual Child Passenger Safety Classes are also available at Monroe Carell at [vumc.org/injuryprevention/car-seat-classes](https://vumc.org/injuryprevention/car-seat-classes).



## Get Well network empowers patients and families

Monroe Carell Jr. Children's Hospital at Vanderbilt has launched a new digital patient engagement system to interact with patients and families during their stay in the hospital as well as provide staff easy-to-use tools to advance the patient experience.

Get Well is a digital technology connecting patients with personalized information and education they need to navigate their health care journey as well as serve as an entertainment outlet.

"We chose this program because it has so many functionalities," said Janet Cross, MEd, CCLS, CPXP, senior director, Patient and Family-Centered Care at Monroe Carell. "We will be able to provide patient education elements as well as entertainment options for TV and movies. The system has the ability to expand as our needs grow, which will allow us to add additional functions as the need arises.

"The system is being rolled out in stages. So far, we have had incredible feedback from patients, families and staff. It's always exciting when we can introduce another tool that will increase our patient and family engagement."

The Emergency Department was the first area to pilot the new system, followed by the 10th and 11th floors. It will subsequently be available to floors 5, 6, 7 and 8 with plans to bring the platform to rooms without TVs (4th floor NICU).

Cross hopes the installation will be complete for the entire hospital by this fall.

In addition to providing information, education and teaching tailored to each patient's health condition, users will be able to access a daily plan and routine page, medications list and review discharge planning and instructions.

A calendar of daily events and relaxation videos will also be available through the platform, which

will also have more than 100 TV stations, internet access, music, games and a wide variety of age-appropriate movies.

"The concierge style of this system really places a lot of control in the hands of the patients and families," added Cross. "They will be more integrated into their care through the interactive programming, which will provide a better patient experience."

Upon admission to the hospital, patients and families will go through an orientation to familiarize them with both the hospital and the new digital system. A Get Well welcome video will help walk each user through the system's features, prompting access with the entire network.

Available in English, Spanish and Arabic, the online tool will be specific to each individual patient. Each room will be outfitted with equipment to use the digital system. 🦋

Filicia McEuen, 11, interacts with the new Get Well Network at Monroe Carell Jr. Children's Hospital at Vanderbilt.



## Operating rooms get makeover

The operating rooms at Monroe Carell Jr. Children's Hospital at Vanderbilt are getting their first major renovations since the hospital opened 19 years ago.

The first phase of renovations will overhaul 10 of the hospital's 18 ORs, focusing on two surgical suites at a time. The first two rooms, recently completed, were the cardiac room and a multiuse room used primarily for robotic surgery cases.

Renovations will redesign some of the rooms and enhance the physical plant structure, including everything from the number of outlets to the capacity of the ceiling to hold new medical booms, monitors and enhanced technology.

"Our mission is to take care of children and their families — infants, children, adolescents — across the whole spectrum of pediatric care, and these renovations will allow us to provide that same quality, compassionate care at a higher and more efficient level for years to come," said Barb Shultz, MSN, RN, NEA-BC, associate chief nursing officer for Pediatric Surgical Services.

Monroe Carell, a Level 1 trauma center, performs surgery on more than 18,000 children each year.

Three more state-of-the-art ORs plus a GI procedure room also serve patients at the Monroe Carell Jr. Children's Hospital Vanderbilt Surgery and Clinics Murfreesboro campus. 🦋

## Benefits of ketamine in children with TBI explored



A common anesthesia drug could be beneficial in reducing pressure inside the skull of children with traumatic brain injuries (TBI), according to a study published in *Critical Care Medicine*.

Ketamine, a drug used for anesthesia since the 1970s, has traditionally been avoided for patients with TBI due to early studies suggesting that it could raise the pressure inside of the skull, known as intracranial pressure (ICP).

More recent studies suggest otherwise, said lead author Michael Wolf, MD, assistant professor of Pediatrics and Neurological Surgery and director of Neurocritical Care at Monroe Carell Jr. Children's Hospital at Vanderbilt.

Wolf and his co-authors reexamined the effects of ketamine on ICP in children admitted to the pediatric intensive care unit with severe TBI, analyzing data from 33 patients ages 1 month to 16 years, 22 of whom received ketamine as part of a treatment protocol informed by evidence-based guidelines.

Eighteen ketamine doses were given during ICP crises in 11 patients, and an overall decrease in ICP was observed.

Wolf said the results are "exciting," and he hopes a larger study repeats the findings. 🦋

DONN JONES



## Family and community guide hospital's new CNO

**P**ersonal experiences and a desire to serve her community led Gretchen K. D. McCullough, MSN, RN, NEA-BC, into a nursing career.

As a child, McCullough saw her parents navigate the complexities of health care systems as they searched for a diagnosis for her younger brother's chronic illness. Ultimately, at age 12, her brother, Thaddeus Yeiser, was diagnosed with cystic fibrosis. She recalls the many hours she spent as a teen with her brother in the hospital.

"I think that experience has really touched the way that I look at health care in terms of thinking of the whole family," McCullough said. "It really is a

family sport to get a child with chronic illness through childhood whole and well."

Her life experiences and her nursing journey continue to guide McCullough as she begins a new role in her career: chief nursing officer for Monroe Carell Jr. Children's Hospital at Vanderbilt.

She joined Monroe Carell March 6, following a nationwide search. She succeeds Kathie Krause, MSN, RN, NNP-BC, NEA, who retired in March.

Previously, McCullough served as associate chief nursing officer for Women's and Children's Services at OHSU Health: Doernbecher Children's Hospital in Portland, Oregon. She believes in impacting a child's health as early in life as possible.

"The way that a child and a family interact with a health care system can determine so much

about that child's future interaction as an adult in health care systems," she said. "It's a real opportunity to impact the way that a human will trust the health care system across their life span."

Health care in rural communities is equally important to McCullough, who lived in the Appalachian Mountains of Maryland as a child, watching her aunt, a nurse, serve families who had few care options.

"One of the things that is critical to me in any job that I consider is that part of the work has to be the ability to impact care in rural communities, and Monroe Carell has a really solid outreach arm," she said.

A native of Oakland, Maryland, and raised in Saxonburg, Pennsylvania, McCullough completed an initial course of undergraduate study at Edinboro University of Pennsylvania. She went on to get an associate degree of nursing from Harrisburg Area Community College and a Master of Science in Nursing, Administration.

McCullough has worked in various capacities across diverse health care environments in Pennsylvania including academic, hospital and ambulatory settings. Among her many roles, she served as senior director of Ambulatory Operations: Children's Services, Women's Services, and Dermatology Services for Penn State Health and Penn State Hershey Medical Center.

McCullough moved to Nashville with her husband, Mac, an attorney and stay-at-home dad, along with their two children, Charlotte, 11, and Jack, 7. As a family, they love theater and the arts, and paddleboarding, and they're excited to explore the Nashville Zoo at Grassmere and the Frist Art Museum. 🦋



# conversations

INTERVIEW WITH DAPHNE HARDISON, MSN, RN, CNML



*Daphne Hardison, MSN, RN, CNML, is the manager of the Monroe Carell Jr. Children's Hospital at Vanderbilt ECMO Program, Continuous Renal Replacement Therapy, Vascular Access Team and Wound Ostomy Care.*

PHOTO BY ERIN O. SMITH



**Q** What is ECMO and how does it work?

**A** ECMO, or extracorporeal membrane oxygenation, is a life-sustaining mechanical system that temporarily takes over for the heart and lungs of critically ill patients, allowing their organs to rest and recover by removing carbon dioxide from the blood, replacing it with lifesaving oxygen, and returning it to the patient's circulatory system.

There are two types of this highly specialized treatment — ECMO VA (venoarterial) is used for both the heart and lungs, and ECMO VV (venovenous) is used to support only the lungs when the heart is functioning well.

**Q** When did Monroe Carell begin using this technology, and what is the volume of our program?

**A** Nationally, the first adult patient was placed on ECMO in 1971, followed by the first pediatric patient in 1975. The technology was first introduced at Monroe Carell in 1989, making it the first ECMO program in Tennessee and propelling it to one of the largest and most successful programs in the world.

Initially used only in the Neonatal Intensive Care Unit at Monroe Carell for neonates in respiratory distress, the program expanded to the congenital heart patient population in 1992, and subsequently, it was used throughout the hospital's intensive care units for heart and lung support.

During the first 10 years, the program treated about 300 patients. In the nearly two decades since it began, the patient population has tripled. And the numbers continue to rise.

**Q** When does a patient need ECMO? And for how long?

**A** ECMO can help children suffering from a variety of respiratory distress conditions including congenital diaphragmatic hernia, pulmonary hypertension and meconium aspiration syndrome. It is also used as a bridge to either having a ventricular assist device implanted or used while the patient is awaiting a transplant.

ECMO supports patients for days or weeks while medical teams treat the underlying illness. The longest time a pediatric patient at Monroe Carell has been on ECMO is 96 days.

**Q** How many ECMO machines does the hospital have? And how many people does it take to operate?

**A** The hospital currently has eight ECMO pumps. There are a host of medical professionals on a patient's team. Among the most visible will be the nurse and ECMO specialist who stay at the bedside to monitor the patient around the clock.

When the program first began at Monroe Carell, there

were 11 members of the team. Today, there are 27.

**Q** What has been one of the biggest changes in ECMO over the decades?

**A** Patients are much more complex and sicker today than when the technology was first introduced. As medicine has progressed, we are able to place more patients on ECMO who would have never been considered 30 years ago. The technology has come a long way.

The quality of life for patients on ECMO has improved over the years as well. A patient on ECMO can be awake, sit up, get out of bed and eat, which is a large part of the recovery process. If a patient can tolerate movement, that is our goal. It takes an entire team to safely move a patient. We encourage movement as tolerated to help prevent deconditioning.

**Q** What is the future of ECMO?

**A** At Monroe Carell, we just began our ECMO Transport Team, which allows us to transport pediatric patients on ECMO to our hospital. Advancements have allowed for smaller, transportable pumps that are compatible with an ambulance. The team of six consists of two ECMO specialists, a neonatal transport nurse, respiratory therapist, an advanced EMT and a physician.

Monroe Carell is the largest pediatric transplant center in the area and a regional referral center. We are continually learning and advancing the technology.





Ramsey Crawford, 2, gains strength while having fun through the Music Therapy Program.

# Play On

Helping children cope through hospitalization with music therapy

STORY BY NANCY HUMPHREY  
PHOTOS BY DONN JONES

**T**wo-year-old Ramsey Crawford holds the hand of her physical therapist in the hallway outside her room at Monroe Carell Jr. Children's Hospital at Vanderbilt as they work to strengthen the toddler's wobbly legs.

Ahead of pony-tailed Ramsey, scooting backward on her knees, is Jess Knoble, MT-BC, one of Monroe Carell's three board-certified music therapists. She's strumming a guitar and singing to the beat of Ramsey's steps, "The ants go marching one by one, hurrah, hurrah." When Ramsey changes her tempo, so does Knoble, modifying the words from the Disney song "Let it go" to "Ramsey, go, Ramsey, go."

On Christmas Day 2022, when Ramsey's parents were unable to awaken her, they rushed her to the hospital in their hometown of Bowling Green, Kentucky. She was diagnosed with ADEM (acute disseminated encephalomyelitis), a rare neurological disorder in which the immune system causes an intense attack on the brain, and sometimes the spinal cord and optic nerve. It often results in loss of vision in one or both eyes due to inflammation of the optic nerve; weakness that

can be severe; and difficulty coordinating intended movement, such as walking.

"We didn't think she'd ever be OK," said her father, Benjamin Crawford. "She's truly a miracle. We were prepared for the worst but are praying for the best. She's come a long way," he said, watching Ramsey working with Knoble. "Music therapy is the highlight of her day."

Music therapists work with children and their families across inpatient areas at Monroe Carell, using music in unique ways with each child to help with chronic pain, physical rehabilitation, psychiatric symptoms, end of life, procedural support and coping with hospitalization and disease. They are part of the medical team supporting the whole patient, using evidence-based music interventions to provide individualized care for each patient's medical diagnosis, course of treatment and discharge timeline.

Knoble sits on the floor with Ramsey, maneuvering a flat electronic drum pad so that Ramsey is encouraged to use her weak side to play. After she tires of the drums, she blows into a slide whistle that is used to improve her respiratory strength. Everything is with a specific goal in mind — to help Ramsey gain strength.

"We're not just playing and having fun. We are (having fun), but with our clinical training, we're using things we have in our toolbox to make it a fun environment where kids want to engage," said Knoble, who has additional training in neurologic music therapy.

"What I'm doing (while Ramsey walks) is called rhythmic auditory stimulation," Knoble explains. "Everybody has a natural rhythm within themselves; it's called entrainment. We naturally want to latch on to an external beat. It's why we tap our foot to a song, why we bob our head to a beat. Our body wants to latch on to this external factor."

Established in 2005 by Tom and Maria Fouce through the Julian T. Fouce Fund, Monroe Carell's music therapy program was developed in memory of their son, Julian, a great lover of music who died that year.

"They saw the impact and the benefit. They have been really passionate about watching the program grow, and we've been fortunate that they've continued to stay involved," said Dana Kim, MT-BC, a board-certified music therapist at Monroe Carell. "We're grateful for all they have done."



# spotlight

MUSIC THERAPY

Music therapy techniques are backed by research showing how they can best assist children during hospitalization.

The hospital's music therapists have bachelor's and master's degrees in music therapy, over 1,200 clinical hours, and have passed a national exam administered by the certification board for music therapists.

"The music therapy program has become a staple in our menu of care for children and families at Monroe Carell," said Janet Cross, MEd, CCLS, CPXP, senior director, Patient- and Family-Centered Care. "The Fouce family had a wonderful vision in 2005, and we are able to continue to grow the program to meet that vision with their support. The role that the music therapists play in the care for hospitalized children is so very important. They are able to connect in even the most stressful situations and provide excellent support for children and families."

Anyone on a child's care team can place an order for music therapy, or it can be requested by the family. It starts with a look at the medical record, then the therapists per-

Ryan Neighbors, 13, right, loves singing with music therapist Dana Kim to help her through long hospital stays.

form an assessment to see how the patient and family respond. There's a strong focus on building a relationship with the patient.

"Everything we're doing, we're trying to do as equals on a playing field," Knoble said. "Rather than just coming in and playing the guitar, maybe we're talking to the patient and seeing if they're having difficulty with being able to relax. We discuss and figure out what music they listen to. We assess if playing the guitar live will be helpful. Rather than us just determining what music might be best, we figure out with them what's going to work well for them."

Music therapy might not be the right fit for every child, says Kim.

"It's very individualized. That's why we work so closely with our other colleagues. Perhaps spiritual care is really what this family needs or something else our child life colleagues have to offer. That's why the assessment is so important. Kids and families can always tell us no and empower that choice making. Maybe it's not right for this hospitalization, but it might be on down the road," Kim said.

To participate in music therapy, patients don't have to be musically inclined.

"Sometimes children and families who don't have that experience and have never utilized music in that way are the ones that can benefit the most," Kim said.

Ryan Neighbors, 13, from Louisville, Kentucky, has spina bifida and was at Monroe Carell in February for an extended stay as she recovered from traction surgery and a spinal fusion for her scoliosis.

Ryan, who is outgoing, loves music and missed her friends, met often with Kim, as they worked on developmental goals and self-expression, including songwriting.

With Kim's help, Ryan wrote a song about the excitement she's feeling about finally getting a golden retriever service dog. She has waited several years for her canine companion and hopes to get it this year.

After talking for a few minutes during a visit, Kim played guitar while Ryan used a bejeweled microphone to sing one of her favorite songs, "Shake It Off." Then, she practiced singing the song about her dog.

Ryan's mom, Shelly King, said music therapy has helped her daughter cope during the long hospital stay. "Music therapy has helped her learn how to meditate and calm down when she's anxious. It helps her get creative and take her mind off things going on medically."

Kim said teenagers in the hospital can have a rough time being isolated from their friends and may withdraw during their time in the hospital.

"Music in the hospital is so important for them. It's an important outlet for expression, for identity and for coping throughout the hospitalization," she said. "It can also help build confidence and empower adolescents to actively participate in their health care." 🦋



**"The role that the music therapists play in the care for hospitalized children is so very important. They are able to connect in even the most stressful situations and provide excellent support for children and families."**

- JANET CROSS, MEd, CCLS, CPXP



# Mysteries Unlocked

The genetics team expands ability to find answers for patients with undiagnosed and rare disorders

STORY BY NANCY HUMPHREY  
PHOTO BY DONN JONES

Before Blake Kirby was born 10 years ago, his mom, Kara Davis, knew from ultrasounds that he was very small and had clubfoot, an abnormality in which one or both feet are twisted out of shape or position.

“Other than that, we thought he was going to be OK,” she said.

When Blake stopped growing altogether, Davis was induced on March 16, 2013, at 36 weeks gestation. His heart rate dropped during labor, and when he was delivered at 4 pounds, 15 ounces, he was taken to the neonatal intensive care unit for observation. Physicians were also concerned about his appearance, and he failed a newborn hearing screening.

For the Mt. Juliet, Tennessee, family it was the beginning of a four-year diagnostic odyssey that at one point involved 16 specialists at Monroe Carell Jr. Children’s Hospital at Vanderbilt. It culminated in August 2017 with a diagnosis from the Vanderbilt arm of the National Institutes of Health’s Undiagnosed Diseases Network (UDN), which brings together clinical and research experts from across Vanderbilt to help solve medical mysteries for patients with complicated conditions and diseases.

VUMC is an original member of the NIH’s UDN, established in 2014. In 2021,

the Vanderbilt Undiagnosed Diseases Program was launched to operate alongside the UDN to expand services to many more patients living with the consequences of an undiagnosed disease.

Blake is one of only 23 known people in the world to have Saul-Wilson syndrome, a very rare disorder first identified in 1990.

The disorder is characterized by skeletal abnormalities, short stature (dwarfism) and growth abnormalities that begin in the womb and continue after birth. The average adult with Saul-Wilson is 3 feet, 6 inches tall.

People with the condition usually have smaller than normal heads — known as microcephaly — and sometimes larger than normal heads — macrocephaly, a pronounced forehead and eyes that appear larger due to shallow eye sockets. The disease can also cause clubfoot, cataracts in the eyes, loss of night and peripheral vision, low levels of white blood cells (neutropenia), heart issues, delayed early speech and motor skills and hearing loss.

Four patients with Saul-Wilson syndrome were reported between 1982 and 1994, but the mutation that causes it wasn’t discovered until Blake’s diagnosis. Now, of the 23, the oldest is 30 and the

youngest is 1. There is no known treatment for the disorder.

“I know finding out a name (of the syndrome) doesn’t change the outcome. There’s still no treatment. But just knowing the name meant the world. Before, everything was unknown,” Davis said.

## Leaders in cutting-edge genetics

While most children are born healthy, about 6% are born with genetic and metabolic disorders. Figuring out how those defects originated and what medical treatments might help can sometimes be a complicated and emotional process for families — a mystery that needs to be unlocked.

The Division of Medical Genetics and Genomic Medicine within the Department of Pediatrics at Monroe Carell helps diagnose, counsel and treat patients with a wide range of genetic disorders, birth defects and developmental concerns. The team also can help families determine if their children’s conditions are hereditary and offer genetic testing to family members who may be at risk for having children with similar problems.

Genes contain the biologic instructions for life — DNA. They make us who we are and contribute to aspects of our





Blake Kirby, 10, with his dog, Buddy

health. Everyone has a unique genetic code, and sometimes changes in genes can result in birth defects or disabilities that require lifelong medical care.

The growing division at Monroe Carell has some of the most highly trained geneticists in the country. They're a local, state and national leader in providing cutting-edge genetics services to patients.

The division leads Vanderbilt University Medical Center and Monroe Carell in the integration of genetics and genomics into medicine and health care with the single goal of improving patients' lives. (Your complete set of DNA is called your genome.)

"Thanks to new genomic approaches, we are now in a position to make remarkable new insights into human health and encounter new opportunities for prevention, diagnosis and treatment of both common and rare conditions," said Rizwan Hamid, MD, PhD, Dorothy O. Wells Professor of Pediatrics and director of the division since 2018.

Recently, a transformative gift from the Potocsnak family established the Potocsnak Center for Undiagnosed and Rare Disorders at VUMC. Hamid is the new center's director, serving children and adults in a collaborative effort that crosses many disciplines.

The center will allow VUMC to accelerate research and serve more patients looking for answers and cures for diseases that, in some cases, have been undiagnosed for decades. There are an estimated 30 million people in the United States with rare diseases, many of whom do not have a diagnosis.

The Potocsnak Center for Undiagnosed and Rare Disorders makes a significantly larger impact possible for patients everywhere well into the future through the development of a robust program emphasizing collaboration, patient-centered care, innovation and training.

Over the years, John Potocsnak, through the Potocsnak Family Foundation, has supported countless nonprofit initiatives. The family's involvement with VUMC, from philanthropy to advocacy, is led by a commitment to others and their own patient experience. In addition, John's daughter, Liz Potocsnak, is a longtime member and now chair of the Vanderbilt Eye Institute Advisory Board.

"We wanted to do something for people who may otherwise be forgotten, and it was clear that VUMC has both the passion and ability to do so," said Liz Potocsnak. "It's our privilege to be part of the solution as the center furthers this wholehearted investment for as many patients as possible both in Tennessee and across the world through information sharing."

The center will use a multipronged approach to grow the current undiagnosed diseases program. Plans include expanding the team dedicated to this cause, increasing the capacity for clinical analysis of genomic data, introducing new higher-resolution genome decoding technologies, and working to improve patient access.

"It's an amazing gift that has the potential to help a group of patients with rare and undiagnosed disorders who have no other recourse or no other source for

help," Hamid said. "These undiagnosed patients don't have a champion because they don't have a diagnosis, but they can come to Vanderbilt and get help. The generosity of this family, and their decision to use their philanthropy to help this group of patients, is unparalleled and so very appreciated."

### Growing to serve more children

Over the past seven years, patient visits within the Division of Medical Genetics and Genomic Medicine have increased from 2,900 a year to more than 5,000, Hamid said. In 2018 there were three physician providers; now there are seven. Genetic counselors have increased from four to seven; nurse practitioners, from four to six.

"Clinically we have grown, and we are seeing significantly more patients both in the outpatient and inpatient setting," Hamid said, adding that the division provides clinical care to patients throughout Tennessee, and into western North and South Carolina, all of Alabama, northern Georgia, all of Mississippi, northern Louisiana, and southern Indiana, Illinois and Missouri.

Regionally, the division has expanded its outreach, seeing patients where they work and live in Murfreesboro, Cookeville, Hendersonville and Clarksville. In addition, the division helps manage patients with genetic conditions at Niswonger Children's Hospital in Johnson City, Tennessee.

The division also helps patients with unique needs and specific diagnoses.

Angela Grochowsky, MD, a provider within the division who treats both pediatric and adult patients, is working to expand Monroe Carell's Down Syndrome Clinic for patients older than 18.

"Dr. Grochowsky's interest in helping patients with Down syndrome transition from childhood to adulthood is fantastic," Hamid said. "These families now have a geneticist who understands the nuances of young adults with Down syndrome."

**While most children are born healthy, about 6% are born with genetic and metabolic disorders.**

Liz and John Potocsnak, second and third from left, with Jeff Balser, MD, PhD, left, Rizwan Hamid, MD, PhD, and Jennifer Pietenpol, PhD. A transformative gift from the Potocsnak family established the Potocsnak Center for Undiagnosed and Rare Disorders at Vanderbilt University Medical Center.



CHAD DRIVER



The division also has a collaboration with the state of Tennessee's newborn screening program.

All babies born in Tennessee have a heel prick with about two to three drops of blood taken on day two of life to test for 67 rare genetic disorders that have treatment options. If tests are abnormal, the division is notified, the baby can be brought to Monroe Carell for tests confirming the condition, and early treatment, if warranted, can begin. Monroe Carell has established clinics for children with genetic disorders that are found on newborn screening, including adrenoleukodystrophy, Fabry disease, Krabbe disease and others.

Additionally, the division has a strong research focus. Joy Cogan, PhD, leads a project of gene discovery in idiopathic pulmonary fibrosis, a lethal lung disorder. Hamid, in collaboration with Eric Austin, MD, is working to discover genes responsible for pediatric pulmonary hypertension. John Phillips, MD, has a large translational research program in finding treatments for rare genetic disorders.

And providers within the division are actively involved in teaching as well. The division is responsible for teaching genetics to the next generation of medical students, genetics counselors and nurse practitioners.

"There aren't enough genetics and genomics providers out there. We're a small division of about 30 folks altogether, but you can see how much we do. Our reach is vast," Hamid said.

## Diagnostic Journey

Several months after he was born, Blake Kirby wasn't meeting developmental milestones. He was seeing 16 specialists at Monroe Carell, including a geneticist.

"All these different doctors were looking into what they could figure out and were treating the symptoms. We were going to Monroe Carell every week and visited doctors on almost every floor of the Doctors' Office Tower. We practically lived at Vanderbilt," Davis said.

His geneticist recommended whole exome sequencing, but their insurance wouldn't pay for the expensive testing. That's when the family was recommended to Vanderbilt's UDN, which took on his case.

After the team performed whole exome sequencing with a blood sample from Blake, a type of genetic sequencing to find out what is causing symptoms or a disease, they had a strong suspicion that they had an answer.

They worked collaboratively with the NIH and the Pacific Northwest UDN site to find more clues and confirm the diagnosis and found that Blake had a mutation in the COG4 gene, one piece of a group of proteins known as the conserved oligomeric Golgi (COG) complex. Since he was the first patient diagnosed with this mutation, a detailed search by several other collaborative teams (some from outside the U.S.) found more undiagnosed or misdiagnosed patients with many of the same symptoms. VUMC's team was critical in solving this mystery due to some unique capabilities only available at Vanderbilt.

The families are now linked through a Facebook group, and now that the underlying cause of the condition is known, researchers are working to better understand the mechanisms of the disease, in hopes that a treatment will someday become available. The Facebook group is run by the two oldest patients with Saul-Wilson.

Davis, who has four other children, ages 31, 26, 13 and 12, said connecting with the group of patients and families through Facebook has been invaluable, allowing individuals with the disease and their families to share successes and hurdles.

"Since we've been able to put a name to it, we have been able to research as much as we possibly can. Knowing other people who have this and being able to ask, 'We went to the doctor and found this out. Does it affect you?' and 'What have you gone through?' has brought this community together and made a family of all of us," she said.

"It seems like everyone's experience has been that they didn't know their baby was going to live. We've all had those doctors who have said, 'Your baby probably isn't going to make it.' We've all walked through that. Then, as they get older, they stabilize and kind of catch up with milestones."

Because of parents they have connected with, they knew that Blake would need cataract surgery. And they know that a hip replacement may be in his future.

Davis has been able to share Blake's success taking growth hormone after several of the patients in the group were told that taking growth hormone doesn't work.

"I've been able to show them Blake's medical records and show that although it's working slowly, it's working," Davis said. "The majority of us in the group are parents of children with Saul-Wilson. We've been able to come together and talk about our experiences and our struggles. We're bonded because of that group. We've become a real family."

Although he struggled to meet early milestones, Davis said Blake is "thriving" and in third grade, which he attends virtually. He is reading at a fourth-grade level and his math skills were at a third/fourth-grade level last year.

"Having a diagnosis doesn't change who Blake is. He's still the funny little firecracker who loves to tell jokes, who is determined and who doesn't let anything slow him down. He finds ways to adapt if he's having any difficulty. He may be small, but he'll find a way," she said.

"But having a diagnosis has given us a community that understands and helps us prepare for the road ahead. It's also given us hope. Before, we didn't know if there would be a future for Blake, but now we know he has a huge, bright future ahead of him, and he is capable of doing anything he sets his mind to. He's already defied what so many doctors thought he would ever be able to do." 🦋

With help from a targeted cancer therapy, Ysa Engel, 18, can envision life beyond her disease and focus on starting college.







# THE ERA OF PRECISION ONCOLOGY

Targeted therapies offer hope for  
improved outcomes



**M**ORE THAN A YEAR AGO, Ysa Engel was close to needing brain surgery. Ysa, 18, has a rare genetic disorder called von Hippel-Lindau (VHL) disease, which causes tumors, both benign and cancerous, and cysts to grow in multiple parts of the body. In Ysa's case, a brain stem tumor — a benign hemangioblastoma — was beginning to cause vomiting and impact her swallowing and some sensory functions. Although surgical removal was a potential treatment, the area of the tumor was risky.

A new targeted therapeutic, belzutifan, had recently been approved for the treatment of VHL-associated tumors in adults ages 18 and older, and Ysa's doctor, Debra Friedman, MD, MS, was able to get approval to treat her with the medication.

Within the first two months of belzutifan therapy, her brain stem tumor stabilized and even shrunk a bit.

"Then the tumor stayed stable for a year, which was great because it wasn't impacting me anymore," Ysa says. A recent scan suggested that the tumor may be growing slowly again, but Ysa is confident she can face surgery if it's in her future (see page 21 to read more about VHL and Ysa).

"I was terrified of having brain surgery," says Ysa, who recently graduated from high school in Canton, Georgia. "Belzutifan gave me room to have a normal life and not have to worry about surgery."

Belzutifan is one of a growing number of targeted cancer therapies — treatments that target molecular properties that are unique to a cancer, aiming to kill tumor cells without harming healthy tissues.

Monroe Carell Jr. Children's Hospital at Vanderbilt is a leader in offering targeted cancer therapies to patients, often in clinical trials that are testing whether these therapies can improve outcomes and reduce harm from traditional chemotherapy treatments.

"The molecular findings coming out of laboratories over the last 10 years have been voluminous," says Friedman, director of the Division of Pediatric Hematology and Oncology. "Month by month we learn more and more about the biologic pathways underlying cancers, and new targeted therapies are developed. We are now really getting to the era of true precision oncology."

## Changing the treatment landscape

Targeted therapies are the latest advance in what has been steady, measured progress in treating children with cancer.

"We cure children today that we didn't cure when I started treating patients," says Friedman, who holds the E. Bronson Ingram Chair in Pediatric Oncology. Friedman completed her residency and fellowship training in the early 1990s and joined the Vanderbilt faculty in 2008.

Traditional chemotherapy and radiation, while potentially curative, can have long-term adverse effects that make the "cured patients of today the chronic disease patients of tomorrow," Friedman says. The hope for precision oncology, she says, "is that we'll be able to cure children in a more targeted and gentle fashion."

But bringing targeted therapeutics into pediatric cancer care can be tricky, says Daniel Benedetti, MD, assistant professor of Pediatrics in the Division of Hematology and Oncology at Monroe Carell.

"We've had far more limited uses of targeted therapies in pediatric cancer than our colleagues in adult oncology, which reflects the fact that we are very successful at curing childhood cancer," Benedetti says. "We cure about 85% of all kids who are diagnosed with cancer, and that's almost exclusively with traditional chemotherapy, radiation and surgery. How do we justify not giving them the standard treatment to give them a targeted therapy that might be as effective, but we haven't proven that yet?"

To test the effectiveness of new targeted treatments, clinical trials usually try them first in patients who have no further curative options. If the treatments are effective for these patients, then they might be used in a trial of initial relapse, or perhaps as an addition to the standard treatment, Benedetti says.

"It takes a stepwise, iterative process, and because childhood cancer is rare, it can take five years to run a trial and another five to get results. So, we're moving at slow paces because we have to figure out how to justify using these new drugs when other treatments are so effective," he says.

For some diagnoses, though, targeted therapies have already changed the treatment landscape, Benedetti says.

One is infantile fibrosarcoma, a fast-growing cancer of connective tissue that occurs in infants and young children. The cancer cells usually have a genetic change that is shared by other adult cancers — a chromosomal rearrangement that activates a certain signaling protein. An inhibitor of this activated protein, called larotrectinib, was effective in treating multiple types of cancer with the chromosomal rearrangement.

"This drug has really changed the treatment of infantile fibrosarcoma and any cancer with that genetic change," Benedetti says. "It's a small group of patients, but it's a huge impact. And hopefully, over time, we'll be able to figure out other places where similar stories can occur."

## Personalized care for patients with neuroblastoma

Benedetti hopes a cancer that will benefit from targeted treatments is neuroblastoma, which develops from immature nerve cells called neuroblasts. It often starts in the adrenal glands but can form in other areas of the abdomen, chest or neck.

Usually diagnosed in children younger than 5, neuroblastoma is the most common solid tumor in children, other than brain tumors as a group. It makes up about 8% of childhood cancer, but accounts for a disproportionate percent of deaths from cancer, about 15%, Benedetti says.

Neuroblastoma is a very heterogeneous disease. Some children need no treatment, and the tumor will regress on its own, while others require only surgery or some chemotherapy. But about half of patients with neuroblastoma have high-risk disease that may have already spread throughout the body. And even with about 18 months of intensive treatment that includes chemotherapy, surgery, autologous stem cell transplant (cells from the patient), radiation therapy and immunotherapy, only half of these patients will be cured.

"Sometimes I sit down with families and say, 'Your child has a cancer called neuroblastoma, and we don't need to do anything about it,' and other times I have to say, 'Your child has a cancer called neuroblastoma;

## Five-year survival rates for childhood cancer



**1950s**  
10% survival

**1970s**  
58% survival  
(ages 1-14 years)

68% survival  
(ages 15-19 years)

**Late 1990s**  
80% (ages 1-19 years)

**Present**  
85% survival

*Sources: National Institutes of Health; National Cancer Institute*



we're going to throw the kitchen sink of every possible cancer treatment at it, and we still may not be able to make it go away," Benedetti says. "It's an important set of conversations with families around the idea that cancer can mean a lot of different things."

Over the last 30 years, clinical trials have made it possible to determine risk categories and personalize

care for patients with neuroblastoma based on factors including their age, the stage of the cancer and the cancer's biology and genetics. Current trials are testing targeted treatments in patients with high-risk neuroblastoma.

"Our outcomes for neuroblastoma are not as good as most pediatric cancers, and so it's a disease where we're trying to bring new therapies in as early as we can, once there's scientific rationale for doing so, and hoping that it will allow us to catch up with other diseases," Benedetti says.

Two targeted treatments being tested are ALK inhibitors (the ALK gene is mutated in about 15% of neuroblastoma tumors) and a highly radioactive form of the molecule MIBG. Because of its chemical structure, MIBG is absorbed by most neuroblastoma cells, and a less radioactive form of MIBG is used in diagnostic imaging for

**Genetic testing of Cora's tumor revealed that it had a mutation in the ALK gene, and her parents did not hesitate to enroll her in the clinical trial that added the ALK inhibitor crizotinib to her treatment.**

ERIN O. SMITH

Cora Devar, 4





neuroblastoma. Both ALK inhibitors and radioactive MIBG have been used in patients with recurrent neuroblastoma and no other treatment options.

"This cancer is even more challenging to treat if it comes back, so we need to try and figure out if these treatments make a difference if we give them earlier," Benedetti says.

### 'There is hope'

Cora Devar is a curly-haired 4-year-old who likes to snuggle her family's pets, help plant flowers and play basketball with her older brother at their Kingston Springs, Tennessee, home.

Her mother, Chelsea Devar, recounts the grueling treatment Cora had for aggressive neuroblastoma that started in the summer of 2020. Cora seemed to be constantly sick with fevers, and then her parents noticed a swollen lymph node in her neck.

"Her pediatrician sent us to Monroe Carell, and it wasn't long before all the scans and a biopsy confirmed that it was neuroblastoma," Devar says. Cora started treatment just before her second birthday in July 2020. She suffered septic shock after the fourth and fifth rounds of chemotherapy and had to be resuscitated after having a cardiac arrest in the emergency room. Fortunately, she did not have any neurological damage, Devar says.

Genetic testing of Cora's tumor revealed that it had a mutation in the ALK gene, and her parents did not hesitate to enroll her in the clinical trial that added the ALK inhibitor crizotinib to her treatment.

"We were willing to do anything, and we trusted the doctors," Devar said. "Our feeling was that we were already facing the worst thing with her diagnosis and that we would try anything that might help."

Benedetti says, "If the tumor cells are driven by a genetic change in ALK, we hope that an ALK inhibitor will improve the sensitivity to chemotherapy and the overall response. It will take us another five years or more to learn and prove whether it makes a difference, but in my patients so far, we've at least seen some encouraging responses."

Patients whose tumors do not have the ALK gene mutation — but whose tumors do take up MIBG — may enroll in a trial of radioactive MIBG as a treatment option, with half of the patients who enroll being randomized to receive the therapy in addition to the standard treatments. Radioactive MIBG delivers radiation directly to the neuroblastoma tumor cells.

Monroe Carell is one of about 20 centers — and the only children's hospital in Tennessee — with a special lead-lined treatment room where radioactive MIBG can be used.

Connor Stamey, 4, received radioactive MIBG as part of his treatment for high-risk neuroblastoma that was diagnosed in August 2020, when he was one month shy of turning 2. Connor ran a low-grade fever for almost two weeks that summer, and his mother,

Connor Stamey, 4



SAMANTHA BLONDELL PHOTOGRAPHY

**"We were thankful with Connor's disease that he was randomized to get that additional therapy to hopefully knock it out for good."**

Heather, repeatedly took him to the family's pediatric practice in Kingsport, Tennessee.

"I knew something wasn't right with Connor," she says, remembering that he had stopped walking and wouldn't let her put him down.

Ultimately, he was admitted to a regional children's hospital, where he was diagnosed with juvenile idiopathic arthritis — a diagnosis that brought the family to Monroe Carell for an appointment with a pediatric rheumatologist.

"The rheumatologist examined Connor, looked at me, and said, 'I don't think this is JIA. Do you mind if I admit him to the hospital?'" Stamey recalls. "That was a Monday, and by the end of the week he'd had a tumor biopsy and bone marrow biopsy and was start-

*These advances in pediatric cancer research and treatment options at Monroe Carell are possible thanks to many generous families, individuals and businesses within our community of support.*





ing treatment. We felt like maybe he was misdiagnosed for a reason, that God had led us to Monroe Carell.”

For the radioactive MIBG therapy, Connor was sedated and treated in the lead-lined room, with his parents in a room next door, connected by video and audio and with very limited access to Connor during the four-day treatment.

“Connor did really great; it was much harder on us than on him,” Stamey says. “It was honestly one of the easiest treatments that he went through, with almost no side effects. We were thankful with Connor’s disease that he was randomized to get that additional therapy to hopefully knock it out for good.”

An MIBG scan after the treatment showed that Connor had little or no disease before he completed stem cell transplants, radiation, and finally, immunotherapy.

“MIBG may have been the kicker that got him into remission,” Stamey says.

Both Devar and Stamey praised the nurses and care their children received at Monroe Carell.

“The nurses would sit and play with Cora and kind of tell us to take a break,” Devar says. “They took really good care of her, and the doctors were great. It was easy to try to stay positive with the team that we had.”

Stamey agrees. “We couldn’t have done it without the nurses on the sixth floor,” she says. “They were so supportive, and when Connor felt like it, they would play, play, play with him.”

“When we started fighting this nasty disease, we wondered if we’d ever make it to the end, or what the end would look like. Connor is out in the yard playing right now, running around and having fun. There is hope.” 🐛

## Comprehensive care for patients with VHL

Von Hippel-Lindau (VHL) syndrome is a rare genetic disorder that causes tumors and cysts and predisposes patients to developing kidney and pancreatic cancer.

“Although it’s rare to see VHL-associated cancer in children, it’s important to be monitoring them and to pick up cancer at the earliest possible stage,” says Debra Friedman, MD, MS, director of the Division of Pediatric Hematology and Oncology at Monroe Carell Jr. Children’s Hospital at Vanderbilt and holder of the E. Bronson Ingram Chair in Pediatric Oncology. “Children are at risk for a variety of nonmalignant tumors, which can have very serious consequences, particularly if they go undiagnosed.”

Benign tumors of the adrenal gland can cause life-threatening high blood pressure and stroke; tumors of the brain and spinal cord can impact function; and tumors in the eye can cause blindness, she notes.

Ysa Engel was a freshman in high school in the fall of 2019 when a routine eye exam revealed a tiny spot in her eye — possibly a birthmark, the eye doctor said. Further evaluation by a retina specialist and then multiple imaging studies showed that Ysa had several tumors in her eye, a brain stem tumor and pancreatic cysts. Genetic testing confirmed that Ysa has a genetic muta-

tion that causes VHL; her parents and younger brother are not affected. About 20% of patients who have VHL have a de novo (spontaneous) gene mutation.

The Engel family lived in Las Vegas at the time, and Ysa saw the only pediatric neurosurgeon in the area, who told them that he didn’t know how to handle the brain stem tumor and wouldn’t operate.

“We were like, ‘Really? So, I have a brain tumor and there’s nobody in this city who can help me.’ That was hard to hear,” says Ysa, now 18.

The family connected with the VHL Alliance, an advocacy organization that promotes research, education and support for those with VHL, which helped them locate a treatment center in Scottsdale, Arizona. Ysa received care there, including the successful removal of her eye tumors, until the family moved to Canton, Georgia, in 2021, both to be part of a family business and to come to Monroe Carell for Ysa’s care.

Vanderbilt University Medical Center is the only VHL Alliance-designated Comprehensive Clinical Care Center in Tennessee, offering care to both pediatric and adult patients with VHL.

“Now I have a team of doctors who all talk to each other about my specific case and also work with all the other VHL patients,” Ysa says.

Ysa has been taking a targeted therapy for the brain stem tumor, but if she needs surgery, she feels confident in the care of pediatric neurosurgeon Michael Dewan, MD.

“He has operated on patients with VHL with the same type of tumor, and that gives me a lot of comfort,” she says.

Ysa’s family is working to promote awareness of VHL and be an example that “many people are fighting a silent battle that we know nothing about or cannot see,” says her mother, Amanda. Her father, William, is serving on the VHL Alliance board of directors and hopes to increase screening for VHL.

“Ysa’s condition was caught in a routine eye exam; this is something that ophthalmologists and optometrists should be aware of,” he says.

For her part, Ysa exercises every day, creates art, works with the family business, and graduated from high school with high honors, credits from dual enrollment and an academic scholarship for college.

“I have VHL; it doesn’t have me,” Ysa says. “It has taught me to see things through a different lens, to be more empathetic. I wake up and try to enjoy every day and appreciate the body that I have, even if it’s really good at making tumors.”

# Chords of Hope

## Personalized care for children and adolescents with seizures

STORY BY JILL CLENDENING  
PHOTOS BY ERIN O. SMITH

**Anna Grace Stephens**, 18, calls the instant she met epilepsy specialist Shilpa Reddy, MD, MMHC, a “miracle moment.”

“The doctors at Vanderbilt got my seizures to stop when they had been uncontrolled for days,” said Anna Grace. “Then I was admitted to the EMU [Epilepsy Monitoring Unit] for the first time so they could start figuring out where my seizures were coming from.”

Reddy, assistant professor of Pediatrics, is director of the Pediatric Epilepsy Monitoring Unit at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

“I remember when Dr. Reddy walked into the hospital room and asked if she could help us,” said her mother, Leigh Ann Stephens. “I tear up every time I think about it.”

When Reddy met the Stephens family, Anna Grace had been transported by ambulance from another hospital after she had been unsuccessfully treated for seizures that continued for three days.

Anna Grace needed a higher level of care, and the Pediatric Epilepsy Program at Monroe Carell is accredited by the National Association of Epilepsy Centers (NAEC) as a level 4 epilepsy center, which means it offers the professional expertise and facilities to provide the highest level of medical and surgical evaluation and treatment for patients with complex epilepsy, including inpatient video-EEG monitoring to evaluate children for epilepsy.

*U.S. News & World Report* consistently

ranks Monroe Carell as a top provider of pediatric neurology care.

“As part of our pediatric epilepsy program, we treat patients who need evaluation for possible seizures and patients with known seizures, whether it be new onset epilepsy or difficult-to-treat genetic epilepsy syndromes,” said Reddy. “We see patients with epilepsy who may be good candidates for different therapies and treatments, including new medications, the ketogenic diet and surgery. We’re a full-service, comprehensive program.”

Epilepsy, which affects about 6 in 1,000 children, is a neurological disorder defined as recurrent, unprovoked seizures. During an epileptic seizure, many neurons in the brain fire or signal at the same time and much faster than normal. This surge of excessive electrical activity causes involuntary movements, sensations, emotions and behaviors, and the disturbance of normal neuronal activity can cause loss of awareness or responsiveness.

Members of the pediatric epilepsy team at Monroe Carell also have specialization in treating other disorders often associated with epilepsy. For example, patients with genetic disorders, such as tuberous sclerosis, Rett syndrome and Angelman syndrome, are at high risk of developing epilepsy, and epileptologists run multidisciplinary clinics for each of these disorders. The team even meets with expectant mothers at The Reed Family Maternal Fetal Clinic at Vanderbilt if their unborn chil-



dren have been diagnosed with a brain malformation, which can result in epilepsy.

“I let the family lead a lot of conversations, and my style of practicing medicine is very team based,” Reddy said. “My No. 1 question — whether we’re treating a child’s epilepsy with medication or diet or doing surgery — is, ‘What is important to your child and your family? How do we optimize your child’s quality of life without compromising other things?’ That’s going to look different for every single patient, depending on their age, their development, the reason for their epilepsy and, of course, the family’s situation. There’s never one right way to do things, and I like to always give families options and access to my thought process.”

When Anna Grace arrived at Monroe





Better-controlled epilepsy allows Anna Grace Stephens, 18, to enjoy the activities she loves like playing the piano.

Carell, she was in a debilitating medical state known as status epilepticus, in which a person experiences a continuous, unremitting seizure or rapidly recurring seizures. If unresolved, it can be life threatening, with an estimated mortality of about 20%.

Before this crisis, Anna Grace had experienced epileptic seizures for two years. Her mother said from the moment of her daughter's first seizure, their family was transformed forever.

"She fell down and started convulsing," she said. "We took her to the emergency room at our local hospital. She was having an EEG and had another seizure while being monitored. She was diagnosed with epilepsy that day. I knew nothing about epilepsy at that point."

Seizures are divided into four big categories: focal, generalized, focal and generalized combined, and unknown. More than 30 types of seizures within these categories have been identified by epilepsy specialists. Focal seizures originate in one part of the brain, and about 60% of people with epilepsy have these type of seizures. Generalized seizures occur when abnormal neuronal activity happens on both sides of the brain at the same time. Some people have seizures that begin as focal but then spread throughout the brain.

Anna Grace's first recognized epilepsy event at age 11 was a tonic-clonic seizure, once called a grand mal seizure. These seizures cause a combination of symptoms, including stiffening of the body, rhythmic jerking of the limbs, and loss of consciousness.



"We see patients with epilepsy who may be good candidates for different therapies and treatments, including new medications, the ketogenic diet and surgery. We're a full-service, comprehensive program."

Though she'd always excelled in academics, her seizures and the intense fatigue that followed them caused Anna Grace to begin struggling in sixth grade. Anti-seizure medications, prescribed one after another, weren't working well and often had extreme side effects. One medication caused her to rage and scream uncontrollably at others with no warning. Another caused continual hunger, while one caused significant cognitive issues.

"With all the drug side effects, my quality of life wasn't even worth it," Anna Grace said. "It was either seizures or no quality of life. There was no middle ground."

Leigh Ann Stephens was earning a bachelor's degree in psychology and a master's degree in social work when they began traveling three hours from East Tennessee to Nashville for Anna Grace's care. The death of Leigh Ann's father during this time made life even more sad and stressful. Leigh Ann's mother, Susan Connors, is a registered nurse, and she chose to retire so she could stay with Anna Grace. School lessons were soon being done at home.

After a high-fat, low-carbohydrate, modified-Atkins diet proved unsuccessful, the Stephens family met another member of the pediatric epilepsy team, Robert Naftel, MD, a pediatric neurosurgeon. With surgery, the area of the brain where seizures begin can be removed or the seizure communication pathway can be disrupted to limit the spread of seizures to other areas of the brain.

For Anna Grace, an invasive diagnostic procedure, stereoelectroencephalography (SEEG), was needed to plan the surgery. With SEEG, electrodes were implanted directly into Anna Grace's brain so the medical team could create a detailed map of where the seizure starts and spreads. After the seizure focus was identified, the epileptologists methodically tested that area to make sure it did not control any important functions such as movement, talking or vision.

The SEEG revealed a large portion of Anna Grace's right frontal lobe was the origin of her seizures, and surgery was scheduled in March 2017.

"I leaned into my faith, and I relied on prayer," Leigh Ann Stephens said. "We felt confident in the medical team, and we all had a kind of peace about it."

Anna Grace was understandably conflicted. She wanted relief from the seizures, but she also feared losing facets of her life that gave her great joy. A very rare potential complication, based on the area of brain that was targeted for removal, was weakness or paralysis on her left side.

"I'm a music kid," Anna Grace said. "I've been playing the piano since second grade. I thought, 'You might take that away from me?' Excuse me?"

The surgery was successful, revealing a structural brain abnormality (focal cortical dysplasia, a group of disorganized neurons) as the cause for her epilepsy. For the next two years, Anna Grace had physical therapy and speech therapy sessions to rebuild her strength and

function. And she had no seizures for three years. Then, in June 2020, her seizures made an unwelcome return.

"Out of nowhere, I fell, hit my head on the brick hearth and was bleeding everywhere," Anna Grace said. "I was on the floor, and I thought, 'Wow, I haven't done this in a hot minute!'"

The family returned to Monroe Carell to find out why the seizures were happening again.

"Over time, because her epilepsy had been longstanding, her brain created new networks or there were existing networks that were unmasked over time," Reddy said. "So, she had a recurrence of her seizures."

The team then recommended implantation of a device called a vagus nerve stimulator, which sends electrical impulses up the vagus nerve into the brain to alter brain activity. The device proved to be only moderately successful.

"Epilepsy is hard and unpredictable, and through it all, it is important to focus on quality of life and what will best help the patient and their family live their best life," Reddy said. "Working together by trying new medications, considering new procedures, and forming relationships is a vital part of treating epilepsy."

The Stephenses have decided to hold off on any other procedures, hoping to wait until Anna Grace's



**Top: Anne Grace Stephens' service dog, Sully, is trained to detect when she is having a seizure.**

**Bottom: Anna Grace and her mom, Leigh Ann, left, travel from Knoxville, Tennessee, to Nashville for epilepsy care.**



brain fully matures at age 25 to see what her new normal looks like then. In the meantime, she takes anti-seizure medication and is under the watchful eye of a new member of the family, her seizure-response service dog, a 50-pound Pyradoodle named Sully.

When Sully spots behavior that signals a seizure, he barks frantically and loudly to alert others. During a seizure, and as it subsides, Sully comforts Anna Grace and often licks her to help her return to awareness. The family credits Sully for saving her life on more than one occasion.

Anna Grace's seizures have been less frequent than before she had surgery, when she was experiencing up to multiple seizures a day. She currently has "small"

seizures which cause her to stare blankly into space for short periods as well as tonic-clonic seizures that usually occur about three to six months apart. In recent months, she's had a tonic-clonic seizure once a month, which Leigh Ann attributes to some added stress.

The family still walks on eggshells, dreading the next seizure. But many days are also filled with planning for exciting, future milestones.

Anna Grace plans to attend college near her home, with the goal of earning a PhD in English and becoming a college professor. She also wants to write a book, possibly about her experiences with epilepsy.

"I mean, I'm 18, and I could probably write a pretty large autobiography at this point," she said. 🐾

## MONROE CARELL'S EPILEPSY MONITORING UNIT CHARTS THE WAY FORWARD FOR PATIENTS

There's a button in the Epilepsy Monitoring Unit (EMU) at Monroe Carell Jr. Children's Hospital at Vanderbilt that's far more important than the room's television remote. It's called the event button.

Pediatric patients as young as infants with known or suspected seizures come to the six-bed specialized unit on the seventh floor of the hospital. There, their brain activity and seizures are monitored 24 hours a day by electroencephalogram (EEG), a recording of the brain's electrical activity, and by video and audio captured in the room.

Monroe Carell is the only facility in Middle Tennessee with video-EEG monitoring for the evaluation of children for epilepsy.

Tiffany Porter, CNCT, supervisor of the Pediatric Neurodiagnostic Lab at Monroe Carell, is the first person families talk to when they're referred to the EMU. In a pre-EMU-visit meeting, she talks them through the monitoring process, answers questions and tries to calm any anxiety they might have.

In the first quarter of 2023, around 150 patients had been

admitted to the EMU, and typically 650 patients are seen there annually, so it's a busy space.

"I reassure them that we have some of the best physicians in the world who will be taking care of their children, and that they have great techs to make sure the monitoring is very precise," Porter said. "Our nurses on the unit are awesome, and we get help from a child life specialist who talks to the family to see if there's anything they can do to help make the visits nicer for the patient."

Patients have electrodes placed on their heads and don't leave their private room during their stay, which can be just 24 hours or a week or more, depending on the complexity and frequency of their seizures. If patients have been taking anti-seizure medication at home, the medication is decreased or stopped to allow seizures in the safe setting of the EMU.

Child life specialist Meredith George, MEd, CCLS, works with the EMU team to create informational packets for families to have in the room, and she's at the ready to supply games, toys, and support that will help

children of all developmental ages and behavioral needs get through the process of EEG placement.

A parent or guardian is required to be their constant companion, and meals and a sleeping space are provided. They keep a watchful eye on the child, and if behavior that signals a typical event begins, they push the event button. This sets off a well-rehearsed response.

Neurodiagnostic technicians who monitor around the clock are already watching the child's EEG record remotely, and they mark concerning patient movements as they occur. These technicians also ensure the patient's movements are clearly visible on video. The adult caregiver has instructions to uncover the child if they're in bed and to step back so the camera view is unobstructed.

Should a seizure occur, a nurse experienced in caring for children experiencing seizures responds quickly, checks their vital signs and asks the child, if they are verbal, questions, such as "What is your name?" and "Do you know where you are?"

The EEG detects abnormal electrical discharges in the

brain such as sharp or spike waves, typically seen in people with epilepsy. The EEG data, along with the video and audio of the event, help diagnose or rule out epilepsy and determine the next steps of treatment. Recording seizures on EEG allows neurologists to better classify seizures and pinpoint their origin in the brain.

The multidisciplinary pediatric epilepsy team at Monroe Carell, which includes epilepsy specialists (epileptologists), a neurosurgeon, neuropsychologists, neuroradiologists and an imaging physicist, review the data from the EEG and other testing to determine a custom care plan for the child. That plan might include additional testing, a recommendation for surgery, a change in medication or even diet therapy.

Patient Anna Grace Stephens has had several stays at the EMU, beginning in 2016. One of Stephens' visits coincided with her birthday, so her mother and grandmother decorated the room in a Paris theme, and a nonstop parade of American Girl dolls and accessories helped ease her stay.

- by Jill Clendening

# faces of hope

MEET THE PEOPLE WHO BRING HOPE TO FAMILIES EVERY DAY

Monroe Carell Jr. Children's Hospital at Vanderbilt delivers high-quality care, creates a welcoming environment for parents and children, and serves as a resource for the surrounding community. None of these things would be possible without the people who make up Monroe Carell — from the physicians and nurses who provide care for sick children to child life specialists, social workers, pharmacists and more.

This wide array of expertise means Monroe Carell is equipped to handle any issue a child may face — no matter how complex.

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STORIES BY DANNY BONVISSUTO

## Dontal Johnson, MD

COMMUNITY PEDIATRICIAN

**D**ontal Johnson, MD, assistant professor of Pediatrics at Meharry Medical College and pediatrician at the Meharry Pediatrics Clinic, gives the same answer to everyone who asks how he's doing.

"I'm just living the dream."

"Every day I go to work and do exactly what I'm supposed to be doing," he said. "And every day I go home feeling like I made a difference, whether it's big or small; whether I saw one patient or 10; whether I taught one medical student or 120 medical students or someone who wishes they were a medical student."

A self-proclaimed "Okie from Muskogee," Johnson moved from Oklahoma to Dallas at a young age and considers Texas home. He met his wife, Erica, during his undergrad years at Texas Tech University, got his medical degree at Meharry, did his pediatric residency at Vanderbilt, and interviewed at Meharry before graduation, even though he knew the one open position in pediatrics had been filled.

"My mentor, Dr. (Xylina) D. Bean, said, 'I can't hire you, but I'll interview you,'" Johnson said. "A

month went by and she called me: The other candidate had fallen through, and I got the position."

Johnson's love of children was born in the church where his mother oversaw the children's ministry, and it grew in high school when he had the opportunity to shadow a family medicine physician.

"My favorite parts were the visits with kids," he said. "I realized I could go to work and play with kids for a living. Be there when they're born. See them grow. I could not imagine a better job."

When he was a third-year medical student, Johnson got a first-hand look at pediatrics from a parent perspective.

The oldest of his four daughters had bronchiolitis, a respiratory infection, and was admitted to Monroe Carell Jr. Children's Hospital at Vanderbilt.

"It got really scary. She was in the emergency department, and they were going to intubate her, but thankfully she went to the PICU to get oxygen instead," Johnson said. "I got to be a parent and understand what happens when you are completely and totally at the mercy of the pediatricians and specialists. They were on our side, battling for our daughter and also putting up with our craziness — because you get a little crazy when your child's life is on the line."



Johnson has been "living the dream" for six years. The people who trained him are now his colleagues and he sees himself in the students he teaches.

"I feel like I'm stealing money most days," Johnson jokes. "I work hard — I do. But I'd do it for a lot less or just enough to get by. I get the privilege of being a pediatrician and professor every day. And I get to do it with patients and students who look like me and come from similar backgrounds."



**"I realized I could go to work and play with kids for a living. Be there when they're born. See them grow. I could not imagine a better job."**

- DONTAL JOHNSON, MD



# faces of hope

MEET THE PEOPLE WHO BRING HOPE TO FAMILIES EVERY DAY



**“I hope with the skills I’ve learned through my master’s and the way I interact with families I can continue to push the needle more toward doing what’s right for the patient.”**

— LYNDY WILCOX, MD, MMHC

## Lyndy Wilcox MD, MMHC

ASSISTANT PROFESSOR  
OF PEDIATRIC  
OTOLARYNGOLOGY-HEAD  
AND NECK SURGERY/  
PEDIATRIC  
OTOLARYNGOLOGIST

**A**fter four years at Furman University, medical school and residency training at Eastern Virginia, fellowship work at Cincinnati Children’s Hospital, and three years at Monroe Carell Jr. Children’s Hospital at Vanderbilt as a pediatric otolaryngologist and assistant professor, Lyndy Wilcox, MD, went back to school.

“The patient care is exactly

what I wanted it to be, but the way we do it could be better,” said Wilcox, who finished the 13-month Master of Management in Health Care program at Vanderbilt University’s Owen Graduate School of Management in fall 2022. “Just coming into my practice, I had ideas to make a difference for myself, my partners and patients, but to really effect change, I had to be able to speak the language that other health care workers and administration could understand. We really don’t get any of that training in medical school.

“I hope with the skills I’ve learned through my master’s and the way I interact with families I can continue to push the needle more toward doing what’s right for the patient.”

Born and raised in Virginia Beach, Virginia, Wilcox chose oto-

laryngology for its intricate and interesting anatomy, mix of medical and surgical management, and the profound effect it has on children and their families.

“There are so many things you can do within otolaryngology,” said Wilcox, whose areas of expertise include breathing and voice disorders, thyroid surgery, and pediatric airway reconstruction. “It’s a lot of quality-of-life improvement that impacts how they breathe, how they talk, and how they interact with the world. It can change the trajectory of their lives.”

When she’s not in the hospital or the classroom, Wilcox spends time in the pool with her husband and dogs, Yeti, a Labrador retriever, and Vesper, a golden retriever, and takes group exercise classes at the YMCA with colleagues. A softball player from childhood through college, she’s trying to build a departmental team but hasn’t had any takers yet. Wilcox will make it happen eventually: People tend to lead where she follows.

As a first-generation college graduate and the first doctor in her family, Wilcox is also inspiring a future generation of doctors.

“I had one patient with papillary thyroid carcinoma, a thyroid cancer. She needed a total thyroidectomy and bilateral neck resections. It’s a big surgery, with an incision that went from ear to ear,” said Wilcox, who sees patients at Monroe Carell’s main campus and the Murfreesboro and Spring Hill locations. “She was so resilient. Children bounce back from things and don’t ask, ‘Why me?’ Her mom told me that, at home, she played with her brother and pretended to be Dr. Wilcox. That said so much about how she views health care and how she views me.” 🦋

DONN JONES



# personal perspective

FIRST-PERSON ESSAY



## Work with purpose

*Caring for the hospital's environment where children  
heal mentally and physically*

STORY BY RAY VAUGHNS JR.  
PHOTO BY ERIN O. SMITH

It's been 10 years since I began working at Monroe Carell Jr. Children's Hospital at Vanderbilt. I remember vividly my first day of work as an environmental services technician, unaware of all that the job would entail. I recall standing in the front of the hospital, a huge building next to large red paper dolls, and thinking it is such a beautiful place. I admired the statue in the front of the building of children playing "Ring around the Rosie."

I learned quickly that inside was just as beautiful with so many bright shapes and colors. More importantly, I learned how many people at Monroe Carell play vital roles in taking care of children. It takes a village. We are all part of the health care team.

The people here are all amazing. My heart goes out to all the little patients who would rather be home playing than in the hospital, but I know the staff does its very best to make the stay bearable.

Through my work over the years, I've met so many children who serve as reminders that our work in the Environmental Services Department is important. Every day, staff from the 102-member team spread out across the hospital with one goal: to keep clean the environment where children need to heal mentally and physically and to keep infection rates down. We are a unified team all dressed in the same maroon uniform with the same purpose. I love what I do.

Environmental Services handles all cleaning of every patient hospital room, ancillary, staffing and public areas and is responsible for deep cleaning the clinic floors in the Doctors' Office Tower. We handle one-on-one communication with the patients' family members to facilitate room cleanings. We also have floor technicians that perform the deep cleaning and maintenance of tile, rubber and carpet floors. There are many steps, procedures and processes I follow to keep infection rates down.

I carry out these tasks because I know they help patients like Sara, the sweetest little girl. I met Sara in my first year of work on the pediatric cancer unit. A 3-year-old cancer patient, she was so proud of her bald head. She captured my heart, always perking up when I entered her room, eager to tell me about all the bows she would wear when her hair grows back. She spent several months in the hospital, and I got to know her well. Her mom told me all the time how much she appreciated what I do and how keeping Sara's room clean helped ensure she didn't catch an infection. That always made me feel good.

One of the last times Sara was in the hospital, she wrote me a note. It reads, "Thank you for keeping my room clean, and most of all, for being my friend. You are the best. Love, Sara."

Sara has since passed away, but I keep her note in my locker. I see it every day. And each day, I'm once again reminded that it takes all of us in health care and the community to take care of children. I do all I can to keep every single one of them healthy by doing my part. We can all do our part. 🦋



**"Every day, staff from the 102-member team spread out across the hospital with one goal: to keep clean the environment where children need to heal mentally and physically and to keep infection rates down."**

- RAY VAUGHNS JR.





*Photo by Susan Urmey*

## Getting patients like Will back to doing what they love

When Will Terry suffered a scooter accident during a family vacation, he was diagnosed with a brain bleed and needed surgery. His parents were told he wasn't expected to live through the night. Upon arrival back in Nashville, Will was transferred to Monroe Carell Jr. Children's Hospital at Vanderbilt, where he underwent two additional surgeries. After recovering in the hospital, he was ready for the next step of his healing journey – rehabilitation.



Today, Will is back at home and continues to improve through outpatient therapy. He communicates through sign language, body language and typing on his tablet, and he loves dinosaurs, elephants and playing soccer with his friends.



Help patients like Will today. Visit **[Give.VanderbiltHealth.org/childrens](https://Give.VanderbiltHealth.org/childrens)** or scan the QR code.

# HOPE

Vanderbilt University Medical Center  
Office of News and Communications  
T-5200 Medical Center North  
Nashville, TN 37232



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And that's not something we take lightly. Bonded by our love of children and medicine, we are doctors, scientists, nurses and care team members who partner together to help children of all ages become authors of powerful stories.



We make health care personal, and  
our story is best told through theirs.  
**Watch them unfold.**



Making Children's Health Care Personal.  
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