

# HOPE

CHILDRENSHOSPITALVANDERBILT.ORG



CELEBRATING 20 YEARS

WINTER 2024



Kathryn Carell Brown, Julie Carell Stadler, John W. Brock III, MD, and Edie Carell Johnson tour construction of the four-floor expansion in 2018.





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SPECIAL ANNIVERSARY ISSUE



# 17

"My goal is to become a research doctor and to find a safe, accessible, successful cure for sickle cell disease."



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The Rice quadruplets, Shep, Elizabeth, Laura Frances and Mary Carter, spent the first several months of life in the NICU. Now age 18, they are about to graduate from high school.



# HOPE



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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



Twenty years ago, on Sunday, Feb. 8, 2004, we rolled patients over the fourth floor skybridge from Vanderbilt University Hospital to Monroe Carell Jr. Children's Hospital at Vanderbilt, with Mr. Monroe Carell Jr. pushing the first patient to his room. The excitement of that day was truly palpable, by our namesake, our staff, and even our patients who were old enough to understand. It was clearly a very memorable day for me, as I helped to push babies in isolettes to our new Neonatal Intensive Care Unit (NICU).

Over the years, as a pediatrician, I have often spoken of our journey at Monroe Carell in terms of childhood developmental milestones. The first few years were truly like birth through infancy, learning how to deliver care in totally different ways because of our expanded geography (moving from two floors plus a NICU to NICUs in two buildings and eight floors). The building of new programs was a little like toddler years with some stumbles along the way, and then came the explosion of growth seen in early elementary years, resulting in the first expansion project, completed and filled just eight years after opening the hospital.

Our adolescent years have been busy pushing the boundaries and building access to our programs closer to where our patients live as well as creating premier multidisciplinary programs here at Monroe Carell. We were able to achieve both of these milestones because of the amazing partnerships across the Department of Pediatrics and our pediatric surgical sections, recruiting some of the best and most talented faculty members. We have closed out our adolescent years with a four-floor expansion that allowed for improved patient care models as well as building new teams and programs. The final two floors of this expansion will open over the course of the next year.

I have been humbled and honored to serve as an executive leader for most of this 20-year journey. As I reflect upon this 20th anniversary, two things come to mind:

The first is gratitude. On behalf of countless children served, I want to thank our Monroe Carell teams, community pediatricians, donors and supporters for unwavering support. We would not be where we are today without you. I also want to thank leaders past, present and future for the vision to keep innovating, keep teaching, keep discovering. It is what we do here in a collaborative and fun way.

The second is the name of this magazine *HOPE*. This word captures so much — expectation, desire to help someone or to have something good happen, and trust. We are here to serve children and families, and it is the hope we offer that brings them to us, trusting in our healing hands and hearts.

May you experience gratitude and share in hope as you read our stories over 20 years.

Thank you for being part of this journey! It has been amazing because of you.

With heartfelt gratitude,

Meg Rush, MD, MMHC  
President



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a difference.





# special issue

20 YEAR ANNIVERSARY

FILE PHOTO



**On Dec. 6, 2003**, more than 1,000 people gathered on a chilly Nashville day for the dedication of the new Monroe Carell Jr. Children's Hospital at Vanderbilt. Streamers traced paths through the air; a brass band played; white birds fluttered through the sky; confetti cannons boomed; and children dressed in red made a chain of live paper dolls. Among those in attendance were Vanderbilt leadership, local, state and national politicians, the community and the family of Monroe Carell Jr. and his wife, Ann Scott Carell. "Dreams really do come true. Thank you for sharing this realization of a dream with me today," Monroe Carell Jr. said. The hospital officially opened Feb. 8, 2004. 🦋



# WHERE HOPE BEGAN

PHOTO SUBMITTED



The late Ann Scott Carell with the late Monroe Carell Jr.

## *Celebrating more than 20 years of the Carell family commitment to children*

**O**n Feb. 8, 2004, Monroe Carell Jr. Children's Hospital at Vanderbilt opened its doors with much fanfare as Nashville's and Middle Tennessee's first full-service children's hospital. Until that time, Nashville was the only city among the top 25 in the nation that didn't have a freestanding hospital dedicated to serving children and their families.

Monroe Carell, named after the hospital's most passionate advocate whose philanthropy with his wife led to its construction, opened as an eight-floor, 206-bed state-of-the-art hospital with 616,785 square feet. The first year exceeded all expectations with hospital teams seeing an incredible demand for children's health care services, and soon leaders realized that the need for an expansion and continued growth of programming were imminent.

Two physical expansions followed, first in 2012, with a 33-bed, 30,000-square-foot addition, and then with the current four-floor, 160,000-square-foot expansion atop the existing building. Once the latest expansion is complete, Monroe Carell will have 401 beds and more than 1 million square feet on the main campus plus its 30 off-site and affiliated locations, including several long-standing partnerships with regional hospitals.

Quickly established as a leading pediatric facility, Monroe Carell has consistently earned accolades as a best children's hospital in the nation and has earned the distinction as a top-four pediatric academic research institute. In 2023, Monroe Carell was ranked the No. 1 children's hospital in Tennessee and was one of just 23 hospitals in the nation ranked in 10 out of 10 pediatric specialty programs in *U.S. News and World Report's* Best Children's Hospitals report.

The vision for the hospital began with two champions for children's health, the late Monroe Carell Jr. and his wife, the late Ann Scott Carell, and has continued with their three daughters, Julie Carell Stadler, Kathryn Carell Brown and Edie Carell Johnson, and their families.

"This facility was a dream for so many for so long. Because of their vision and dedication to children

and our entire community, the Carell family created what I call the most important building in this part of the world," said John W. Brock III, MD, the Monroe Carell Jr. Professor, Surgeon-in-Chief Emeritus and longtime family friend. "The entire Carell family truly embodies the compassionate spirit and mission of this special hospital. I am so grateful and humbled to be a part of this journey as our extraordinary health care teams, along with incredible community support, provide children with the quality care they deserve at a premier comprehensive pediatric facility."

## **Dream Big**

More than 20 years ago, Ann and Monroe Carell dared to dream big — and to share that dream with others.

Frequent visitors to and advocates for what was then two pediatric floors plus a NICU within Vanderbilt University Hospital, they felt compelled to realize a decades-long community goal to build Middle Tennessee's much-needed and first-ever stand-alone children's hospital.

The Carells believed so strongly in that mission that they kick-started the fundraising efforts for a freestanding children's hospital with a cornerstone transformational gift in 1999. Additionally, Monroe signed on as chair of the "Shape the Future" Campaign to create a building for what he called the community's "most precious asset — children." Every aspect of the Carells' philanthropy was rooted in causes that supported children.

Nashville's first dedicated pediatric hospital wouldn't just be any building. Indeed, Monroe Carell, founder of Central Parking Corp. and former chair of the then-Children's Hospital Board of Directors, had a grand vision for what a pediatric hospital could and would be: a brightly colored and welcoming facility that



DANIEL DUBOIS



Pictured from left: Julie Carell Stadler, Kathryn Carell Brown and Edie Carell Johnson.

cared for not only children but also for their families; a place full of compassion, empathy and even fun; and a top pediatric health facility and research institution devoted to enhancing health outcomes and the well-being of all children.

“Caring for children meant everything to our parents, Ann Scott Carell and Monroe Carell Jr., and this hospital was the result of that sincere compassion for others. Our family cherishes being connected with their legacy and all that Monroe Carell has accomplished for children already,” said daughter, Julie Carell Stadler, a Monroe Carell Advisory Board member. She has also served as executive producer of the Nashville Christmas Parade and Nashville Holiday Music Special which benefited the hospital.

## Carrying on their parents' legacy

Ann and Monroe always instilled in their daughters the importance of giving, both in time and philanthropy.

That included involving them in activities and sharing stories about visits to the hospital. Monroe recounted one of his visits with them, sharing how a family couldn't afford to call long distance to get updates on their baby when they couldn't be at the hospital. So, he paid for the long-distance calls

between the family and the nurses because he wanted to help.

Part of the Carell family's long tradition of giving includes funding endowed chairs, and that has been carried on by Julie, Kathryn and Edie. Chairs funded include: the Ann and Monroe Carell Jr. Family Chair in Pediatric Cardiology, the Julia Carell Stadler Chair in Pediatrics, the Monroe Carell Jr. Chair, the Ann Scott Carell Chair, and the Edie Carell Johnson Chair in Pediatrics.

“The hope this hospital provides through dedicated researchers and by training leaders and the healing happening through patient-focused care is astounding. We are proud to be part of this community — from those who trust Monroe Carell to care for their children to the many who volunteer, give back or take part in events to further the hospital's impact,” said Edie Carell Johnson, who has served as chair of the VUMC Board of Directors since it was formed in 2015.

Following in their parents' footsteps, the Carell daughters and their families made a cornerstone gift in 2014 that launched the Growing to New Heights expansion effort to build the current four-floor expansion.

Kathryn Carell Brown also led the campaign, which exceeded its fundraising goal of \$40 million

to support the four-floor expansion and included recognition of their mother with the Ann Scott Carell Pavilion.

## Continuing the tradition

The family continues to be active in shaping the hospital's future, including making a lead gift to support the vision to build the first inpatient pediatric rehabilitation facility in Tennessee.

“The creation of a freestanding children's hospital was only the beginning. It remains so important to our family to continue to support children in the region. Even more, we're touched to be joined by others in growing the hospital to serve more families and energized as we look ahead to an inpatient pediatric rehabilitation unit,” Kathryn Carell Brown said.

The passion and commitment to the health and well-being of children has truly become a family affair that now encompasses not only Julie, Kathryn and Edie, but also their six children and their families. There are also six great-grandchildren. Together, the second and third generations (and eventually the fourth) have carried

forward the dream of and dedication to caring for young patients, volunteering and serving the community.

In May 2023, the family gathered at the hospital with leaders to celebrate and reflect on its tremendous impact on health care over many decades.

Julie's son, Monroe Stadler, volunteered for several years at the hospital when he was younger and recently joined her and Kathryn on the Monroe Carell Advisory Board, representing the commitment of the family's next generation to children's health care.

“It's an honor to partner with everyone at the hospital and others who believe in its mission and share my grandparents' enthusiasm for helping children. By building on their vision, families will receive the care they need and benefit from advances for years to come,” Monroe Stadler said. 🦋



Watch more about the Carell family's legacy.

Pictured from left (back row) Nick Brown, Kathryn Carell Brown, Carell Robinson and Monroe Stadler; and (front row) William Johnson, Ann Scott Johnson, Edie Carell Johnson, Julie Carell Stadler and Claire Stadler Lawhorne.



SUSAN URBAN



# THROUGH THE YEARS

The origin story of Monroe Carell Jr. Children's Hospital at Vanderbilt traces back to nearly a century ago when in 1923 the Junior League Home for Crippled Children opened in Nashville. A partnership between Vanderbilt and the Junior League of Nashville was born to provide convalescent and rehabilitative medical care for children with polio and other diseases. That foundation evolved as the Home moved to its own floors of the Children's Regional Medical Center at Vanderbilt in 1971 and to Monroe Carell in 2004. Across a range of initiatives – from child life to NICU follow-up care to capital expansions – the Junior League of Nashville has supported children and families through special programs, volunteerism and philanthropy for over 100 years.

As we celebrate 20 years of Monroe Carell, we look at some of the many dates and chapters in our long, rich history to provide compassionate care and healing to thousands of children and families.

The Pediatric Surgery Center is named for Rascal Flatts, whose members have avidly supported Monroe Carell over the years.



Monroe Carell Jr., CEO of Central Parking Corp., and his wife, Ann Scott Carell, kick off a fundraising campaign with a cornerstone donation for the new free-standing children's hospital, which now bears his name.



"Champ" becomes the official hospital mascot.

Monroe Carell Jr. Children's Hospital at Vanderbilt opens Feb. 8 after four years of construction. The eight-floor, 616,785-square-foot facility is the largest building on the Vanderbilt Campus.

Outpatient Pediatric Rehabilitation Services moves to its new facility at Vanderbilt Health One Hundred Oaks.

1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010

The Vanderbilt University Board of Trust proposes a free-standing children's hospital.

Groundbreaking ceremony held for the new children's hospital on the Vanderbilt campus.



Junior League of Nashville pledges a leadership gift to support a new freestanding children's hospital.

The helipad makes its debut thanks to the Christy-Houston Foundation with support from Mr. and Mrs. Robert Oliver Rolfe.



Monroe Carell is named among the top 25 children's hospitals in the nation in six pediatric specialties by U.S. News & World Report.



Leadership roles take shape for the new children's hospital. Picked to lead alongside Arnold Strauss, MD, medical director of the hospital and chair of Pediatrics, were: John W. Brock III, MD, director of Pediatric Urology, named the first-ever surgeon-in-chief for Monroe Carell, and Jim Shmerling, named executive director and CEO.

Monroe Carell earns top national accolades as U.S. News & World Report and Child Magazine name the hospital one of the top children's hospitals in the nation.





The Growing to New Heights Campaign, led by Kathryn Carell Brown, Kix Brooks, Rick Dreiling, Steve Hostetter, Bob Rolfe and Clarence Spalding is launched to support expansion of Monroe Carell.

A \$30 million, 33-bed, 30,000-square-foot expansion opens.



The new 10th floor of Monroe Carell opens, featuring a 40,000-square-foot Pediatric Heart Institute.

Monroe Carell Jr. Children's Hospital Vanderbilt Surgery and Clinics Murfreesboro opens.

The Reed Family Maternal-Fetal Clinic at Vanderbilt opens thanks to a leadership gift from the Reed family, building on the groundwork provided by a foundational gift from the Junior League of Nashville for comprehensive maternal fetal care.



2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022 2023

Monroe Carell announces plans to build a four-floor inpatient expansion on top of the existing hospital structure to increase the pediatric inpatient capacity to nearly 1 million total square feet.

Construction begins on four additional floors for the hospital.

The Ryan Seacrest Foundation opens a multimedia broadcast studio, Seacrest Studio, for patients inside Monroe Carell.

Monroe Carell launches A Campaign Against Childhood Cancer, led by Allison DeMarcus and Kailey Hand, to expand the pediatric cancer clinic and to support research, training and programming.

Monroe Carell opens new inpatient space on the 11th floor, housing one of the largest Neonatal Intensive Care Units in the country.

Monroe Carell welcomes Squid, the first facility dog.

Build-out begins on the final two floors of the four-floor expansion at Monroe Carell. Once complete, the hospital will have 401 licensed beds.

For the 17th year in a row, Monroe Carell is named among the Best Children's Hospitals.



After first pioneering the surgery in 1998, Monroe Carell offers groundbreaking fetal surgery to treat spina bifida.



Dolly Parton is honored at the dedication of the Hannah Dennison Butterfly Garden, named for her niece, following Parton's gift to the pediatric cancer program.





# OUR STORIES

**During the 20-year** history of Monroe Carell Jr. Children's Hospital at Vanderbilt, the hospital has provided compassionate, comprehensive medical and surgical care to countless children and their families. With 31 pediatric and surgical specialties, our more than 500 physicians and surgeons have cared for children with everything from broken bones to those who need complex medical care, including heart disorders and cancer. Many of the 11 patient stories featured here are patients you've "met" before in *Hope* magazine stories over the years. Here, we update you on where they are now and how, for many, Monroe Carell is still "like home." 🦋



*Rice quadruplets*



*Janelly Martinez-Amador*



*Jurnee Scantling*



*Callie Gill*



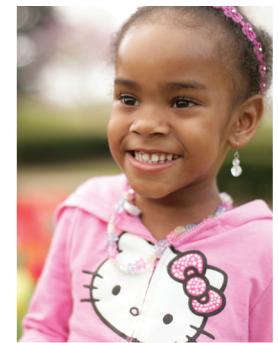
*Zion Horton*



*Carter Ray*



*Maddie Wright*



*Zakia Onyekwere*



*Dalton Waggoner*



*Noah Smith*



*Brooklyn Burney*





**“Overall, their health today is fantastic. They are healthy kiddos.”**

– ANN RICE

*Pictured from left: The Rice quadruplets, age 18: Shep, Elizabeth, Laura Frances and Mary Carter.*

## Rice quadruplets

### PREMATURITY

**T**his fall when the Rice quadruplets leave for college, the Rice household will be very quiet, something that Ann Rice and her husband, Chuck, both dread and celebrate.

Eighteen years ago, on Oct. 17, 2005, Charles Shepherd (Shep), Elizabeth, Laura Frances (Franny), and Mary Carter Rice entered the world too soon, each weighing less than 2 pounds and fighting for their lives. Their parents’ hope that they all might one day be healthy young adults ready to spread their wings in college was just a whispered prayer.

They were born at 26 weeks, barely over halfway through the normal 40-week pregnancy gestation period. After birth, the babies

endured infections, kidney failure, underdeveloped lungs, feeding issues and heart surgery. “Mary Carter was definitely the sickest child. We were told she would probably never come home,” Ann said.

The staff in the Neonatal Intensive Care Unit (NICU) at Monroe Carell Jr. Children’s Hospital at Vanderbilt did everything they could to ensure the quadruplets would survive.

“Overall, their health today is fantastic,” Ann said, adding that they have each had some surmountable health challenges along the way. Their greatest challenge right now is making a final decision on which colleges to attend. Ann and Chuck have encouraged the girls to attend different colleges so they can grow individually.

“I was talking to a friend re-

cently (about the quadruplets leaving for college at the same time),” Ann said. “She really put it into perspective. She said, ‘You know, Ann, we have to give thanks for the fact they are able to go to college.’ And I thought, ‘Yes, you’re exactly right.’ It took that moment for me to remember that our path could have been very, very different,” she said.

“They were born at 26 weeks, functioning as 24 weeks. They were sick and fought for every breath. The doctors and nurses at Monroe Carell worked around the clock to save my life and theirs. We could have four children in wheelchairs, the effects of cerebral palsy, all the things. It’s not lost on me that things could have turned out very different.”

Instead, all four are active in their church and youth group, have been on numerous mission trips, have jobs, and have very individual personalities.

Shep is the athlete of the family. He plays soccer at his high school and competitive soccer. He is choosing between the University of Mississippi and the University of Tennessee for college. He has a large group of friends and good grades, Ann said.

Elizabeth will more than likely attend the University of Kentucky in the fall. She’s social, but also “a homebody. She works summers as a lifeguard and enjoys being home with her siblings,” Ann said.

Franny, who remained in the NICU for four months after birth, is the quietest and most inquisitive of the bunch and is very active in community service. “She’s always concerned about world events,” Ann said. She plays on the varsity bowling team at her school and is leaning toward attending the University of North Alabama. She and Mary Carter both had surgery to repair congenital heart defects (patent ductus arteriosus), and



SUSAN URMAY



they suffered some hearing loss and vocal cord paralysis as a result of the surgery. Franny has had several eardrum and vocal cord reconstructions.

Mary Carter, who weighed only 510 grams at birth (1.1 pounds) and stayed in the NICU for five months after she was born, is the most social of the four and plans to attend either University of Tennessee Martin or Western Kentucky University. She lifeguards during the summer. Both she and Franny are “full of grit” and work hard to make good grades. “They dig and dig until they get it right,” Ann said.

Both Mary Carter and Franny have been shaped by their many experiences as patients at Monroe Carell. They want to become child life specialists. “After enduring more surgeries after they became older, they always felt connected and very intrigued by the (young women) that would come around and talk to them before surgery.”

On the night before their 18th birthday, Elizabeth became a little emotional and told her mom it could be the last time they celebrated their birthday together at home since they will be away in separate colleges.

“Things will definitely be different, especially birthdays,” said Ann. 🍁

— by Nancy Humphrey

## Janelly Martinez-Amador

HYPOPHOSPHATASIA

**J**anelly Martinez-Amador captured hearts and headlines around the world when her story — first published 11 years ago — told about a rare metabolic disorder that left her with no bones and unable to move or lift an arm or her head as an infant. X-rays of her body early in life revealed only

dark shadows where bone should exist — until a drug therapy trial became available to her at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

“I am so grateful for the doctors and the staff. They have always been there and attentive for Janelly. I will always be eternally grateful for them and eternally grateful to God for putting them in our lives,” said Janelly’s mom, Janet Amador, in a recent interview.

Born with a genetic disorder called hypophosphatasia (HPP), a metabolic disease that affects the development of bone and teeth, Janelly’s body was unable to make bone. An enzyme deficiency causes the bones to become soft because they can’t absorb important minerals such as calcium and phosphorus, increasing the risks for pain, broken bones and bone deterioration.

While there are varying degrees of severity, the most severe forms of HPP occur before birth and early infancy and are thought to affect about 1 in 100,000 babies born in the United States. Prior to the development of enzyme replacement therapy, more than half of babies born with the disease did not survive beyond their first birthdays. Now, there is an estimated 85% survival rate for these infants at five years while on therapy.

Under the care of Jill Simmons, MD, a pediatric endocrinologist, Janelly entered a clinical trial that gave her family hope. As a leading pediatric research institution, Monroe Carell physician-scientists work to find therapies that improve outcomes for patients like Janelly.

At 18 months old, Janelly was one of 11 children, age 3 years and younger, to participate in a clinical trial to receive an enzyme-replacement drug therapy, asfotase alfa, for the life-threatening form of HPP. She had the worst case of the group.



Janelly Martinez-Amador, 17

About eight months into the treatment, Janelly’s parents felt her fingers — which had been soft and boneless — and they could feel traces of developing bone. Her head also began to develop bone. At 18 months into therapy, X-rays showed, for the first time, the visible development of her rib cage. The drug was approved in 2015 by the FDA.

Janelly was 7 when she became an inspiration for children and adults worldwide suffering from different forms of HPP, and her story created an awareness about the expertise and comprehensive care that pediatric and adult physicians at Vanderbilt University Medical Center (VUMC) and Monroe Carell provide for the disorder.

Simmons, along with Kathryn Dahir, MD, an adult endocrinologist at VUMC, run a comprehensive, multidisciplinary clinic with more than 200 patients from across the U.S., which is among the largest HPP cohorts in the country.

Now 17, Janelly is no longer respirator dependent. She attends



**“My goodness, to go from no bones to bones. That’s the most impressive thing I have seen as a physician. It’s incredible.”**

— JILL SIMMONS, MD



the Harris-Hillman Special Education School in Nashville, and she enjoys spending time surrounded by her family.

Janelly has appointments with Simmons about every six months and with her pediatrician annually for well visits.

"Janelly is still receiving the treatment, and it truly was lifesaving for her," Simmons said.

The treatments at Monroe Carell changed life for the Martinez-Amador family. "She used to have to be with the respirator 100% of the time, and we would constantly have to be by her side. Now, for her and for ourselves, we have a more normal way of being," Janet Amador said.

At Monroe Carell/VUMC, Simmons and Dahir continue to be part of an international study evaluating the natural history of HPP as well as the long-term effects of its treatment.

Simmons' words in 2013 still

ring true today for Janelly and other patients like her:

"This is why we get into medicine in the first place: to truly make a difference in the life of a child," Simmons said. "My goodness, to go from no bones to bones. That's the most impressive thing I have seen as a physician. It's incredible." 🦋

—by Christina Echegaray

## Jurnee Scantling

### ACUTE LYMPHOBLASTIC LEUKEMIA

In June 2015, when she was two and a half, Jurnee Scantling was diagnosed with acute lymphoblastic leukemia (ALL), the most common childhood cancer. Jurnee's treatment at Monroe Carell Jr. Children's Hospital at Vanderbilt started immediately with a 37-day inpatient stay and would continue for the next two years.

It was a stressful and frightening time that her mother, Erika Scantling, will never forget. Jurnee, however, does not remember it.

Now 11 years old, the preteen has no recollection of chemotherapy, surgery or even her Make a Wish® trip to Disney World. She is a thriving fifth grader who enjoys dancing, particularly to TikTok videos, and gymnastics.

"She has picked up drawing and is actually pretty good. She can look at something and free-hand draw it," Erika said.

When Jurnee was diagnosed with ALL, the toddler was eligible for a trial that was testing a new therapy. The trial compared a new treatment to the standard of care. Jurnee's treatment started with "induction" chemotherapy, a high-dose treatment administered in the hospital and aimed at putting the disease into remission.

"It was hard to hear the diagnosis, but I knew something was wrong months in advance," recalls Erika, who is a licensed practical nurse. Despite having recently given birth to her fourth child, she spent every night in the hospital with Jurnee when she was diagnosed.

Inpatient stays and oncology clinic visits are behind them now. Jurnee has yearly checkups at the Vanderbilt Children's Childhood Cancer Survivorship Clinic. Afterward, she and Erika will occasionally walk across the street to Monroe Carell to visit with the hematology/oncology nurses who cared for them.

"She's been doing well health-wise. To look at her you'd never know anything was wrong," Erika said. "Sometimes chemo has adverse effects on short-term memory, and she'd been having issues with this, especially with reading. She no longer needs extra support with that, though."

Vanderbilt's program is the

DONN JONES



Jurnee Scantling, 11



"You have a story to tell; you have a journey to tell people about. Your name matches your story."

— ERIKA SCANTLING



only childhood cancer program in the state that has all the subspecialties needed to support children who are receiving cancer therapy under one roof. Active collaboration with the Vanderbilt-Ingram Cancer Center also brings special expertise to the care of children with cancer, and the pediatric oncology program is the only program in the state that is part of a National Cancer Institute-designated Comprehensive Cancer Center that treats children and adults.

"She is a typical preteen. She likes her own space now," Erika says of her daughter. "She's very friendly and doesn't meet a stranger. She's carefree.

"About a year and a half ago she asked me, 'What happens to your body when you die? And when do you get to come back?' I had to explain to her what death was. I don't think she realized until that point how serious what she had could have been. She didn't like to tell people she had cancer; she was embarrassed. And I told her, 'You have a story to tell; you have a journey to tell people about. Your name matches your story.'" 🦋

— by Kathy Whitney

## Callie Gill

### SCOLIOSIS

In March 2023, Callie Gill, 12, became the first patient in the state of Tennessee to undergo an innovative procedure using her own growth to correct one of two spinal curvatures from scoliosis.

Surgeons at Monroe Carell Jr. Children's Hospital at Vanderbilt performed the minimally invasive surgery, called Vertebral Body Tethering, to allow the sixth grader the best chance of mobility and flexibility as she aged.

In Callie's case, she had two

curvatures — thoracic (upper spine) and lumbar (lower back).

A thoracic spine fusion was performed to join the bones in the upper back to eliminate movement between them. It was followed by the tethering surgical procedure of the lumbar curve.

"Tethering is a nonfusion option to treat scoliosis that essentially works like an internal brace," said Craig Louer, MD, assistant professor of Orthopaedic Surgery at Monroe Carell. "It is approved for patients with a significant amount of growth remaining. The tether is a strong, flexible cord which modulates growth of the spine to gradually correct a curve. This is what straightens out the spine but maintains flexibility."

Tethering is different from fusion treatment in that it allows the spine to bend and flex. With fusion surgery, the vertebrae are fused together, not allowing any movement due to the metal rods placed along the spine.

Callie's family is thrilled with the success of her surgery.

"We are so glad we chose the tethering option," said Crystal Gill, Callie's mother. "It is allowing her to function as a normal 12-year-old. That is the main reason we decided to move forward with this procedure.

"It was very important that Callie be able to have free movement and the ability to bend. If she had the fusion on the lower spine, she wouldn't have the mobility.

"We are just so pleased, and everyone was phenomenal, friendly and incredibly informative about the process and answered all of our questions," she added.

Each year, nearly 200 patients receive surgical treatment for scoliosis at Monroe Carell.

Considered a common condition, scoliosis affects 6 million to 9 million people in the United States

and is typically treated with external bracing or spinal fusion surgery.

Louer and his team expect that 20%-30% of the clinic's patient population will be candidates for this surgical option. Tethering surgery candidates must have a curvature of more than 45 degrees.

"Callie is doing fantastic," said Louer. "She has met all the goals, and she continues to progress. The tethering is maintaining the correction that she needed."

Teams at Monroe Carell began intensive training in 2021 to prepare for the launch of the cutting-edge curvature correction procedure, which was FDA approved in 2019.

The surgical team is composed of Louer, Gregory Mencio, MD, who holds the Neil Green, MD, Chair of Pediatric Orthopaedics, and Jeffrey Martus, MD, professor of Orthopaedic Surgery. 🦋

— by Jessica Pasley



**"Callie is doing fantastic. She has met all the goals, and she continues to progress."**

— CRAIG LOUER, MD

Callie Gill, 12



ERIN O. SMITH





**“Zion is continuing to thrive in our comprehensive PCD center with the help of her loving and dedicated family.”**

– MICHAEL O’CONNOR, MD

## **Zion Horton**

### PRIMARY CILIARY DYSKINESIA

**S**ince Zion Horton was a preschooler, her mom, Valency, has worked hard to instill in her daughter that primary ciliary dyskinesia (PCD) is what she has, not who she is.

“We’ve taught her to be her own advocate as well and to speak up for herself,” Valency said in a 2018 story on Zion (who was 5 years old at the time) that was published in *Hope* magazine.

Before she was born, Zion was diagnosed with PCD, an inherited rare disease that affects the cilia, the tiny, hairlike structures that line the airways, including nasal passages, sinuses, lungs, Eustachian tubes of the ear, the reproductive organs and ventricles of the brain.

Now an 11-year-old fifth grader, Zion has taken her mom’s advice to heart and is advocating for herself at medical appointments at Monroe Carell Jr. Children’s Hospital at Vanderbilt. Zion also has taken charge of her daily medications and breathing treatment. It’s crucial that she blow her nose thoroughly throughout the day — to help clear mucus. She wears a heavy airway clearance vest twice a day (before school and before dinner) and takes medication to keep her airway clear.

“When we go to her doctors’ appointments now, I can just sit back, and she can handle the conversation with her medical team. She understands everything. Now, when they ask her how this feels or how that feels, she doesn’t turn to me. She can answer by herself how she feels,” Valency said. “At home I don’t have to say, ‘It’s time to take your medications; to do your treatments.’ Zion will say, ‘Hey, I’m going to do my treatments.’ It’s taken the load off of me, but also, it’s made me proud

to see her doing it on her own as well,” she said.

Michael O’Connor, MD, associate professor of Pediatrics in the Division of Allergy, Immunology and Pulmonary Medicine at Monroe Carell, said Zion is “continuing to thrive in our comprehensive PCD center with the help of her loving and dedicated family. Like all children with PCD, Zion has had her share of respiratory challenges, but she always handles everything in stride, focused on what she needs to do to get better. Every day she must do breathing treatments to help keep her airways clear. She shows tremendous dedication to her therapies for her age.”

PCD affects the lung’s ability to get rid of the normal things we breathe in every day and creates extra mucus in the lungs, putting those who have it at risk for repeated respiratory infections and pneumonia.

It can take a long time to get a diagnosis. Monroe Carell is one of a limited number of comprehensive PCD centers and one of only two centers in Tennessee that offers specialized nasal nitric oxide testing to diagnose PCD.

In addition to breathing difficulties, PCD can also lead to ear

and sinus infections along with hearing and speech development issues. It affects between 1 in 10,000 and 30,000 births, but most children with PCD have a normal life span ahead of them. Ciliary activity is also responsible for organ placement in the developing embryo. A condition called situs inversus totalis occurs in about 50% of all PCD patients, including Zion, whose heart, stomach, liver and spleen are on the opposite side of the body from where they should be.

Zion is doing well. She was hospitalized with pneumonia for two weeks in October 2022, and it was hard on her not being with her sister, Nia, but Nia was able to visit, and they spent time together in one of Monroe Carell’s activity rooms, Valency said.

“Schoolwise, she’s doing great academically,” Valency said. Zion received her school’s “Little Hawk Award” the past two years, determined by teachers, principals and the administration who vote on top students who embody the school’s motto, have character, and are on the A/B honor roll. “We are really proud of her.” 🦋

– by Nancy Humphrey



Zion Horton, 11

DOHN JONES



## Carter Ray

### ESOPHAGEAL ATRESIA

Carter Ray, 4, plays on his tummy and has earned the nickname roly-poly as he rolls all over the playroom at home.

"We can now see what can be possible for the future — sitting, standing, attending preschool," said his mom, Lacey Ray. "None of this was possible before."

When Carter was born on Nov. 3, 2019, Lacey and her husband, Chris, were focused on saving their son's life.

He was born with a very rare form of esophageal atresia (EA), transesophageal fistula (TEF) Type B and tracheobronchomalacia, conditions that ultimately required reconstruction of the esophagus to allow secretions and nutrients to reach Carter's stomach.

A new innovative and potentially lifesaving minimally invasive procedure offered the Ray family hope. Carter became the first patient in the United States to have this procedure, which was performed at Monroe Carell Jr. Children's Hospital at Vanderbilt, where Carter spent the first 18 months of his life.

The complexity of his case required the specialized care of a comprehensive, multidisciplinary surgical team at Monroe Carell, led by Irving Zamora, MD, MPH, assistant professor of Pediatric Surgery and director of Advanced Minimally Invasive Surgery, who put together a team of experts including surgery partners Harold Lovvorn, MD, Nathan Novotny, MD, as well as ENT colleagues Christopher Wootten, MD, and Lyndy Wilcox, MD. Together they focused on repairing the esophagus and airway with the ultimate goal of getting Carter home.

And it worked.

After performing an anterior aortopexy and a thoracoscopic

posterior tracheopexy to repair Carter's airway, which collapsed when he breathed, the multidisciplinary team repaired the airway in a two-stage, minimally invasive approach several weeks apart.

With a Connect EA – Magnamosis device, the procedure used magnets to connect the two ends of a congenitally separated esophagus in patients with complex TEF/EA. Zamora collaborated with Michael Harrison and his team at University of California, San Francisco (creators of the magnet device) and Oliver Muensterer, MD, PhD, in Munich, Germany (the only other surgeon at the time to use the magnets).

Given the novel nature of this approach, the procedure required a compassionate use approval from the FDA. It was accomplished using minimally invasive techniques — the least intrusive pathway to performing a wide range of medical procedures and surgeries. This allows children to recuperate faster and with less pain.

On April 27, 2021, Carter was able to leave the hospital for the first time and join his family at their home in Lynchburg, Tennessee.

"He is doing fantastic," Zamora said. "He is thriving. It's just so awesome to see his development."

"We were able to accomplish the same goal using a minimally invasive technique that proved to be much better for the patient. It's almost magic, right?"

Prior to the implementation of Magnamosis, a half-hour procedure, the operation to connect the esophagus took nearly four hours.

While Carter was the first of two published cases at Monroe Carell, there have now been a total of 10 cases performed in the U.S.

"He is making a lot of strides," said Lacey. "He is getting stronger, building up stamina and getting into everything. "Dr.



Carter Ray, 4

Zamora and this team gave him the best chance to be able to function, giving him a chance at living his best life. They saved his life," she said. "We get to watch our boys grow up together. Seeing them be brothers is a really big deal. We are able to be a family and look toward the future."

Carter has been cleared to begin feeding therapy and breathes on his own while awake, only requiring the use of a ventilator while asleep at night.

Zamora reflects on what his team accomplished:

"We gave this family hope, and that's huge," he said. "It also allowed us to provide this technique to others, providing more families an opportunity for future milestones. We are leading the way in the innovation of minimally invasive approaches and helping other institutions navigate this journey both nationally and internationally." 🦋

— by Jessica Pasley



**"We gave this family hope, and that's huge. It also allowed us to provide this technique to others, providing more families an opportunity for future milestones."**

— IRVING ZAMORA, MD, MPH





**“In kids’ eyes, hospitals aren’t fun; they’re about needles and shots. I want to change the way that kids and other people look at it.”**

– MADDIE WRIGHT

## Maddie Wright

### CYSTIC FIBROSIS

**M**addie Wright is an active 16-year-old who does karate, volunteers with a horse therapy program for children with special needs, and loves playing with her emotional support dog, Quip. She’s thriving, and she credits her health care team at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

“Monroe Carell means everything to me,” Maddie says. “Without them I wouldn’t be here. Literally. I wouldn’t have the opportunity to enjoy life — to be with my cousins, and my friends and my dog.”

Maddie, who lives in Murfreesboro, Tennessee, has cystic fibrosis, a genetic disorder that affects the lungs, liver, pancreas and many other organs. She was

born 10 weeks early and spent three months in the Neonatal Intensive Care Unit at Monroe Carell. Chronic lung infections led to regular hospitalizations about four times per year throughout her childhood.

At age 4, Maddie was diagnosed with cystic fibrosis liver disease. Over time, she developed progressive liver scarring, eventually leading to liver cirrhosis. Maddie had a liver transplant in February 2021.

“She was in and out of the hospital all year after the transplant; it caused a lot of medical PTSD,” says her mother, Leanne Wright.

As Maddie reflects on the time she’s spent at Monroe Carell — much of it confined to her room to protect her from infectious diseases — she emphasizes the relationships she’s made with hospital staff.

“The doctors and nurses are amazing,” she says. “And the child life specialists have been so helpful to me. They’ve brought me things to do to keep me from focusing on the fact that I’m in the hospital sick and can’t leave, and they’ve kept me calm before anesthesia.

“And it’s not just doctors and nurses and child life, it’s the nutrition people and the cleaning people and the people in the gift shop and at Seacrest Studio who have all known me for so long. They’re family. Monroe Carell is a home away from home for me.”

Maddie has been serving as a patient ambassador for the hospital since she was 5. Her first big event was the Iroquois Steeplechase, one of Monroe Carell’s largest fundraisers. That was especially fun, she says, because she loves horses, and she got to meet the winning jockey, who gave her his trophy.

“I have it on my shelf to this day,” Maddie says.

She likes sharing her experience at Monroe Carell.

“In kids’ eyes, hospitals aren’t fun; they’re about needles and shots. I want to change the way that kids and other people look at it,” Maddie says. “A lot of us owe our lives to these hospitals, and I feel like the nurses and doctors and everyone else deserve to be seen for what they really do behind the scenes.”

“They know Maddie so well, which carries over into the mental health aspect of her care,” Leanne Wright says. “Things do get complex, and they’re able to do things to help minimize the stress of being in the hospital — like not wake her up for early morning vitals unless it’s necessary.”

Anita Pai, MD, assistant professor of Pediatrics and a liver transplant specialist, has been caring for Maddie since 2019.

“Maddie knows she’s not just a 16-year-old with cystic fibrosis in this room, but that we know her as Maddie — our animal lover, our fashionista, our empath,” Pai said. “It is important to appreciate these other facets of her personality and to understand what she values.

“Having a chronic medical condition takes a physical and emotional toll on our patients. I’m lucky to collaborate with an incredible team to optimize the care we provide to patients like Maddie. She knows that we value her as a person, which creates a safe space for her to share things that make her nervous or that are bothering her...she knows that we are going to do our best for her,” Pai said. 🦋 — by Leigh MacMillan

ERIN O. SMITH



Maddie Wright, 16



## Zakia Onyekwere

### SICKLE CELL DISEASE

**A**t age 3, Zakia Onyekwere may not have fully understood the genetic blood disorder that had caused her to spend so much time at Monroe Carell Jr. Children's Hospital at Vanderbilt. But she was clear about the disease's impact on her and her plans.

"My sickle cell doesn't stop me," she said in a story published in *Hope* magazine in 2011. "I want to be a medical doctor because I want to look for a cure for sickle cell."

Zakia, now a poised 16-year-old junior in high school who loves and excels in biology, has the same — and even bigger — aspirations.

"My goal is to become a research doctor and to find a safe, accessible, successful cure for sickle cell disease. But not only sickle cell, I would like to research and find cures for other diseases to help people like me, and people in general," she says.

Sickle cell disease occurs when a mutation is inherited in the gene for hemoglobin — the protein in red blood cells that carries oxygen. Instead of being flexible discs, red blood cells with abnormal forms of hemoglobin are hard, sticky and crescent-shaped, like the sickle farm tool. The cells die early, causing anemia, and they can get stuck in small blood vessels, causing pain, infection, stroke and other complications. Sickle cell disease affects about 100,000 Americans and is most common in people of sub-Saharan African descent, according to the Centers for Disease Control and Prevention.

Community support has helped advance the mission of the Sickle Cell Program at Monroe Carell to help patients like Zakia. This generosity includes a leadership gift that the Junior League of Nashville made in 2012 to estab-

lish the Sickle Cell Disease and Asthma Program.

Zakia was diagnosed with sickle cell disease at 2 weeks old and spent much of the first year of her life in and out of Monroe Carell, fighting infections, fever and pain. With the addition of hydroxyurea, a medication that helps improve the shape and flexibility of red blood cells, to her treatment regimen, Zakia's sickle cell crises eased, and her family focused on healthy eating, paying attention to potential pain triggers, such as cold, and managing stress.

"She's doing great," says Zakia's doctor of more than a decade, Michael DeBaun, MD, MPH, the J.C. Peterson, M.D. Professor of Pediatrics at Monroe Carell and director of the Vanderbilt-Meharry Center of Excellence in Sickle Cell Disease. "She's an A student; she's involved in extracurricular activities; she's rarely admitted to the hospital for pain. In fact, she can't remember the last time she had a significant pain episode that required hospitalization.

"It's a tribute to her wholesome living, her good dietary habits and the supportive environment of her mom and dad."

Zakia says she's missed out on some childhood activities, like playing in the snow and swimming in pools, and she still experiences pain crises that she manages with ibuprofen and heating pads or a warm shower. Overall though, sickle cell disease hasn't kept her from pursuing her passions. She's an artist who enjoys creating animations; she sings in the choir at her high school, Hume-Fogg in Nashville; and she loves performing in theater productions, most recently the musical "Footloose."

Monroe Carell and the Center of Excellence in Sickle Cell Disease have helped Zakia flourish.

"I don't really know where I

would be without their influence," she says.

"Dr. DeBaun and the whole team have been a great support system," says Zakia's mother, Zanira Dudley. "They have always educated us on sickle cell disease, answered every question and referred us to opportunities like summer camps. They are outstanding."

Zakia has shared her career aspirations with DeBaun, along with her interest in possibly attending Vanderbilt and working with him.

"I've said, 'Come on. I'm waiting for you,'" DeBaun says. "I've mentored multiple undergraduates who have gone on to become physicians, and several with sickle cell disease. This is why I became a pediatric hematologist — to have an impact on the lives of children and help them fulfill their dreams." 🦋

— by Leigh MacMillan



**"My goal is to become a research doctor and to find a safe, accessible, successful cure for sickle cell disease."**

— ZAKIA ONYEKWERE



Zakia Onyekwere, 16





Dalton Waggoner, 19

## Dalton Waggoner

### CONGENITAL HEART DEFECT

**W**hen he was 2 days old, Dalton Waggoner was diagnosed with critical unicuspid aortic stenosis, a congenital heart defect in which his aortic valve could not open well, restricting the blood flow to his body. The pediatric cardiac team at Monroe Carell Jr. Children's Hospital at Vanderbilt told Susan and Guy Waggoner that Dalton would go into cardiac arrest and die within hours without a cardiac procedure.

"At that point as a parent, your world stops," Susan said. "You can't think; you can't process; and you definitely can't comprehend what your child and your family is about to endure."

Dalton had his first heart catheterization at 3 days of age, with balloon dilatation of his narrowed aortic valve. When he was discharged 10 days later, he was gray, lethargic, weighed 5 pounds and wasn't expected to live through the week. Today, at age 19, Dalton is more than 6 feet tall and is a sophomore at the University of Tennessee, Knoxville where he is double majoring in supply chain

management and accounting. He is also a student manager for the men's basketball team and active in his fraternity.

In the years in between, Dalton has had two open-heart surgeries, two heart catheterizations, countless cardiac tests/procedures, and he has never gone longer than six months between cardiology appointments. His heart condition can't be cured; every surgery is a repair until the next one.

Going to clinic appointments or cardiac surgeries "unfortunately wasn't a choice," Susan said. "I always told him that he'd better own it, love it, appreciate it because it's not going away. We are just thankful that Dalton has an outstanding medical team caring for him. They have helped him (and us) understand what his medical conditions mean to him specifically."

In 2019, the hospital's 40,000-square-foot Pediatric Heart Institute opened on the 10th floor, one of the four additional floors supported by the Growing to New Heights Campaign, through a significant gift from the Country Music Association. Dalton participated in the opening celebrations, sharing his story and appreciation for his cardiac team.

Susan joined the Junior League of Nashville when she was pregnant with Dalton and was ironically placed at Monroe Carell, volunteering shortly after he was born with two nonprofit organizations for peer support and as a NICU cuddler. In addition, she felt a deep need to find a higher purpose in Dalton's condition. For almost 17 years now, Susan has served on the Monroe Carell Family Advisory Council. As a family, the Waggoners decided to be advocates for Monroe Carell.

"We wanted those going through something like this to look at Dalton and see a light — maybe not at the end of the tunnel yet,

but maybe in the middle of the tunnel," Susan said. "A light that lets them know they are not alone in this journey, and they too can get through this."

Since 2006, Dalton has helped raise support for Monroe Carell as a patient ambassador for various campaigns and fundraising partners, including Tri Star Energy-Twice Daily, Children's Miracle Network Hospitals®, and the Dierks Bentley Miles and Music for Kids. A room in the cardiology clinic bears his name, and the Waggoner Family Pediatric Heart Research Fund was also named in Dalton's honor.

"I wish no other kid had to go through what I have been through, but I hope that by volunteering, raising awareness and fundraising, we have helped in some small way," Dalton said. "I hope we have made a difference not only with the hospital's expansion and growth but also by helping find cures and treatments for patients like me."

Dalton was born in 2004, the year Monroe Carell opened as a freestanding children's hospital.

"Every time I passed it as a kid and saw the paper doll logo, I called it 'my hospital,'" he said. "For most appointments, we would visit the train on the first floor, find my butterfly in the butterfly garden and eat ice cream. Monroe Carell Jr. Children's Hospital at Vanderbilt is just a part of who I am. It is my home away from home."

Today Dalton returns for clinic visits as an adult — one who will eventually transition his cardiac care to the adult congenital heart disease program at Vanderbilt University Medical Center. He's now taller than his longtime cardiologist, James Johns, MD, professor of Pediatrics, who vividly remembers meeting the Waggoners when Dalton was 2 days old.

"I remember examining Dalton in his mother's arms and real-



**"I wish no other kid had to go through what I have been through, but I hope that by volunteering, raising awareness and fundraising, we have helped in some small way."**

– DALTON WAGGONER



izing that he had a serious congenital heart disease,” said Johns, who’s in his 40th year of caring for pediatric cardiology patients at Monroe Carell. “It is an amazing privilege to be with a family on what is undoubtedly one of the scariest days of their lives, and to be able to give them hope that their child will be able to lead a happy, healthy life thanks to the care that our team of doctors, nurses and other professionals at Monroe Carell can provide. It has been wonderful to see the advancements in pediatric cardiology and congenital heart surgery over the decades, with new treatments that allow children who would have had no options 40 years ago to thrive and grow into adulthood.” 🦋

— by Danny Bonvissuto

## Noah Smith

KIDNEY/LIVER DISEASE

**S**tephanie Smith can rattle off the milestones that her 4-year-old son, Noah, has experienced since having a lifesaving transplant in January 2021.

The innovative surgery — the first-ever dual kidney/liver transplant to be performed at Monroe Carell Jr. Children’s Hospital at Vanderbilt — not only saved his life but also provided quality of life for the entire Smith family.

“For the first 20 months of his life, he was, we all were, fighting for his survival,” said Smith. “Before transplant, we were taking care of a sick baby around the clock. Long days, longer nights on dialysis with no sleep from constant vomiting.

“And today, he is laughing, running, playing with friends, attending school and involved in sports classes. Noah is now able to live a life that we weren’t guaranteed. They didn’t expect him to make it past delivery.

“We are forever thankful for Noah’s incredible team of specialists who always give him such intentional and incredible care.”

Noah’s medical journey began during Stephanie’s 26th week of pregnancy when an ultrasound detected enlarged kidneys. Further tests led to a diagnosis of autosomal recessive polycystic kidney disease (ARPKD), a rare genetic disorder characterized by fluid-filled kidney cysts.

Affecting 1 in 20,000 children, the disorder often impacts the lungs. About 30% of newborns born with ARPKD die within the first week of life.

Noah was born at 35 weeks gestation via cesarean section.

Within weeks after his birth, he underwent a double nephrectomy and began dialysis. The removal of both of his kidneys allowed his lungs to expand, which made it possible for him to breathe on his own.

After 77 days, he was discharged home to continue the 12-hour nighttime dialysis regime and to work on gaining weight to become eligible for transplant.

During routine monitoring for a liver-related complication of ARPKD, the family was dealt another blow. Imaging showed a liver mass, followed by a biopsy which revealed hepatoblastoma, liver cancer.

Noah completed one round of chemotherapy and was listed for a dual organ transplant. Three days later, the nearly 12-hour surgery was performed.

Noah’s case marks a milestone for the pediatric transplant program and further highlights the culture of collaboration and innovation at Monroe Carell.

“It has been incredibly rewarding to witness Noah’s transformation after transplant,” said Anita Pai, MD, assistant professor of Clinical Pediatric Gastroenterology



Noah Smith, 4

at Monroe Carell. “It’s remarkable to see his developmental progress during his visits. We continue to collaborate in his long-term care.”

The multidisciplinary team overseeing Noah’s case, which included cancer treatment, transplantation and postoperative and long-term care, created an individualized treatment plan to ensure the best care possible.

It’s been three years since the transplant on Jan. 31, 2021 — dubbed by the family as the “best birthday wish ever.” That date also happens to be the birthday of Noah’s older brother, Peyton, and he had prayed for new organs for his younger brother for months. Now the family celebrates the gift of life for both boys.

“When I think about his journey, it’s overwhelming, honestly. Just the gift of life is so incredible. Look at where we are now,” Smith said.

“We were given a deathly diagnosis when I was pregnant. And now when people come to me with the same diagnosis, I can say



**“When I think about his journey, it’s overwhelming, honestly. Just the gift of life is so incredible.”**

— STEPHANIE SMITH



that there is still hope. That is what I see when I look at Noah, and I can show them and share our story.” 🦋

— by Jessica Pasley

## Brooklyn Burney

### PERINATAL STROKE

**S**hortly after Brooklyn Burney was born in 2014, what her parents thought were hiccups turned out to be a perinatal stroke.

Then, on her 1-month birthday, Brooklyn turned blue while nursing. A visit to her on-call pediatrician showed a concerning increase in her head circumference. On their way to Monroe Carell Jr. Children’s Hospital at Vanderbilt from Clarksville, Tennessee, Laura and Justin Burney stopped by their house to make peanut butter and jelly sandwiches. When they left Monroe Carell for the first time a few days later, Laura Burney’s sandwich was still in the back seat.

“Once we arrived at Monroe Carell, things quickly changed: It felt like bam-bam-bam,” Laura said. “The whole care team knew something serious was happening and got her back into triage immediately. We still talk now about

how calm everyone was while acting with a sense of urgency.”

A CT with contrast showed that Brooklyn had a bleeding aneurysm.

“We sat there flabbergasted,” Laura said. “We didn’t know babies could have an aneurysm. Brooklyn was looking worse and worse by the minute. She wasn’t crying or reacting to anything. She was deteriorating in front of our eyes.”

Brooklyn had an emergency craniotomy, a five-hour surgery that included removing a piece of her skull, the blood clot, and some of the damaged tissue to allow her brain the extra space to swell and heal. A couple hours later, just as Laura and Justin lay down in the family room, a nurse asked them to return to the PICU.

“They took us into one of those consultation rooms like you see in the movies — the one you never want to be in — and told us that, shortly after we said goodbye, Brooklyn’s heart stopped,” Laura said. “They performed CPR for three minutes and were able to resuscitate her.”

The care team took Brooklyn for another scan to see if the aneurysm ruptured. And that, according to the Burneys, is when “Superman” — or Jay Wellons III, MD, MSPH, Cal Turner Chair and Chief of Pediatric Neurosurgery, came in.

“It was, by far, the scariest conversation we’d ever had,” Laura said. “He walked in, Justin shook his hand and tried to sit back down. Dr. Wellons said, ‘This isn’t a sit-down conversation.’ He said Brooklyn was dying and if we wanted him to save her, he needed to operate immediately. We told him to do whatever was needed.”

Brooklyn recovered well, but her issues continued. When she turned 2, she was diagnosed with myoclonic epilepsy, which caused her body to jerk. Before she

turned 3, she was back at Monroe Carell for a hemispherectomy, a brain surgery that disconnects the right side of the brain from the left, performed by Robert Naftel, MD, associate professor of Neurological Surgery. Brooklyn had to learn how to use the left side of her body again and doesn’t have full control of her left hand, but within three months she was off every medication.

“It was, by far, the best decision we ever made, and we are beyond grateful they guided us in that direction,” Justin said. “Even today, there are still things we see her do, and (we) say, ‘Can you believe she just did that?’”

Today Brooklyn is a 9-year-old student with an autobiographical memory who plays piano and takes singing lessons. According to Wellons, she’s full of love for her family, gratitude for everyone at Monroe Carell and mature beyond her years.

“It takes so many people to take care of children like Brooklyn. From the moment they hit the door, there are PICU doctors and nurses, child neurology stroke specialists like Dr. Lori Jordan, the OR team, anesthesia, all that goes into post-op care and rehabilitation. The list goes on and on and on,” Wellons said.

“This is about way more than two surgeons doing their procedures to positively impact her life. It is about a culture of saving children that is inherent here at Monroe Carell. It is what we do. We practice for it. We are ready for it. And seeing Brooklyn living her life with her wonderful family makes it all worthwhile.” 🦋

— by Danny Bonvissuto

🦋

**“This is about way more than two surgeons doing their procedures to positively impact her life. It is about a culture of saving children that is inherent here at Monroe Carell.”**

— JAY WELLONS, MD, MSPH



Brooklyn Burney, 9

SUSAN URBAN

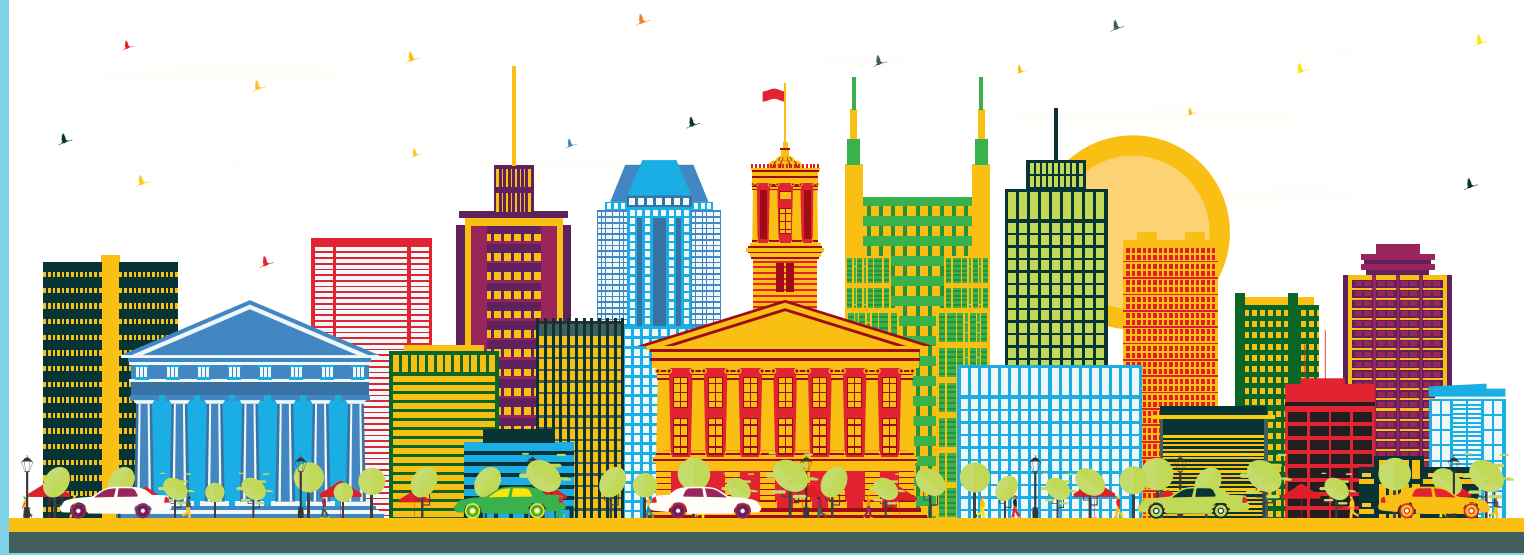


# COMPANIES FOR THE CAUSE

**The ever-changing downtown** skyline is only one indicator of Nashville's growth over the last 20 years, yet it is an important one. Just a short mile or two from the main location of Monroe Carell Jr. Children's Hospital at Vanderbilt, a slew of new downtown towers represents the corporations that chose Nashville as their home.

Fortunately, doing good is also good for business.

Across various sectors, from finance to retail to insurance and beyond, corporate leaders have joined the cause to advance children's health. "Our corporate partners have made a tremendous difference to our patients and families," said Meg Rush, MD, MMHC, President of Monroe Carell. "It's incredible to think about our growth as a city and the resulting impact at Monroe Carell from corporate support. We are so grateful for the creativity, enthusiasm and energy brought forth from our partners and their employees."





## Building Our Hospital

274 corporate donors have given more than \$16.7 million to support the original building campaign for the freestanding hospital or to help expansion efforts at Monroe Carell.



## Advancing Children's Health

Since the freestanding hospital opened in February 2004, 4,530 corporate donors have given more than \$76 million to support children's health.

This includes more than \$19.9 million for capital projects and more than \$56.1 million for funds that support training programs, research and patient care.



## Top 5 ways companies support

- 1 Cause marketing campaigns
- 2 Employee giving
- 3 Event sponsorships
- 4 Outright gifts
- 5 Research grants



## Top 5 areas of support beyond capital

- 1 Pediatric research
- 2 Patient- and family-centered care, including music therapy, the facility dog program, spiritual care and more
- 3 Greatest needs
- 4 Injury prevention
- 5 Pediatric cancer







*"We're deeply proud of our long-standing partnership with Monroe Carell. When I look back on my career, I believe we've shown that it is possible to run a successful business and be socially responsible. It's been our privilege to give back to our community – especially children in need – because of the commitment of the Delta Dental team."*

### **Delta Dental of Tennessee**

**Phil Wenk, DDS, President, Delta Dental of Tennessee's Smile180 Foundation**

## **40 Years of Miracles**



**Last year in 2023**, Monroe Carell Jr. Children's Hospital at Vanderbilt celebrated 40 years of partnership with Children's Miracle Network Hospitals®, a collaboration of 170 children's hospitals across the U.S. and Canada.

Monroe Carell's connection with CMN began in 1983 as one of the 20 founding CMN hospitals. In the four decades since, support from Monroe Carell's 30 CMN partners has been life-changing for patients and families at the hospital.


Walmart, one of CMN's largest corporate partners, has exceeded \$1 billion raised for CMN Hospitals nationwide over the last 36 years — more than any other corporation has given to pediatric hospitals. Locally, Walmart/Sam's Club has donated more than \$13 million to Monroe Carell, or approximately \$500,000 annually.

Through their annual communitywide fundraising effort, with customers asked for donations during a four-week period,

Walmart associates and customers support the needs of children who receive care at Monroe Carell. Always listening to the hospital's greatest needs, Walmart has supported important programs, services and initiatives at Monroe Carell. This includes support of pediatric rehabilitation efforts, as well as the Growing to New Heights Campaign, including the construction of Seacrest Studio and multiple patient consult rooms and nurses' stations.

"Walmart's longtime partnership with Children's Miracle Network Hospitals in support of Monroe Carell has grown into an incredibly special experience for our associates and our customers," said Jason Schwindt, Walmart Regional VP of Opera-

tions and a member of the Monroe Carell Advisory Board. "We truly believe that when you change kids' health, you change the future. We are proud to make such a positive impact on the lives

of children across Tennessee and beyond who depend on Monroe Carell for their care." 

— by Sydnie Hochstein



*Employees from the Walmart Supercenter in Smithville, Tennessee, a participating CMN partner. Pictured from left: Walmart employees Leeza Parker, Johna Summers, Margaret Street, Karen Adams, Vada Smith and Jesse Retter.*

# Nashville Predators



**Fans know** a high-stakes hockey game captures attention, builds crowd excitement and rallies community support for the team.

For almost 20 years, the Nashville Predators and its players have brought this same energy to their partnership with Monroe Carell Jr. Children's Hospital at Vanderbilt.

The Nashville Predators support patients and initiatives at Monroe Carell through the Nashville Predators Foundation.

"The Preds Foundation is devoted to serving the community and helping those in need," said Nashville Predators Vice President of Community Relations Rebecca King. "Our mission and values align so well with those at Monroe Carell Jr. Children's Hospital at Vanderbilt, where children and their families receive support and care when they need it the most."

The NHL team regularly hosts pediatric patients and their families at games. And at Hockey Fights Cancer games, child ambassadors are invited not only to take part in a luxury suite experience but also to participate in special activities during the game like the puck drop and riding the Zamboni. Off the ice, players visit young patients at Monroe Carell, making memories for children who are experiencing a


challenging health journey.

Leveraging fan support to advance health care is also a key part of the Predators partnership. The 365 Pediatric Cancer Fund presented by Twice Daily, founded by former Preds players Pekka Rinne and Shea Weber, creates opportunities for fans to make contributions that fund childhood cancer research and improve outcomes for patients. This initiative has raised over \$4 million in donations

and in-kind contributions for the pediatric cancer program at Monroe Carell.

Looking forward, a partnership extension of 10 years between Vanderbilt Health and the Nashville Predators was announced in 2023.

"Every season we ask ourselves, 'How can we do more?', 'Where can we get involved?' Through the years of collaboration, it is easy to measure goals scored and dollars raised. But the real impact becomes evident when talking with patients and families who benefit from this partnership," King said.

"Our most treasured memory is the very first time we were escorted down to the locker room area to meet the players after a game," said Margaret Lantz, whose daughter, Caroline, receives care at Monroe Carell. "The players have always been extremely gracious, engaging with the children and families in a way that makes everyone feel so special. The Nashville Predators walk the walk — they are an organization that truly cares about their local community and how they bring positivity into fans' lives." 

— by Jay Carnes

*Child ambassador Jurnee Scantling, 11, drops the puck at a Hockey Fights Cancer game. Jurnee, a patient of Monroe Carell Jr. Children's Hospital at Vanderbilt, is joined on the ice by Nashville Predators captain Roman Josi and Chicago Blackhawks player Nick Foligno.*



JOHN RUSSELL

*"We are grateful to have a nationally recognized children's hospital in our hometown to provide expert care for children and their families in an environment designed for kids. It feels good to support Monroe Carell's critical work and join them in advancing healing and hope."*



## Dollar General

Denine Torr, Vice President of Corporate Social Responsibility and Philanthropy





# Hope on Wheels



**At an event in September 2023**, 1-year-old Edo Beeri, with the help of his parents, Kelse and Tom, dipped his hand in paint and placed his palm print on a Hyundai white sport utility vehicle.

Each handprint on the vehicle represented a different pediatric cancer patient like Edo, who was diagnosed and treated at Monroe Carell Jr. Children's Hospital at Vanderbilt.

Every handprint on the vehicle tells a story, from diagnosis through treatment, of each child's cancer journey. Hyundai Hope on Wheels and Hyundai Motor America hope one day that the vehicle is void of handprints as they work to raise funds and award research grants to prevent and improve outcomes of childhood cancer.

Since 2007, Hyundai Hope on Wheels, which includes funding from Hyundai Motor America and local dealerships, has awarded nearly \$2 million in funding to pediatric cancer researchers at Monroe Carell. Each year in September during Childhood Cancer Awareness Month, representatives from the automaker and local dealerships

celebrate grant award recipients and pediatric patients with a handprint ceremony, representing their personal stories of courage and hope.

"We could not do what we do every day to advance research and improve outcomes for pediatric cancer patients without the tremendous generosity of businesses like Hyundai Hope on Wheels and Hyundai Motor America," said Debra Friedman, MD, MS, holder of the E. Bronson Ingram Chair in Pediatric Oncology. "We cure 85% of patients, but until that number is 100%, we're not going to stop doing what we're doing and trying to learn."


Friedman, director of the Division of Pediatric Hematology/Oncology at Monroe Carell and deputy director of Vanderbilt-Ingram Cancer Center, has been a repeat recipient of Hyundai Hope on Wheels grants/impact awards, including

in 2015, 2018 and 2023. Her work includes researching survivorship, physical and psychosocial effects of cancer, and targeted cancer therapies.

Every 36 minutes a child is diagnosed with cancer in the United States. With advancements in research, diagnosis and treatment, childhood cancer survival rates have improved to 85%, but a lot of work remains to improve outcomes and reduce long-term side effects.

"Our goal is to help kids grow and succeed in a world that is free from pediatric cancer. We won't stop until we find a cure,"

said John Fratianni, senior merchandising manager for the Hyundai Motor America Southern Region.

"Every handprint tells a story in the fight against pediatric cancer. That's the theme of this annual initiative. It reflects the idea that there are many hands involved in the fight against pediatric cancer — patients, researchers, doctors, parents, supporters and more. And each one plays an important role in this fight. It's an enduring symbol of our collective hope and progress." 

— by Christina Echegaray

*Edo Beeri, 1, gets his hand painted at a Hyundai Hope on Wheels event.*



DOAN JONES



## Tri Star Energy

Steve Hostetter, Chief Executive Officer



*"We're supporting a great cause, and our efforts play a part in helping children and families in our community. On top of that, rallying around Monroe Carell is so critical to our employee engagement and our approach to servant leadership. It's been a powerful unifying force for our entire staff for more than 24 years."*



## Bank of America

Tyson Moore, President of Bank of America Nashville

*"Bank of America is committed to strengthening the communities we call home, and we truly value our long-standing partnership with Monroe Carell Jr. Children's Hospital at Vanderbilt. They offer a gift of hope and healing for families, not only in Middle Tennessee, but across the nation."*



# Friends of Monroe Carell Jr. Children's Hospital



**Kathy Rolfe still** tears up when she recalls the day Monroe Carell Jr. moved the first patient into the new pediatric hospital that bears his name.

As president of what was then known as Friends of Children's Hospital, Rolfe had been involved, along with other Friends, in the planning and fundraising for the new building — and the big moment had finally arrived.

"It was a special day," Rolfe said. "I was so excited to see a freestanding hospital that would serve so many children and their families for the surrounding Middle Tennessee region. I was also so proud of the community. They were so generous and encouraging to the team that was charged with funding and building the hospital."

The volunteer organization was started in 1972 by a group of forward-thinking women who saw a need to support families

with young children in the hospital. In 1974, they held a fundraiser featuring Lawrence Welk at the Grand Ole Opry; proceeds were used to buy 57 recliners so parents could stay in the hospital with their children.


As the hospital has grown, so have the size and scope of the Friends organization — always aligned with its core mission of fundraising, outreach and programs for patients and families. Funded largely through events like Friends & Fashion, philanthropic gifts have touched a broad range of departments and programs, including an endowment for prematurity and support for palliative care, music therapy, diabetes research and complex care.

Hands-on volunteering brings a personal touch to fami-

lies. Friends' volunteers distribute thousands of free meals to families each year, run bingo games and put on special events like a Fourth of July picnic.

When the COVID-19 pandemic put in-person fundraisers and in-hospital volunteering on hold, the Friends were quick to meet the challenge. They took some events online and created new ones to sustain fundraising momentum. And although they couldn't personally deliver meals, they continued to provide them.

From its beginnings with 150 members, the Friends organization has grown to more than 3,000 supporters today.

"Friends is a very special organization," said Rolfe, who remains an active Friend. "From my first day as a volunteer in the playroom to now, I have loved every minute of being part of it. I can't wait to see what the future holds for this very special place and the Friends organization." 

— by Peggy Caldwell

*Friends volunteer, Emma Anderson (left), and guest services representative, Erica Shannon, prepare to hand out lunch to families at Monroe Carell Jr. Children's Hospital at Vanderbilt.*



DOAN JONES



# FAMILIES SUPPORTING FAMILIES

**No parent ever** expects a doctor to say, “your child has cancer” or “your child needs multiple surgeries to fix prematurely fused bones.” Monroe Carell Jr. Children’s Hospital at Vanderbilt care teams meet families during some of the hardest moments in their lives. Doctors, nurses and staff commit to provide hope and healing to countless families. And in turn, many of those families feel passionate about paying it forward to help other children. We share two such stories here. 🦋

## Daughter’s cancer journey inspires Morrison family to give back

**W**hen Lindsay and Erik Morrison’s daughter, Caroline, was diagnosed with cancer at age 2, they found strength and faith in family and the community.

They also found inspiration to turn their daughter’s cancer diagnosis and journey into a meaningful way to help other children and families at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

Within weeks of Caroline’s diagnosis of neuroblastoma, a cancer that originates in the nerve tissue cells and primarily affects children younger than 5, the Morrisons began the process to establish the Caroline Morrison Pediatric Oncology Research Fund.

“There was obviously a flood of emotions after Caroline’s diagnosis,” Erik said. “You think about your family and how you can take care of your family, but I also know we’ve been very fortunate and have resources that many others don’t have. I thought immediately, ‘What can we do to try to improve the circumstances for others that are facing a similar situation?’”

In 2019, Lindsay didn’t think

anything was seriously wrong with her youngest child, Caroline, when she brought the toddler to the pediatrician. Caroline had trouble with balance, but the couple thought it could be related to antihistamine medication.

The pediatrician saw how she struggled to stand from sitting position on the floor, prompting concerns that Caroline might have a form of muscular dystrophy. A referral to a Monroe Carell pediatric neurologist ruled out muscular dystrophy, but he discovered that Caroline had no sensation or reflexes in her legs, knees and feet. He wanted an MRI to look for any possible neurologic disorders affecting her spine.

“They found a 4-inch tumor on her spine. You know something’s wrong, but you don’t know what’s wrong, and you don’t think it’s cancer. You don’t ever think it’s cancer, right? Especially for a 2-year-old,” Lindsay said. “At first, there was this panic, and my first thought was, ‘I don’t want my baby to die.’”

As they met with Caroline’s team of Monroe Carell doctors — Dan Benedetti, MD, MA (pediatric oncology); Chris Bonfield, MD, (pediatric neurosurgery); and Bo Lovvorn, MD, (pediatric surgery) — they learned more about the neuroblastoma, including that it is



ERIN O. SMITH

the most common solid tumor found in young children. It makes up about 8% of all childhood cancers, yet represents about 15% of all childhood cancer deaths.

The cancer and symptoms look and present differently in each patient with neuroblastoma, requiring personalized therapies and treatment plans, says Benedetti.

*The Morrison and Wise families have made it their mission to give back to support children diagnosed with cancer. Seen here (clockwise from left): Jack Morrison, Erik Morrison, Lindsay Morrison, Donna Wise, Emma Morrison and Caroline Morrison.*



**“Even a small gift can make a tremendous impact on someone’s life.”**

– ERIK MORRISON

Caroline’s tumor was on her spine and extended into her abdomen.

“We’ve learned through decades of research that we can take those different kids who have different presentations, and rather than giving them all the same treatments, we can customize the right treatment for the right child, like we did for Caroline,” Benedetti said.

“We are able to look at a big group of kids with neuroblastoma, and based on age, stage of disease and a tumor’s location, we can personalize their treatment, such that we can be confident some kids can be cured with no treatment after just a biopsy, and yet other kids will need all of it — radiation, chemo, surgery, immunotherapy — just to try to cure them. None of this would be possible without research support including from grateful patients and families like the Morrisons,” he added.

For Caroline, the team wanted to shrink the tumor and then surgically remove it. After two rounds of chemotherapy, the tumor hadn’t shrunk. Surgery was set for Aug. 23, 2019.

“Dr. Lovvorn came out during the surgery and said, ‘Cancer lost big today,’” Lindsay recalled. “They said the tumor just peeled out of there. They got everything out except a 1-millimeter bit of tumor. I truly believe we got a miracle that day.”

Right after surgery, the team checked Caroline’s reflexes. “Her reflexes kicked in like they should have before surgery, and I started crying,” she said.

Caroline was discharged within a week. Now 7 years old, she hasn’t had any treatments or surgery since, with the exception of physical therapy.

“She’s super charismatic; the friendliest kid you’ll ever meet. And now, she’s running, jumping,

dancing, and does gymnastics and dance class,” Lindsay said.

The family’s commitment to supporting research for neuroblastoma is stronger than ever. Erik clearly recalls the inspiration behind his decision to give back.

“As we received more information regarding her diagnosis, we also received an information packet that outlined the many resources that Monroe Carell has, and I remember vividly that there was some information on Lily’s Garden,” Erik said.

The Lily’s Garden initiative was established by a family faced with similar circumstances more than a decade ago. Diagnosed in 2008 at age 7 with B-cell acute lymphoblastic leukemia, Lily Hensiek decided to raise money to find a cure so no other children would have to go through what she has been through. She declared she would raise \$1 million for childhood cancer efforts at Monroe Carell. And she did.

The fund has far surpassed the original goal and is supported by three generations of Lily’s family, including parents Larisa and Phillip Featherstone and grandparents Carol and Ron Johnston. Despite a relapse of her leukemia at age 15, Lily is again cancer-free, just graduated from college and works in cancer research. She and her family continue their efforts to raise funds for childhood cancer.

Caroline’s family is also involved in giving, including her grandmother, Donna Wise, who made a gift to support fellowships by establishing an endowment, the Caroline Rose Morrison Fellowship Fund.

“I truly believe that Monroe Carell is a world-class children’s health institution. Dr. Benedetti is incredible, and Dr. Chris Bonfield and Dr. Bo Lovvorn are top notch. We found all the staff to be incredibly nurturing and caring, and we are very lucky to have Vanderbilt

in our Nashville community. I know that Monroe Carell is the best place for childhood cancer in the South,” Erik said.

“There’s just so many ways to give, and you know, whatever amount someone decides, there is a need for funding, and there is a need for research. Even a small gift can make a tremendous impact on someone’s life.” 🦋

– by Christina Echegaray

## Health challenges prepared Hanai family to assist others

**F**or their b’nai mitzvah service project, Sara Hanai’s two youngest children raised money to buy a charging station for the Emergency Department waiting room at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

“This is their space, and I absolutely love that they chose that as their project,” she said.

Three of Sara and Ramin Hanai’s four children experienced serious childhood illnesses, and the family became familiar with just about every corner of Monroe Carell.

Their son, Shmuli, was diagnosed with craniosynostosis, a birth defect where the skull bones fuse prematurely. He had reconstructive craniofacial surgery at 8 months old. When daughter, Ilana, was born, she had the same condition, but her first surgery was delayed until she was 14 months old.

Her experience was completely different.

“She was already self-feeding and walking but didn’t have language yet,” Sara said. “The surgery is invasive, and her eyes were swollen shut for a week. She couldn’t tell us if she was scared or in pain.”

Ilana would have five corrective surgeries at Monroe Carell,



the last during first grade. As the Hanais juggled work, school, after-school activities and hospitalizations, they experienced the restorative power of Monroe Carell's patient- and family-centered care. Assistance from child life specialists and other resources ensured the family's nonmedical needs were met.

Realizing her family's perspective could benefit others, Sara joined the Patient and Family Advisory Council, which is made up of individuals whose children have received care at Monroe Carell's hospital and clinics. The council collaborates with clinicians to improve care and provides input on programs and policies. The Hanai children also returned often to Monroe Carell as patient ambassadors, taking countless photos with their favorite mascot Champ and helping raise awareness about the hospital.

Then, Sara was diagnosed with stage 3 breast cancer, and she became the patient.

"We had to figure things out," she said. "The kids ranged in age from 7 to 12. I stopped working so I could do treatments and rest during the day. Then, from after school until bedtime, it was the same for them. I was still going to baseball games. I was helping with homework. With drains in, with no hair. It didn't matter. We made treatment and surgery decisions based on outcome, but also on recovery time and what would have the least impact on the kids."

As Sara finished treatment, her oldest daughter, Iris, began experiencing joint pain. In 2018, she was diagnosed with juvenile idiopathic arthritis and systemic lupus.

"With the younger two, their conditions were stressful but finite," Sara said. "With Iris, it's a chronic condition. She was diagnosed as a child, and it will continue through adulthood. She's had to navigate the idea of transition of care.

"It's been amazing to watch.

She's learning to advocate and not just for herself. She wants to get involved in advocacy work because she knows, through our experiences, that just because things are one way, that's not how it has to be. But she also knows not everybody knows that, and not everybody has a voice."

Sara joined Vanderbilt University Medical Center as a patient experience consultant in 2019. She was then named director of the Junior League Family Resource Center at Monroe Carell, a job she believes she was made for.

The Family Resource Center assists families with any nonmedical needs. Visitors can get help signing up for My Health at Vanderbilt, check out books about a diagnosis, get connected to community resources, or even curl up to watch a movie.

One resource she "shouts from the rooftops" is the emergency clothing closet "because

there's nothing worse than a family member who's been here for three days in the same clothing because they didn't know they had support."

And when she sees families coming through the doors of the Family Resource Center, her family's experiences have given her a special understanding of what might help them.

"We spent a lot of time here, as patients and as caregivers, in all the spaces," she said. "It takes a village, and this is part of their village. We're all good now. Three of our kids have graduated from high school, our oldest is about to graduate from college, and our youngest, Ilana, is a sophomore in high school.

"We will always be grateful for the care we received at Monroe Carell, and I imagine we will always find ways to ensure others have that same opportunity." 🦋

—Jill Clendenning



**"We will always be grateful for the care we received at Monroe Carell, and I imagine we will always find ways to ensure others have that same opportunity."**

— SARA HANAI

*For the Hanais, giving back to the hospital is a family affair. Seen here: Ilana Hanai with her mother, Sara.*



SUSAN URBAN

# BEHIND THE SCENES

**Monroe Carell Jr.** Children's Hospital at Vanderbilt was built to care for the children and families of Nashville, Tennessee, and beyond. At the center of that care are the doctors, nurses and staff – on the front lines and behind the scenes – who aim to give children the best care they need and deserve. Four longtime employees, who began their careers in pediatric care at Vanderbilt well before the current facility was built, share what they're proud of as well as their hopes and dreams for the future of the hospital. 🦋



I have had the privilege to witness the magic that happens daily at Monroe Carell, and what we have accomplished over the last two decades is truly remarkable.

I'm proud of our teams for being leaders of excellence in innovative, quality and compassionate care, and we are blessed to be entrusted to care for children and families from all over the country. Our successes are a direct reflection of teamwork from every person in both our inpatient and outpatient care areas. We are surrounded by people committed to doing their best for patients every step of the way.

Our children's hospital system has evolved to match the tremendous growth of Nashville and beyond as we continue to bring care closer to where families live and work. We are dedicated to carrying forward our mission through discovery and innovation to provide the very best care to all children, because that's what they deserve.

**John W. Brock III, MD**

*Professor of Pediatric Urology, Monroe Carell Professor, Surgeon-in-Chief Emeritus*



I am most proud of the high-quality care Monroe Carell has provided to my patients and their families. We have grown from a hospital-within-a-hospital where our oncology patients were hospitalized on two medical units along with all other medical diagnoses and four myelosuppression beds to the current Monroe Carell, a freestanding children's hospital with two dedicated oncology inpatient units and 18 myelosuppression rooms. The advances we have been able to pass along to children with cancer are palpable with the ability to provide immunotherapy/targeted therapies and manage the potential side effects. Our nursing staff has gained unique expertise in caring for hematology/oncology patients with the dedicated units within the hospital.

My hope for the future is to experience the expansion of our pediatric hematology/oncology clinic. I am also hopeful for Monroe Carell to have the expanded ability to serve our patients needing inpatient rehabilitation services and inpatient behavioral health services."

**Allison Duffey, RN**

*Patient Care Coordinator, Pediatric Oncology*



Over the past 20 years, I have enjoyed the growth of our pediatric social work department and hospital. We not only reach families as they are inpatient but also in the clinic and off-site settings. We continue to impact families as they journey through chronic and acute medical conditions as well as adjust to trauma and end of life issues. We are fortunate to conduct psychosocial assessments and assist families as they navigate their health journey, hospital and clinic environments. Monroe Carell is known for its research and innovations in health care.

It has been a joy to see families receive the benefits of these innovations that include transplant and clinical trials, just to name a few. My hope is that we continue to be committed to the long legacy of providing family-centered care to patients and families on their medical journey. We are one team working to make the world better for everyone."

**Deanna Reese, LCSW, MMHC**

*Manager, Pediatric Social Work Department*



I am proud of our growth not only in the numbers of children, teens and families we serve, but how we intentionally and strategically expanded in ways that provide dedicated spaces for pediatric health care. We have expanded not only in the physical spaces and location that we now know as Monroe Carell, but we also have grown our health care teams with a focus on the very best medical care for pediatric patients and their families with evidence-based emotional, developmental and psychosocial patient- and family-centered care.

I am especially hopeful and committed to the ongoing efforts surrounding the care we provide so that every child and family receives quality emotional care and therapeutic interventions needed to navigate the process of illness, injury, disability and trauma associated with health care experiences."

**Stephanie VanDyke, CCLS**

*Director, Child Life Services and Volunteer Services*



# FUTURE FORWARD

TWENTY YEARS IS JUST THE BEGINNING OF MONROE CARELL JR. CHILDREN'S HOSPITAL AT VANDERBILT

**The stories recounted** in the anniversary edition of *Hope* illustrate the history of Monroe Carell Jr. Children's Hospital at Vanderbilt; how the dedicated pediatric facility moved from dream to reality; how the hospital's care teams have provided hope and healing to countless children and families; and how much the community has rallied around the hospital and its programs since day one. Meg Rush, MD, MMHC, President of Monroe Carell, recently sat down with *Hope* editor Christina Echegaray to discuss and give insight into what's next for the hospital. 🦋

## What are some of the projects we can expect to be completed in the next three to five years at Monroe Carell?

We have experienced so much growth over the past 20 years at Monroe Carell, yet we're always excited to be looking ahead to the future. We are finishing the build-out of the last two floors, 12 and 14, of our four-floor expansion atop the original hospital structure — a few years ahead of initial planning. This will mark the culmination of the multiyear Growing to New Heights expansion project, made possible by the generous support of our community. These floors will enable developing even more comprehensive and multidisciplinary programs of care for the children and families we serve. We expect the 14th floor to be completed and opened in late 2024, with the 12th floor set to open in early 2025.

Simultaneously, we're thrilled to move forward with plans to upgrade and expand our comprehensive childhood cancer center, which was paused during the pandemic. The renovations will enable us to offer a robust, state-of-the-art space to match our nationally recognized pediatric oncology expertise and research programs. The renovated outpatient space will include increased capacity, more private spaces for our cancer patients, and added chairs for chemotherapy and medical infusions. These enhancements were made possible by the generosity of individuals and businesses in the community through Monroe Carell's Campaign Against Childhood Cancer.

We are in the process of moving our general pediatric practice to a larger space, off the main campus, at Vanderbilt Health One Hundred Oaks. We'll have about 10,000 square feet more than our existing space, with increased capacity for exam, lactation and consultation rooms. The vacated space on campus will allow us to grow medical specialties as well as add a dedicated pediatric dialysis space.

## Are there any "wish list" projects for Monroe Carell?

Our strategic approach historically has been to build programs to meet the needs of children. The next big gap to fill for pediatric services will be a pediatric inpatient rehabilitation unit. Our vision is to build a unit of Monroe Carell that would enable children who require inpatient rehabilitation services and ongoing health care to do both under one roof. Currently, Tennessee does not have a pediatric inpatient rehabilitation facility, and children in Tennessee who need this type of care must travel out of state, which can put a tremendous burden on families.

The inpatient pediatric rehabilitation space at Monroe Carell will help patients and families remain in state, closer to home, and enable all our teams to come together in a multidisciplinary care model. We are so grateful for the many generous philanthropic partners — the Carell family, Cal Turner Jr., Walmart, Willow Branch Homes, Joe Galante, the Junior League of Nashville, to name a few — who have signed on to support this incredibly important effort. We are excited, and hopeful, for more partners across Tennessee to join us in making this much-needed service a reality for our state's children and families.

## Are there specific programmatic expansions underway or that are planned?

As leaders in pediatric specialty care, we will continue to build on our excellence and journey in delivering personalized medicine for children — something we can do because of the comprehensive expertise across specialties. One program that comes to mind is gene therapy, which has allowed us to treat diseases for children that were once fatal.

We are currently able to offer some of the leading gene therapy treatments for diseases like spinal muscular atrophy and Duchenne muscular dystrophy, two genetic disorders that cause severe, progressive muscle loss. Because of our experience with rare diseases and our long-standing genetics program, we're poised to become a leading center in delivery of these very personalized treatments and to offer continued hope for many of our families.

Our expansion on the 12th floor will allow us to have space for a new clinical research unit, contributing to the development of new therapies as well.

We are also excited about and anticipate continued expansion of our solid organ transplant program, including beginning some double organ transplants as well as lung transplants. This growth will position us to become a major regional referral center for these services.

## Are there plans to expand the facility dog program? Can we get another dog?

Yes! I would love to have at least four facility dogs! The Facility Dog Program at Monroe Carell, supported by Mars Petcare, has proven to be so vital and comforting for our patients, families and our staff.

Our first dog, Squid, a Canine Companions for Independence-certified facility dog, incorporates something soft and gentle and

that's not scary into patient care, whether it's to help a critical care patient come off a ventilator or help a child get out of bed to do physical therapy. I've been impressed by the power of this program, by the work that Squid has been able to do over the past four years, and by the incredible stories of patients he has helped. It's also fun when he visits my office to say hi!

Not unlike our child life and music therapy programs, it's a tangible part of how you can help a child get better faster in a way that feels familiar, is fun and motivating. It is part of a different way to look at the healing process, and it's been hugely successful. We're currently planning our second dog, with help from several generous partners like Dunkin', the Teddy Bear Ball hosted by Kacey Musgraves, and Amazon. More to come soon!

### **How will we continue to keep up with the continued growth in Nashville, the entire Middle Tennessee community and beyond?**

Looking to the future growth of Nashville, we know that Vanderbilt University Medical Center has continued to invest in the growth that's needed to accommodate the demand for our expertise, and that's been especially true in pediatrics. That's why we've been able to add four floors and expand our outpatient footprint across the entire state to bring care closer to where families live. That investment in supporting the children in our community will continue over time. The success of Monroe Carell will allow us to enable continued expansion and growth — where and what that looks like is several years away.

### **How will Monroe Carell play a part in training and recruiting the next generation of health care workers?**

One of the biggest challenges for pediatric health care — and really health care as a whole — will be the future workforce. Fewer

people are choosing pediatrics and then fewer residents are going into pediatric subspecialty care. While our Monroe Carell building is only 20 years old, we have a 100-year history at Vanderbilt in the space of pediatric medical education, training and research. It is because of that, coupled with our expertise in pediatric care and multidisciplinary programs, that I believe we are poised to continue to attract the best trainees as well as the best faculty and nurses from across the country. As true innovators in the area of discovery and in creating models of medical education, I am confident we will continue to contribute to growing the next generation because the work we do at Monroe Carell is really amazing.

### **How can the community continue to support Monroe Carell?**

We have been blessed with great generosity from our community over many, many years. Our building and programs truly would not be where they are today without that support. We need to make more people aware of the magical things that happen in this building 24 hours a day, seven days a week, 365 days a year.

Community engagement is and will always be a part of what we do, and those relationships are so important. We are so incredibly grateful to our community and partnerships to help us achieve our missions and build our programs.

Our namesake, Monroe Carell Jr., passionately put into words the meaning of this building at the ribbon-cutting 20 years ago. He said, 'For those of you who have been building this facility, I know you have probably built larger facilities and taller facilities, but you will have never worked on a facility that is more important.' That still rings true today. This is still the most important building in Nashville.



*Meg Rush, MD, MMHC, President of Monroe Carell, tours the new 14th floor's construction progress.*

ERIN O. SMITH



# fun facts

DID YOU KNOW?

Monroe Carell Jr. Children's Hospital at Vanderbilt is a place where children and families come for compassionate, comprehensive care for a full range of pediatric health issues from colds and broken bones to complex heart diseases and cancer. When the hospital was built, every detail – the colorful decor, the paintings on the wall, the playful statues, and everything in between – was created and designed to make the hospital welcoming, a home away from home and even fun! The hospital has:

1



2



3



4



5



7



8



**1.** Eight age-appropriate playrooms.

**2.** The Friends Shop, with balloons and stuffed animals for patients and the latest in clothing fashion.

**3.** A line of holiday cards designed by patients: These works of art are featured on various cards and gifts, with proceeds benefiting Monroe Carell.

**4.** A facility dog, named Squid, who just turned 6.

**5.** An outdoor garden with a pond full of large koi fish.

**6.** An interactive train set.

**7.** A 4-foot-tall bronze "The Cat in the Hat" statue.

**8.** A teen cancer lounge specifically for adolescents and young adults.

6





## *A round of applause*

“In the entertainment industry, we have a lot of awards. And when you receive an award, the first thing you do is thank all the people who made it possible.

To my colleagues and friends in the entertainment industry, **I can't thank you enough for the many ways you've supported Monroe Carell over the years.** You've done so much for patients in their time of need.

I know we'd agree — the best award of all is helping countless children and their families.”

— **Kix Brooks**

Former Chair, Monroe Carell Jr. Children's  
Hospital at Vanderbilt Advisory Board



# HOPE

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



## It's amazing how generosity can build so much more than a hospital.

This year we're proud to celebrate **20 years** of caring for children at this very special place in the heart of Nashville. Impacting the lives of children and their families from around the country with the care, research and innovation that only we can provide, is our greatest mission.

To everyone who has donated, thank you.  
Because you didn't just build a hospital.

**You made a difference.**



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