

CHILDRENSHOSPITALVANDERBILT.ORG

# HOPE



## A Kidney for Finley

Comprehensive care for complex urologic and kidney conditions

FALL 2022





Hannah Kinslow,  
patient of Monroe  
Carell Jr. Children's  
Hospital at Vanderbilt,  
meets Nashville  
Sounds mascot,  
Booster.



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FALL 2022



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"Having programs like Child Life genuinely helps families to keep going, and that's all we want to do for our kids."



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Finley Hickman, 4, born with his kidneys fused together and not fully functioning, received a lifesaving kidney transplant in January 2022. Photo by Lauren Smith.

“Patient care, education, research and advocacy are at the center of what we do.”

## 09



# HOPE



## President

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### Pediatrician-in-Chief, Chair of the Department of Pediatrics and James

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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

**S**ummer months brought longer days, more free time and moments where we could hit the 'pause' button to reflect and embrace traditions, even as we looked forward to the return of routines, like school for kids and football for adults. The past two-plus years have most likely disrupted some of your pause routines. As we shift seasons to bright colors, shorter days and approaching holidays, we invite you to curl up in your favorite chair with a cup of spiced tea or hot cider and pause as we share our stories of hope that reveal how our past continually shapes our future at Monroe Carell Jr. Children's Hospital at Vanderbilt.

This year, we celebrate a few centennial milestones that are foundational to our history of innovating in pediatric health care. In late July, Mildred T. Stahlman, MD, the pioneer of the field of newborn intensive care medicine, celebrated her 100th birthday. She not only innovated in the clinical space, but also contributed to the scientific understanding and therapeutics of treating our tiniest patients, all while training hundreds of leaders in the field. We also celebrated the centennial of our community partner, the Junior League of Nashville. For 100 years, League members have helped us establish care for children through support of novel clinical programs that continue today but always with an eye on future needs.

Through our patient stories, we showcase the amazing expertise and innovation that enable development of state-of-the-art multidisciplinary programs. From enhancing the safety and care of our young athletes to caring for children in need of transplants, our teams deliver personalized care based on discovery and best practices. We also introduce you to some of our program leaders to highlight the passion and compassion behind our program development to ensure we support the complex needs of all children in their journeys. And we close out this issue with special words from one of our closest friends, volunteers and philanthropic partners, Fran Hardcastle.

As we pause and reflect, we are grateful for the opportunity to lead, support and walk beside all our teams, our doctors, our nurses and staff and our community partners. Through their actions and working together, we are able to make a difference in the lives of children and their families, through healing hands and the gift of hope — built upon our past and always looking forward.

Sincerely,

Meg Rush, MD, MMHC

*President*

Steven Webber, MBChB, MRCP

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

Jeffrey Upperman, MD

*Surgeon-in-Chief and Chair of the Department of Pediatric Surgery*

John W. Brock III, MD

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Go to  
[Give.VanderbiltHealth.org/childrens](https://Give.VanderbiltHealth.org/childrens)  
to find out how you can make  
a difference.





# good to know

NEWS FROM MONROE CARELL



**The 'Tri My Best' Triathlon**, an adaptive race sponsored by Monroe Carell Jr. Children's Hospital at Vanderbilt, took place Saturday, July 23, at Gaylord Opryland Resort. The race paired a child with a disability (ages 5-18) with a peer buddy to complete the race together as a team, using any modifications necessary to ensure the success of each child. By working as a team, each child learns that winning is not at the end of the race, but in the journey getting there together. Buddy teams are accompanied by an adult buddy throughout the race, which includes swimming, biking and running. Shown above: Lydia Jo Careen Horton, with her peer buddies Olivia and Owen Beard, and adult buddy Simone Herzberg. 🦋



## good to know

NEWS FROM MONROE CARELL

### Autism and sleep problems



Sleep problems are common in people with autism spectrum disorder (ASD), and the consequences of poor sleep may be more profound in people with ASD.

Prior studies of sleep problems and ASD were small and often cross-sectional instead of longitudinal. To combat those limitations, Beth Malow, MD, Emily Singer, MD, and colleagues used de-identified electronic health records (EHR) to determine the feasibility of a chart review process within an EHR to identify people with ASD and characterize their sleep problems.

The research team reviewed 230 EHR charts — 108 patients were male and 52 were female, with an age range of 6 through 30. Every chart was reviewed in its entirety by two reviewers for 13 sleep problems. They found that 86% of the patients had sleep problems, with insomnia being the most prevalent.

This approach, reported in *Sleep Medicine*, improved the identification of patients with ASD and sleep problems, proving that this method can be used to guide future work using the EHR and other neurodevelopmental disorders. 🦋

### Teen's life saved thanks to AED training program

Just before the second bell rang at Station Camp High School in Gallatin, Tennessee, Linton Beck, 16, was sitting at his desk, talking to a fellow student.

Students filled the room waiting for chemistry class to start.

Then Linton's eyes rolled back. He slumped over.

His classmate sprang into action and alerted the teacher, which set off a series of lifesaving events.

Linton was having a sudden cardiac arrest.

Station Camp High School is among 326 schools to achieve the Heart Safe School designation through Monroe Carell Jr. Children's Hospital at Vanderbilt's Project ADAM (Automated Defibrillators in Adam's Memory).

Project ADAM is a national

organization committed to making schools "heart safe" by preventing sudden cardiac death in schools and communities through education and lifesaving programs.

"The presence of AEDs (automated external defibrillators) in schools and throughout the community, combined with people who are prepared to respond, is key to saving lives," said English Flack, MD, assistant professor of Pediatric Cardiology and medical director of Project ADAM Middle Tennessee. "Sumner County has been a shining example of emergency preparedness, and Linton's school has consistently engaged with us to perform their annual AED drills in compliance with Tennessee legislation."

Monroe Carell's Project ADAM, now in its sixth year, is one of 34 affiliate organizations across 26 states.

"Our goal is for every school in Middle Tennessee to have a

practiced sudden cardiac arrest emergency response plan in order to act in the very manner that Linton's school did," Flack said.

Station Camp High School has five AEDs on school grounds.

Sumner County Schools was one of the first school districts in the Midstate to achieve the Heart Safe School designation in 2018.

Linton and his family are grateful that the school was prepared.

"I don't remember anything from the event," said Linton, a cross-country runner who had no previous health issues. "I remember walking to class, and then I remember waking up in the hospital."

"I'm just happy I was in the right place at the right time; I was around people who knew what to do. There was a plan in place."

"In the past, I noticed there's a box on the wall with an AED, but now that I've gone through this, that sign is a bigger deal."

"I will be more alert to where AEDs are located when I am out. It will be on my radar to get training to help others."

An estimated 350,000 out-of-hospital sudden cardiac arrests occur each year in the United States, and about 7,000 of those are in people younger than 18, according to the American Heart Association.

"Because of the quick response of the school staff, Linton is alive and will be able to continue being a member of the cross-country team," said Stephen Beck, Linton's dad. "My son is here today because of the school's response." 🦋



Linton Beck, 16

SUBMITTED PHOTO

# 30

Since opening in 2004, Monroe Carell Jr. Children's Hospital at Vanderbilt has significantly expanded the size and scope of its comprehensive, specialized pediatric care beyond the walls of its main campus in Nashville. Monroe Carell, named No. 1 children's hospital in Tennessee and in the Southeast by *U.S. News & World Report*, has 30 off-site clinic and affiliate locations to bring care closer to where children and families live. Pediatric physicians and surgeons provide medical and surgical care in locations across the state, and into Kentucky and Alabama. Locations include after-hours clinics, walk-in care, specialty care clinics and a full-scale outpatient clinic, surgical and after-hours care complex. 🦋



## good to know

NEWS FROM MONROE CARELL

SUBMITTED PHOTO

Becky Long (seated, middle) and family made a transformational gift to establish the Dr. William R. Long Fund in the Department of Pediatrics.



### AN ENDURING LEGACY

The legacy left behind by the late William (Bill) Long, MD, goes beyond his many years as a beloved Nashville pediatrician. He was a quintessential clinician-educator, always helping advance the mission of Vanderbilt's Department of Pediatrics and Monroe Carell Jr. Children's Hospital at Vanderbilt.

The family of the longtime pediatrician at Old Harding Pediatric Associates, who died in June 2020, made a gift to establish the Dr. William R. Long Fund to support directorships, resident education, fellowships and psychologists in the Department of Pediatrics at Vanderbilt University Medical Center.

Through this fund, established by Long's wife of 50 years, Becky, with her children and their spouses, Matt, Suzanne, John, Lindsley, Emily and Dan:

- Rebecca Swan, MD, professor of Pediatrics, vice chair for Education in the Department of

Pediatrics and assistant dean for Graduate Medical Education, has been appointed the inaugural holder of the Dr. William R. Long Directorship in Pediatric Medical Education.

- Sarah Jaser, PhD, director of the Division of Pediatric Psychology and associate professor of Pediatrics, has been appointed the inaugural holder of the Dr. William R. Long Directorship in Pediatric Psychology.

- Kelsey Gastineau, MD, a second-year fellow in Pediatric Hospital Medicine, has been awarded the inaugural Dr. William R. Long Fellowship.

"Dr. Long was a beloved community pediatrician who dedicated his long career to caring for thousands of children and their families in Nashville," said Steven A. Weber, MBChB, MRCP, James C.

Overall Professor, chair of the Department of Pediatrics and Pediatrician-in-Chief of Monroe Carell.

"He had an intense passion for teaching, and through his practice, he welcomed countless Vanderbilt medical students and residents to observe and learn, while also exemplifying the vital role pediatricians play in a child's health journey. We are forever grateful to Becky Long, and the entire Long family, for their tremendous generosity and for allowing his work and commitment to pediatric health care to endure through the support of these three outstanding clinicians."

A native of Louisville, Kentucky, Long received his undergraduate degree from Vanderbilt University, his medical degree from the University of Kentucky, and was a resident at Vanderbilt University Medical Center.

Becky Long said that her husband would approve of the ways the fund is being used. "He was passionate about his work. He would be thrilled." 🐛

### Food allergy linked to lower risk of SARS-CoV-2 infection

People with food allergies are less likely to become infected with SARS-CoV-2, the virus that causes COVID-19, than people without them, a study funded by the National Institutes of Health and co-led by Vanderbilt University Medical Center's Tina Hartert, MD, MPH, has found.

In addition, the Human Epidemiology and Response to SARS-CoV-2 (HEROS) study published in the *Journal of Allergy and Clinical Immunology* found that a high body mass index and obesity raise risk of infection, but asthma does not.

The HEROS study also found that children 12 or younger are just as likely to become infected with the virus as teenagers and adults, but 75% of infections in children are asymptomatic. The study confirmed that SARS-CoV-2 transmission within households with children is high.

"The finding of a decreased risk of infection among those with food allergy was an unexpected finding," said Hartert, professor of Medicine and Pediatrics, the Lulu H. Owen Professor of Medicine, director of the Center for Asthma Research and vice president for translational science at VUMC.

Hartert said further research is needed on the relationship between food allergy and COVID infection.



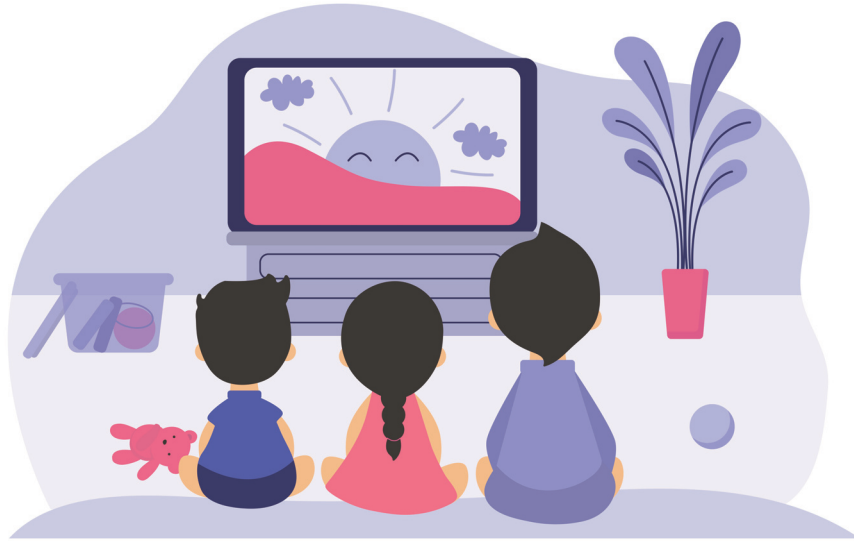


## good to know

NEWS FROM MONROE CARELL

# Excessive screen time impacting health of children

Nearly 50% of Tennessee parents say their children spend two hours or more on noneducational screen time each day. More than 70% of parents say they have some level of worry about how much screen time their kids are getting, according to a recent analysis of the annual Vanderbilt Child Health Poll. A growing body of research suggests that their concerns are warranted.



## How much time do kids spend on screens?

# 7.5 hours

Kids ages 8-18 now spend, on average, a whopping 7.5 hours in front of a screen for entertainment each day.



Children ages 8-10



Children ages 11-14



Children ages 15-18

## How much screen time is OK for young children?



The American Academy of Pediatrics recommends that babies younger than 18 months get no screen time at all. The exception to this rule is video chatting with grandparents or other family members or friends, which is considered quality time interacting with others.

Toddlers 18 months to 24 months old can start to enjoy some screen time with a parent or caregiver. Children this age can learn when an adult is there to reinforce lessons.

By ages 2 and 3, it's OK for kids to watch up to one hour a day of high-quality educational programming.

## How can parents help?

1

Ensure kids have one hour of physical activity each day

2

Limit kids' total screen time to no more than one to two hours per day

3

Remove TV sets from your child's bedroom

4

Encourage other types of fun that include both physical and social activities



Sources: CDC, AACAP



## good to know

NEWS FROM MONROE CARELL

### New clinic ensures comprehensive care for Fontan patients

By age 2, Gabe Ezell had two open heart surgeries to repair his congenital heart condition — tricuspid atresia with a hypoplastic right ventricle.

Diagnosed in utero during a 20-week ultrasound, doctors found that the right side of Gabe's heart was underdeveloped resulting in his having only one functional pumping chamber rather than two. Gabe's two complex heart surgeries, a Glenn and a Fontan, were part of a two-staged approach to help reroute deoxygenated blood coming back from the body to the lungs without using a pump. His one functional pump is used to pump oxygenated blood to the body. The surgeries, however, don't fully correct the defect, but make it more manageable.

"We had a fetal echocardiogram, and our cardiologist, Dr. David Parra, was very compassionate. We were very, very upset (when we found out the diagnosis

in utero)," said Gabe's mom, Sandra Ezell. "We didn't know what it meant for Gabe short term or even long term."

As children like Gabe, now 11, live longer following these palliative heart procedures, cardiologists at Monroe Carell Jr. Children's Hospital at Vanderbilt want to ensure they have a quality life well into adulthood. Monroe Carell recently launched a new multidisciplinary Fontan Clinic, which will provide an ongoing, coordinated care plan for children and teens, ages 10-19, who have had the Fontan procedure for single ventricle heart disease.

Led by cardiologist Angela Weingarten, MD, the comprehensive team coordinates care to address the long-term impact that these congenital heart conditions have on children and adolescents beyond the original diagnosis. The team, which works in consultation with a child's primary cardiologist, consists of two cardiologists, a cardiac nurse and nurse practitioner, a liver expert, a pulmonologist, a psychologist, a physical therapist and a nutritionist. Patients will be seen once every three years, with

follow-ups as needed for various evaluations and care plans.

"We don't fully know the real long-term effects of the Fontan. In the span of medical history, it's still a relatively new procedure," said Weingarten. "We want to be able to optimize people's outcomes while they're adolescents and still doing well, so that hopefully it will help them long term. Monroe Carell has everything we need in one place to take good care of a patient, and we have the expertise across multiple areas."

Sandra Ezell is thrilled with the experience of the clinic.

"We've met with several specialists, and we're going back for some further testing," she said. "I love knowing we can be aware of areas of concern and be proactive in trying to fix them. Vanderbilt has needed this for so long, and I can't wait to see it expand and help others. These kids are basically pioneers, as more of them are living longer. We need to explore more ways to help them." 🦋

**Gabe Ezell visits with Fontan team members Anita Pai, MD, left, and Angela Weingarten, MD.**



### BEST for Babies

Vanderbilt University Medical Center was named a BEST for Babies hospital by the Tennessee Department of Health.

The award recognizes labor and delivery, nursery and postpartum service efforts to reduce infant mortality utilizing Breastfeeding, Early elective delivery reduction and Safe sleep for Tennessee babies (BEST).

VUMC is one of 10 Tennessee birthing hospitals named for the 2021 award cycle.

"This award reflects the hard work of our obstetric and pediatric teams," said Anna Morad, MD, associate professor of Pediatrics and director, Newborn Nursery at Monroe Carell Jr. Children's Hospital at Vanderbilt.

"We consistently have excellent breastfeeding initiation rates and very low early elective C-section rates. The newborn nursery recently completed a yearlong quality improvement project with Tennessee Initiative for Perinatal Quality Care to improve safe sleep for infants in our hospital." 🦋



## good to know

NEWS FROM MONROE CARELL

### Delta Dental gift to support pediatric craniofacial program



Delta Dental of Tennessee's charitable arm, the Smile180 Foundation, has made a \$1.075 million commitment to the Cleft and Craniofacial Program at Monroe Carell Jr. Children's Hospital at Vanderbilt.

Monroe Carell will use the funds to establish the Delta Dental of Tennessee's Smile180 Foundation Directorship for the Cleft and Craniofacial Program and to provide critical support as the program seeks to expand its services to care for more young patients and their families.

The commitment expands on Delta Dental's longstanding support of Monroe Carell. Since 2001, Delta Dental and Smile180 have donated more than \$2.3 million to the hospital and supported various fundraising events and initiatives.

This program cares for patients with a wide range of facial differences and is led by Michael Golinko, MD, medical director of the Cleft and Craniofacial Program and chief of Pediatric Plastic Surgery, along with Jim Phillips, MD, co-director of the Cleft Lip and Palate team. The complexity of this team's cases means that patients often stay with the program for multiple years and require care from an integrated team of specialists. 🦋



DOHN JONES

### Duchenne Clinic first in Tennessee to be certified

**T**he Duchenne Muscular Dystrophy Clinic at Monroe Carell Jr. Children's Hospital at Vanderbilt has been recognized as a Certified Duchenne Care Center Program by the Parent Project Muscular Dystrophy (PPMD).

PPMD, a nonprofit organization founded in 1994, is focused on ending Duchenne, the most common fatal, genetic childhood disorder that affects approximately 1 out of every 3,500 boys worldwide each year. There is no cure.

Monroe Carell, the largest provider of Duchenne care in the region and the only one in Tennessee, joins 28 accredited centers in the United States providing standardized care and services.

"There has been some form of a center for Duchenne at Vanderbilt since the late 1960s," said

Bryan Burnette, MD, MS, associate professor of Pediatrics, Neurology and Neuromuscular Medicine. "In the last few years, we have concentrated on developing a multidisciplinary clinic with great attention to the patient experience and care in one physical location.

"We recognize the importance of standardized care and collaborative research efforts to provide the best care not only for our patients, but Duchenne patients across the globe," he said.

The recent PPMD accreditation allows Monroe Carell access to major clinical trials, cutting-edge treatments and a community of support. PPMD advocacy efforts have garnered hundreds of millions of dollars in funding for research and treatment development and secured five FDA approvals for drug therapies.

The clinic, led by three co-

directors, Burnette, Andrew Sokolow, MD, assistant professor of Pediatric Allergy, Immunology and Pulmonology, and Jonathan Soslow, MD, associate professor of Pediatric Cardiology, draws patients from Kentucky, Alabama, Georgia, Louisiana, Mississippi, South Carolina and Missouri.

The clinic also incorporates teams from palliative care, nutrition, physical and occupational therapy and social work for a one-stop-shop collaboration. Other specialties that work closely with the clinic include speech therapy, endocrinology, gastroenterology, orthopaedics and surgery.

"Having one single clinic offers a great advantage to both our patients and our medical teams," said Soslow. "We are able to communicate in real time about issues that have been identified. It helps that we collaborate in the moment for evidence-based care planning." 🦋



# conversations

NEWS FROM MONROE CARELL



*Alex Diamond, DO, MPH, FAAP, FAMSSM, associate professor of Orthopaedic Surgery, Pediatrics and Neurological Surgery at Monroe Carell Jr. Children's Hospital at Vanderbilt; director, Vanderbilt Youth Sports Health Center; and team physician: Vanderbilt University and Nashville Predators*

PHOTOGRAPH BY ERIN O. SMITH



**Q** Monroe Carell recently opened the Youth Sports Health Center. Tell us more about this endeavor.

**A** The Center is an opportunity to provide comprehensive, collaborative and innovative care for the child and adolescent athlete at all levels (recreational and competitive) and is the only one of its kind in the region. Through a partnership between Vanderbilt Sports Medicine and Monroe Carell Jr. Children's Hospital at Vanderbilt, the Center brings together the same specialists who care for our elite sports teams like the Predators, Sounds, Nashville SC, Vanderbilt athletics and the Tennessee Secondary School Athletic Association with nationally and internationally recognized care teams from the No. 1 children's hospital in Tennessee and the Southeast. This allows us to offer a holistic approach to care for and to help the young athlete compete at their best.

**Q** How did this Center come about?

**A** I've had this vision for a very long time. For most of my career, I've focused on societal-level sports-related population health issues and community-based interventions that impact current and future generations of children when it comes to their physical, mental and social-emotional well-being. We have amazing people here at Vanderbilt. I'm so impressed every day by

the knowledge, skill and level of caring by my partners, colleagues and staff across the Medical Center. I love collaboration. There is tremendous power as to what can be accomplished when we harness all of that into one room looking at the same problems together but with different vantage points. I believe Vanderbilt is uniquely situated for this Center because it is so naturally collaborative, and when you combine that with our academic foundation, research curiosity and evidence-based clinical expertise, we are going to be able to develop treatment pathways, diagnostic evaluation and an overall health and wellness model that is better for patients and their families.

**Q** Why is this level of care needed?

**A** Sports matter to kids, and sports also matter for kids. We know that sports offer a pathway for children to engage in physical activity. We know that physical activity affects morbidity, mortality and quality of life. When children are physically active, they do better in school, work and multiple health measures. Kids who are physically active tend to become adults who are also physically active. Sports are a stepping block to healthier lifestyles, and I believe, are a fundamental part of child development. When you think about the child and teen athlete, you have to think about the whole kid. We have created a Center that focuses on physical, mental and social health. Establishing a comprehensive approach to care is key to providing the most advanced, personalized care possible. We are here to serve all children who want to be physically fit and active through sports

at all athletic levels — elite, high school, club-level or recreational. We also want to engage in community advocacy work to help impact the future health and safety of young athletes.

**Q** How will the Center work?

**A** We have physicians and surgeons from more than 25 different specialties represented in the Youth Sports Health Center. All team members involved understand the special needs of athletes whether the injury or illness is a result of sports involvement or an underlying condition. The Center is geared toward treating the pediatric and adolescent school-aged athlete. There will be multiple access points for convenience for families and referring providers.

**Q** What are your expectations for the Center?

**A** My goal for our Center is to continue to improve the lives of children and teens along with their families not only here in Middle Tennessee but across the Southeast and the country. We want to be on the forefront of innovation while upholding our commitment to our local community, but also create societal-level change to implement policies that make sports safer, healthier and as injury-free as possible. Patient care, education, research and advocacy are at the center of what we do. 🦋

*For more information about the Center, visit the website at: [childrenshospitalvanderbilt.org/yshc](http://childrenshospitalvanderbilt.org/yshc)*



## spotlight

PIONEER IN CARE

ARCHIVE PHOTO

Mildred Stahlman, MD



# A Legacy Lived

Honoring 100 years with neonatology pioneer  
Mildred Stahlman, MD

STORY BY BILL SNYDER

10 • CHILDRENSHOSPITALVANDERBILT.ORG



n July 31, Mildred Stahlman, MD, known internationally for advancing the treatment and care of premature babies, reached another milestone — her 100th birthday.

Professor of Pediatrics at Vanderbilt University Medical Center, Stahlman does not like to be called a pioneer in her field of neonatology. “Many people did much more than I did,” she said in 2005. “My idea of science is that everything is built on the backs of somebody else.”

Yet among her many achievements, Stahlman is credited with establishing, in 1961, the nation’s first newborn intensive care unit to use monitored ventilation therapy on infants with damaged lungs.

She worked tirelessly to regionalize medical care services for newborns and high-risk mothers. To get sick babies safely to the hospital, in the early 1970s she helped develop a neonatal transport system called “Angel” that has been copied nationwide and which continues today.

“For my 30 years here, she has been an example of what the single-minded determination of an extraordinary woman can do to make things better for babies and their mothers,” said William Walsh, MD, professor of Pediatrics and past Chief of Nurseries at Monroe Carell Jr. Children’s Hospital at Vanderbilt. “I am honored to know her.”

At the start of her career, Stahlman was among few women faculty members in the Vanderbilt University School of Medicine (VUSM). She insisted on the highest standard of excellence, both for herself and for the many resident physicians and research fellows she trained.

“She was terrifying,” recalled Meg Rush, MD, MMHC, President of Monroe Carell and professor of Clinical Pediatrics, who first encountered Stahlman as an intern in Pediatrics in 1984, “... but it was with an eye to make you a better physician and to challenge you intellectually, building critical thinking skills.”

Now retired to her log house in Brentwood, Tennessee, and in frail health, Stahlman’s essential quality — her love of people — is undimmed. “In my eyes, she remains one of the most significant role models and inspirations in my life,” said longtime friend and colleague Odessa Settles, RN, MSN, CM.



## spotlight

PIONEER IN CARE

"Millie" Stahlman and her sister Ann, who died in 2014, grew up in the 1920s and '30s in Nashville's then-rural southern outskirts. Their father, James G. Stahlman, was publisher of the afternoon newspaper, the *Nashville Banner*, and a longtime member of the Vanderbilt University Board of Trust.

Stahlman attended Vanderbilt University and graduated in 1946 from VUSM. After a yearlong fellowship at the famed Karolinska Institute in Stockholm, Sweden, she returned to Vanderbilt in 1951 as an instructor in Pediatrics.

In 1954, she received a small grant from the National Institutes of Health to study hyaline membrane disease, the failure of the alveoli, or small sacs in the lungs, to expand with air. When severe, the condition, also known as respiratory distress syndrome, was nearly always fatal.

Through studies of fetal lambs, Stahlman and her colleagues developed ways to diagnose and monitor the course of hyaline membrane disease. They also began clinical studies using an infant-sized version of the "iron lung" that had been developed for polio victims.

Then on Oct. 31, 1961, a baby girl was born at Vanderbilt University Medical Center two months prematurely and gasping for breath. With the permission of her parents and pediatrician, baby Martha was placed in the ventilator to keep her alive, and with the hope that her lungs would mature enough so that she could breathe on her own.

Stahlman put up a folding bed in the next-door lab so she could help monitor the baby, day and night. "I was there for four nights," she recalled in 2005. "On the fifth day, we managed to get her weaned off."

Today Martha Lott is a registered nurse who has worked in the neonatal intensive care unit at Monroe Carell since 2004.

"It is amazing to see all the changes that have happened in the last 18 years," Lott said. "I sometimes look around in awe, knowing how much Dr. Stahlman's research, knowledge and care of the newborn did for me and for so many babies/people in the 60 years that I have been alive."

For much of her career, Stahlman, who never married, set a grueling pace for herself, working most evenings and on weekends. What drove her was the desire to better the lives of others and avoid unnecessary suffering through research and clinical care.


"Research is the method by which you can step back and see something else happening besides a disaster," she told the *Nashville Banner* in 1981.

Stahlman went on to establish the Division of Neonatology that today bears her name, served as president of the American Pediatric Society, and in 1996 received the society's highest honor, the John Howland Award.

"I have enjoyed my clinical work always, but it is extremely demanding in both time and effort and changes your lifestyle," she said in an interview several years ago. "You make choices, and sometimes the choices are hard to make."

Yet, according to those who know her best, Stahlman has always been a generous spirit and loyal friend.

Settles helped launch the Angel newborn transport service and currently manages the follow-up program for young children with bronchopulmonary dysplasia (BPD), a chronic

  
**"Prematurity is not a medical problem. It's a social and economic problem."**

— MILDRED STAHLMAN

lung disorder that is a complication of premature birth.

She met Stahlman soon after her arrival at Vanderbilt in 1969, and the two women, who had grown up on opposite sides of then-segregated Nashville, bonded almost immediately.


"It was life changing for me," said Settles, BPD Clinic Coordinator, "to form a friendship with a woman, who against the odds, became a pioneer in the field of neonatology, and in a sense on a certain level, understood the impact of discrimination."

"If society doesn't recognize problems," Settles told a reporter in 2003, "they can never be fixed, whether it's health care, or lack of insurance or segregation. I learned that from her. She made me view my life that way. It opened my eyes."

Noting that poverty and lack of prenatal care increase the risk for premature delivery, Stahlman would tell her trainees, "Prematurity is not a medical problem. It's a social and economic problem."

"Until we set priorities and find ways to offer Americans a good education, which can lead to job opportunity, decent housing (and) the availability of adequate medical care..., prematurity will continue, with all its costly consequences," she wrote in the *New England Journal of Medicine* in 1989. "We are wasting precious time."

To help open the door to opportunity for those with limited means, Stahlman established a college scholarship program for high school students in rural Humphreys County, where she has a 700-acre farm.

When asked to define her mentor's greatest legacy, Rush said simply, "People. She is wholly invested in developing the science and the clinical care, but always with the idea of creating the next generation of people who would keep carrying it forward. We are so grateful to her for her gifts and contributions to many generations of children." 

Left: Mildred Stahlman, MD, in the NICU with one of the countless babies she helped. Right: Mildred Stahlman, MD, and Jeffrey Whitsett, MD, a frequent collaborator from Cincinnati Children's Hospital Medical Center





# A KIDNEY FOR FINLEY

Pediatric urology, nephrology and transplant coordinate care for children with complex urinary tract conditions

STORY BY LEIGH MACMILLAN  
PHOTO BY LAUREN SMITH

There's a new sound these days in the Hickman family's Seymour, Tennessee, home. It's 4-year-old Finley, running.

Finley had a lifesaving kidney transplant at Monroe Carell Jr. Children's Hospital at Vanderbilt in January, and since recovering, he loves to run.

"You hear the little pitter patter of his feet all over the house, from dawn to dusk," says Finley's mom, Alyssa. "It's a beautiful sound."

When he stops running, it's to make silly faces and giggle at his sister, Leila, 7, or to snuggle with his mom and dad.

"One of his favorite things to do is cuddle, which we do not complain about at all," Alyssa says. "He's just a little blond-haired, blue-eyed ball of sunshine."

Late last year, Finley was not well enough to run. He was in renal failure, having hemodialysis three days a week to

filter waste and water from his blood, and waiting — waiting for a kidney that would save his life.

## Genitourinary system anomalies

Finley was born in September 2018 in Knoxville, Tennessee, at 31 weeks of gestation and weighing just over 2 pounds. He spent four months in the neonatal intensive care unit in Knoxville before being transferred to the NICU at Monroe Carell.

"It was scary and very overwhelming, but we felt confident that the doctors at Monroe Carell could meet Finley's needs and take care of him," Alyssa says.

The Hickmans had learned at the 20-week ultrasound scan during Alyssa's pregnancy that there were problems with Finley's kidneys.

Two kidneys — shaped like the beans named after them — are located just below the rib cage on each side of the spine. They filter the blood, removing waste and extra water to make urine, which flows from the kidneys to the bladder through thin muscular tubes called ureters and is excreted from the bladder through the urethra.

The kidneys, ureters, bladder and urethra form the urinary tract, which is grouped with organs of the reproductive system as the "genitourinary system" because of proximity, developmental origins and common structures (like the male urethra). During embryonic development, complex interactions between various tissues direct the formation of the genitourinary system, and disruptions can occur.



Finley Hickman, 4





“The genitourinary system is the second most commonly affected organ system for congenital anomalies after the cardiovascular system,” says John Pope, MD, professor of Urology and Pediatrics and director of the Division of Pediatric Urology, which is ranked No. 8 in the U.S. “There’s a vast number of children who have congenital anomalies of the kidney, ureter, bladder, genitalia and pelvic organs.”

Often, anomalies of the genitourinary system are detected on prenatal ultrasound, and patients are referred to pediatric specialists in urology and nephrology for prenatal evaluation.

“When I was training, people would have surprise diagnoses after birth, but now most people learn about congenital abnormalities before birth,” says Kathy Jabs, MD, associate professor of Pediatrics and chief of the Division of Pediatric Nephrology. “The mother gets seen before the child is born by nephrology and urology, and also by neonatology, so we can talk about what to expect — the range of things to expect. It’s a really nice partnership.”

### Intertwining specialties

Parents are sometimes confused about the two specialties that care for the same system, Jabs says. She explains that nephrologists are pediatricians who specialize in kidney diseases, and urologists are surgeons who specialize in the urinary tract.

Nephrologists care for children with congenital kidney abnormalities, kidney injuries — perhaps because the child was born prematurely and had heart problems and limited blood flow to the kidneys, glomerular nephritis (inflammation of the kidney) for various reasons, high blood pressure and kidney stones.

In addition to filtering waste and excess water, the kidneys maintain the blood’s acidity and balance of salt and minerals. They also produce hormones that regulate blood pressure, participate in red blood cell production, and contribute to bone maintenance. Children with kidney failure require multiple medications to do the things that their kidneys can’t do, Jabs says.

Urologists perform surgeries ranging from more common procedures such as circumcisions, inguinal hernia repairs, and undescended testicle relocation, to complex repairs of kidney and bladder abnormalities.

Children often see specialists from both disciplines.

“Our relationship with nephrology is incredibly interconnected,” Pope says. “Pediatric nephrologists are caring for children with renal function problems and renal failure, and we (pediatric urologists) are dealing more with the drainage system: the structural anatomy of the genitourinary tract.

“We work very closely with each other because many children have nephrology and urology issues that intertwine.”

Kidney stones — hard deposits of minerals and salts in the urine — are a good example. Monroe Carell offers a Pediatric Kidney Stone Clinic where patients see both urologists and nephrologists in the same

clinic. Kidney stones can require a surgical intervention performed by a urologist, while a nephrologist seeks to understand what is causing kidney stones and what can be done to prevent them.

“In the case of kidney stones, and for many issues, we work together on different aspects of the same problem,” Jabs says.

### Finley’s urologic and kidney concerns

Finley’s care has involved both urologists and nephrologists, along with a range of other specialists.

Although it was clear from imaging studies that Finley’s kidneys were not correctly formed, his most urgent needs after his transfer to the NICU at Monroe Carell were urologic. He required several urologic surgeries, including a ureterostomy — the connection of his ureters to the abdominal wall so that urine could exit outside the body.

Finley also has feeding and gastrointestinal concerns and sees gastroenterologists at Monroe Carell. He has a gastrostomy tube (G-tube), a surgically placed device to give direct access to the stomach.

After his discharge from the NICU, Finley had recurrent urinary tract infections and fevers. “He was in and out of the hospital quite often,” Alyssa says. “It would be like his body had raging infections, but then it didn’t. It was very confusing.”

Because of his kidney concerns, Deborah Jones, MD, professor of Pediatrics at Vanderbilt, who was Finley’s nephrologist at the time, managed his care even when he went to the hospital in Knoxville.

“Eventually, we got to the point where we just came straight to the emergency room at Monroe Carell,” Alyssa says. “It was worth it to drive three-and-a-half hours for care that was more tailored to his needs. Finley’s body doesn’t follow the rules. Every doctor in the nephrology group knows Finley, and they’re all phenomenal.”

Finley was born with a “pancake kidney” — his two kidneys are fused together and centrally located in the pelvis. For a short time, his fused kidneys worked well enough, Alyssa says, but they gradually started losing function. Alyssa, who is a high school math teacher, watched as the laboratory test values for kidney function changed.

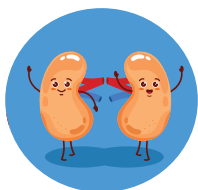
“I like to know the numbers; they make sense to me,” she says. “From the labs, you could see his kidney function deteriorating; it was really obvious.”

So, although it wasn’t a surprise when Jones officially referred Finley to be evaluated for a kidney transplant, “it was a lot scarier than you think it’s going to be — to actually be going down that road,” Alyssa says. “Thankfully, we were so confident in who was taking care of Finley that we were able to go into it with a lot of peace.”

### The wait for a kidney

Patients who are referred to Monroe Carell for a kidney transplant undergo a thorough evaluation and





**Kidneys for transplant can come from a living donor (an adult with two healthy kidneys) or from a deceased donor.**

are presented to a selection committee that discusses their case and determines if the child is ready to be listed for a transplant.

Michelle Mitchell, RN, BSN, pediatric kidney transplant coordinator, works with families from the time of referral throughout the transplant process. She schedules all the appointments, makes sure that requirements are met, does pre- and post-transplant education for patients and families, and makes sure that families have all the supplies and medications they need after discharge.

Jabs, medical director of the Pediatric Kidney Transplant Program, cares for all of the pediatric transplant patients — 10 to 15 per year.

Kidneys for transplant can come from a living donor (an adult with two healthy kidneys) or from a deceased donor. A living donor is preferred when possible because the transplanted kidney “performs better, lasts longer and has fewer complications,” says David Shaffer, MD, professor of Surgery, surgical director of the Pediatric Kidney Transplant Program, and Finley’s transplant surgeon.

Transplants from living donors can also be scheduled preemptively before a patient needs dialysis.

After Finley was evaluated in February 2021 and then listed for transplant, the Hickmans hoped to find a living donor. Neither of Finley’s parents qualified, and after searching among close family and friends, they began sharing Finley’s story via social media and news stories.

As they waited, Finley’s health deteriorated. In October 2021, he was admitted to the Monroe Carell in-

tensive care unit with a marked decrease in his kidney function, so that he urgently needed to start dialysis treatments. He was able to be discharged for outpatient dialysis three times per week, and the family moved to Nashville for his care.

In November 2021, they got the news they had prayed for — a living donor was available and surgery could be scheduled. After a delay from a positive COVID-19 test, Finley received his kidney transplant on Jan. 5.

Shaffer was able to place the new kidney without removing the pancake kidney, which had been a concern, and Pope moved Finley’s urostomy conduit to a new location. Transplant and urologic surgeons “work often and well together,” Shaffer says. He adds that “Monroe Carell has all the subspecialties aligned to be able to provide complicated care to the most challenging patients, and we have very good outcomes.”

“We have been very impressed with Monroe Carell and everything they’ve done, specifically urology and nephrology,” Alyssa says. “Those doctors have worked so hard for Finley.”

The transplanted kidney continues to “work beautifully,” Alyssa says. “We’ve had to troubleshoot some things and tweak medicines, but he’s growing and doing great.”

Alyssa remains in awe of Finley’s donor, a stranger — now a friend — with three children, who saw a Facebook post and felt drawn to Finley.

“She told us that she felt like she had Finley’s kidney, and she wanted to get it to him so he could be a wild little boy, like her little boy is,” Alyssa says.

A wild little boy, running through the house. 🐾

## HOSPITAL WELCOMES NEW DIRECTOR OF PEDIATRIC SOLID ORGAN TRANSPLANT CENTER



Saeed Mohammad, MD, MS, was recently named director of the Pediatric Solid Organ Transplant Center at Monroe Carell Jr. Children’s Hospital at Vanderbilt, following an extensive na-

tional search. In this new role, Mohammad will work to grow Vanderbilt’s pediatric transplant services.

Mohammad, an internationally recognized pediatric transplant physician, joined Vanderbilt from Northwestern University Feinberg School of Medicine. There, he was an associate professor of Pediatrics, fellowship director for the transplant hepatology fellowship, and

medical director for the Hepatology and Liver Transplantation program at the Ann & Robert H. Lurie Children’s Hospital of Chicago.

This is a kind of homecoming for Mohammad. Following medical school at The Aga Khan University in Karachi, Pakistan, Mohammad completed his pediatrics residency training at Vanderbilt. He then moved to Northwestern University, where he completed a pediatric gastroenterology fellowship and a transplant hepatology fellowship before being recruited to the Northwestern faculty.

Throughout his career, Mohammad has established himself as a leader in his field. He has developed several innovative clinical programs at Northwestern and has served in leadership roles in the Society of Pediatric Liver Transplantation; American Association for the Study of

Liver Disease; North American Society for Pediatric Gastroenterology, Hepatology and Nutrition; Autoimmune Hepatitis Association; American Liver Foundation, and the United Network for Organ Sharing.

“I feel privileged to be able to return to Vanderbilt where my professional career began,” Mohammad said.

“Vanderbilt has a proud history of excellence in both pediatrics and transplantation, and I am excited to be part of this team as we work to develop a comprehensive pediatric-focused transplant center to care for the children in Tennessee and across the nation.”

— by Matt Batchelder



DONN JONES



Jameson Wall's parents were inspired to get him a therapy dog, Sushi, (shown here) after his interaction with Squid, the facility dog of Monroe Carell Jr. Children's Hospital at Vanderbilt.

# CANINE CONNECTIONS

Stories of impact two years into the hospital's facility dog program

STORY BY JESSICA PASLEY

**F**or nearly three years, Laura Wall and her family only felt comfortable venturing outside of their home for work, school and doctors' appointments.

Her concerns of leaving home began to lessen after an interaction between her 7-year-old son, Jameson, and a four-legged member of the Monroe Carell Jr. Children's Hospital at Vanderbilt staff, Squid, a facility dog.

The two met during one of Jameson's hospital admissions, which proved to be a life-changing experience for the family. Wall had Squid to thank.

Squid, a 4-year-old Canine Companions for Independence-certified dog, joined the hospital staff in February 2020, and has shown a positive impact on patients, families and staff. Jameson is one of nearly 700 patient interactions for Squid since he arrived.

Wall and her husband, Corey, are both officers with the Metropolitan Nashville Police Department and known in their community for fostering children. They met Jameson when he was 19 months old after his grandparents, who had no ability to care for him, asked them to take him. His mother was in jail, and the toddler had been born addicted to drugs.

The Walls agreed, became permanent legal guardians, and later adopted Jameson at age 3.

In 2020, Jameson began experiencing extreme behavioral swings, an inability to control anger and sleep issues. He was diagnosed with pediatric acute-onset neuropsychiatric syndrome, or PANS. Children with PANS develop severe physical, neurological and psychological disturbances that interfere with their daily functioning.

Frequent hospitalizations became a regular part of their lives.

"We were really struggling," said Laura Wall. "As he progressively became sicker, with extreme neurological and movement disorders, doctors were concerned that Jameson's condition was terminal. There were so many tests and scans being done to help determine what was going on.

"Jameson was in a lot of distress the entire week we were in the hospital. It was very hard for us to find a happy moment, and in walked Squid and his handler, Leslie," said Wall.

"When a child who never smiles, suddenly does ... that was enough to keep us going. Squid changed our lives and gave us hope again. He made all the difference."



So much so, said Wall, that the nursing staff asked if the family had a pet dog they could bring in from home.

Unfortunately, interacting with their pets was not an option. The family had always known their son to be aggressive with animals, which made the interaction with Squid so remarkable.

The pair began researching service dogs. Both the cost and long waitlist made it out of reach.

Wall, who had previous experience with therapy dogs as the director of humane education and a dog trainer for a no-kill animal shelter in South Florida, began reaching out to dog trainers for guidance. Armed with key traits, appropriate age and other details for a service dog, she stumbled upon a rescue organization in Cumberland County that was housing a dog that fit the description to a T.

"One of the things, outside of the fact that he met all the criteria, was that he was wearing a green bandana," said Wall. "Green is Jameson's favorite color. On Mother's Day, volunteers from the animal rescue made the four-hour, round-trip drive to bring Sushi to us because we couldn't leave with Jameson."

"He walked into the house, immediately went to lie next to my son, and Jameson completely relaxed. It was as if they knew each other for years. I knew that with training, the relationship would only get better."

Sushi recently completed his four-week training. Life in the Wall household is settling.

"Before Sushi, we had everything delivered to the house," said Wall. "Now, we are able to go to the grocery store without having to restrain Jameson in a cart or wheelchair."

"Now, we can go places. I feel normal. We are no longer isolated, and we don't have the overwhelming feelings of hopelessness."

"Jameson is so proud of his dog," exclaimed Wall. "His impulse control issues have improved. I know things will continue to get better."

The Facility Dog Program at Monroe Carell was announced in 2018 through a collaboration with Mars Petcare's BETTER CITIES FOR PETS program, which seeks to bring the healing power of pets to more children and families like the Walls. Mars Petcare has generously supported the program since its launch.

Squid completed an extensive two-year training regime and graduated in 2020 from an intensive two-week instruction with Leslie Grissim, MA, primary handler, and Erin Munn, Certified Child Life Specialist, who serves as the secondary handler.

"Facility dogs are trained to engage patients to help them achieve a specific treatment goal and have been shown to decrease anxiety," said Grissim, facility dog coordinator. "People are drawn to the human-animal bond. Animal-assisted interventions offer both patients and staff the ability to talk without barriers and opportunity to express themselves in a way that may not be possible with another human. Connecting with an animal can break down walls," added Grissim.

The human-animal bond was apparent with 6-month-old Rose Daniel who was born with biliary atresia (a congenital condition in which the bile ducts inside or outside the liver do not develop normally) that eventually required a lifesaving liver transplant. Squid was a frequent visitor during her multiple admissions.

"It is one of the things that really impacted us," said Emily, Rose's mother. "I had never been in a hospital and wasn't aware of the intricacies of the teamwork and the comfort that seeing familiar faces can bring."

"From our first admission at 2 weeks old, the brightest spot was the facility dog, Squid. I cannot explain it, but even when she was teeny tiny they would look at each other in the eyes."

"It was incredible. They were connected and in tune. We were absolutely amazed by this," recalled Daniel. "Every hospitalization Squid would come visit. For me, that's been the best part of the experience. It was pure joy when he was there with us."

At 4 months old, Rose began reaching to touch Squid's ear, which progressed to smiling at him, watching his every move and petting him.

As Rose's health declined, Daniel remembers the dark moments watching her baby grow sicker while awaiting a liver. Watching Squid stand on his hind legs to peer over the crib to see Rose brought Daniel comfort.

"I will never forget — 15 minutes after getting word that we were going to transplant, Squid came in," laughed Daniel. "I was hugging him and crying. Those are the memories I want to keep from this — it makes it easier when there are bright spots like this."

Rose received her liver on July 9. Now at home, she continues her road to recovery.

For Rose's family, Squid was a key part of the team caring for them.

"I am so grateful that this hospital places such importance on the value that a facility dog offers. I am so thankful for the incredible care we received both medically and through support staff," Daniel said. 🐾

**Squid, the Monroe Carell facility dog, brought comfort to patient Rose Daniel and her mom, Emily, during many hospital stays.**



SUBMITTED PHOTO





# Bridges of Support

**Advances in care and technology help children on the road to heart transplant**

STORY BY CHRISTINA ECHEGARAY  
ILLUSTRATION BY IKON IMAGES

Rob Fulford and Tracey Hicks — one from West Tennessee and the other from East Tennessee — probably wouldn't have ever met except for happenstance.

Both extremely sick and in heart failure at the same time, they bonded over the need for a single device that saved their lives and served as a bridge to receive heart transplants, and perhaps as a bridge to a lifelong friendship.

Rob, 15, and Tracey, 16, were the first two pediatric patients, respectively, at Monroe Carell Jr. Children's Hospital at Vanderbilt to receive an Impella 5.5 left ventricular assist device (VAD) — each receiving their device exactly one week apart in August.

The Impella 5.5 is an implantable mechanical device that supports the left ventricle of the heart and helps circulate blood throughout the body. It is designed to supplement the pumping function of a patient's heart when it's too weak to pump blood adequately on its own and to serve as bridge to heart transplantation.

An added benefit of the Impella, which can be used for up to 14 days, is that it does not require open-heart surgery. Instead, the device is inserted by catheter percutaneously, or through the skin, entering through the axillary artery (the main artery of the upper limb), to the aorta.

"The other VADs all require open-heart surgery with a sternotomy. With this device we are able to put it in with just a small graft to the axillary artery, so the incision is much smaller. This is much less invasive in how it's placed while still providing the full VAD support to the heart," said David Bearl, MD, MA, a pediatric cardiologist at Monroe Carell and medical director of the Pediatric Ventricular Assist Device Program. "With both of these young men, we were able to get them extubated fairly quickly and up and moving around in 24 hours."

## Growing the VAD program

Monroe Carell has used ventricular assist devices for about 17 years. As the VAD program has grown and evolved, the team's toolbox to provide the best heart support possible has also grown. Along with Bearl, the VAD Program is supported by Nancy Jaworski, APRN, DNP, VAD Program coordinator, and Nhue Do, MD, surgical director of the program and a pediatric heart surgeon.

The team works to evaluate patients sooner since evidence shows that VADs help improve the health of patients as a bridge to transplant. When the heart doesn't have to work as hard, other body systems have time to

recuperate, which can help improve post-transplant recovery.

Since the hospital's first pediatric ventricular assist device surgery was performed in 2005, VADs have been implanted in 52 children at Monroe Carell, with 19 of those implanted since 2020.

"As our program has matured, we've been able to think about what next technologies we might be able to bring to the hospital, especially in the setting of how it provides a unique care opportunity for the patient," Bearl said. "We're doing six to eight devices a year now, whereas it was two to three before we established the program, and every single one of those patients has made it to transplant. It is a testament not just to our work, but to the entire Pediatric Heart Institute and the support work of that team."

In the 25 years since the first pediatric heart transplant was performed at Vanderbilt, the program has become one of the highest-volume, most experienced pediatric heart transplant programs in the nation. The team follows about 150 transplant patients with continuing care at any given time. More of these patients are evaluated for VAD support as a bridge to transplant.

Currently, the VAD program employs four different VADs — Berlin Heart, PediMag/CentriMag, HeartMate 3, and most recently, the Impella.

Monroe Carell is among about 25 heart centers in the United States using the Impella in adolescents and adults with congenital heart disease. Use of the device in pediatrics is more recent. Vanderbilt University Medical Center has used the Impella in adults since 2008.

Nearly 170 people across the Pediatric Heart Institute at Monroe Carell were trained in preparation for the first implantation of the Impella. They are trained for the Impella 5.5 and CP models, which are indicated for adolescents and larger children because the patient's axillary artery must be 7 millimeters or greater.

### 'The VAD saved my life'

On Aug. 8, Rob became the first pediatric patient at Monroe Carell to receive the latest VAD. He was in heart failure, a consequence of the long-term effects of chemotherapy and radiation treatments when he was 3 years old.

The Memphis teen, who loves to play harmonica and video games, was diagnosed at age 2 with a Wilms tumor, a rare kidney cancer that primarily affects child-ren. He lost his left kidney and had aggressive treatments.

(From left) Tracey Hicks, 16, and Rob Fulford, 15, both of whom had heart failure, bonded during their hospital stay. They received heart transplants four days apart in August.

Just before his 14th birthday, he became sick and fatigued, and was diagnosed with heart failure, becoming increasingly ill over the next year. On July 29, he was admitted to Monroe Carell with fluid building in his lungs and around his heart.

"The VAD saved my life," Rob said. "It is a blessing. To have the machine is a lifesaver."

"The Impella is designed to protect his organs," said Rob's mom, Teresa Howard. "It protected his lungs — they were bad when he came here."

A week after Rob had his Impella implanted, Tracey got his device on Aug. 15.

Having already been through the procedure, Rob would walk by Tracey's room. "I am an inspirational person, so I would say to him, 'Stay strong my brother. You got this.'"

"When you're feeling down and you only have your parents, having a friend in the hospital who can relate, he knows how you feel too," Rob said.

Tracey's health decline was sudden and unexpected. What his parents believed was a cold turned out to be more serious. He went to an urgent care clinic near their home in East Tennessee. When an antibiotic for an ear infection didn't work, they took Tracey to the ER, where he was diagnosed with pneumonia and sent to Niswonger Children's Hospital in Johnson City. A matter of hours later, he was on a mechanical ventilator for breathing support and was transferred to Monroe Carell on July 25.

"It turned out he has a genetic mutation of the

### HISTORY OF VENTRICULAR ASSIST DEVICES AT MONROE CARELL JR. CHILDREN'S HOSPITAL AT VANDERBILT

In 2005, the first pediatric ventricular assist device (VAD) was placed; 52 VADs have been implanted since that time.

In 2013, the first Berlin VAD, specifically designed for infants/small children, was placed at Monroe Carell.

In 2021, Monroe Carell, for the first time, discharged a teen with a portable VAD to wait for a heart transplant at home.

The first use of the less invasive Impella VAD in pediatric patients at Monroe Carell was in August 2022.

Nearly one-third of the VADs implanted in children at Monroe Carell (19 implantations) has occurred since 2020. Of those patients, 10 were younger than 1 year of age, and five had single ventricle congenital heart disease.



ERIN O. SMITH





**The Pediatric Ventricular Assist Device team: David Bearl, MD, MA, medical director, Nancy Jaworski, APRN, DNP, program coordinator, and Nhue Do, MD, surgical director.**

RBM20 gene that caused the dilated cardiomyopathy,” said Tracey’s mom, Kimberly Courtner. “This was something we never knew he had until he got so sick.”

Dilated cardiomyopathy is a type of heart muscle disease that causes the heart ventricles to thin and stretch, making it harder for the heart to pump effectively. Medicines didn’t work to mitigate Tracey’s heart failure. His lungs continued to fill with fluid. That’s

**“We want children to be able to wait in as healthy of a state as possible for their transplant in as normal a childhood situation as possible.”**

when the team decided to put him on the VAD.

“The Impella allowed him to live and breathe well while waiting on the heart transplant without being on the ventilator. He was able to talk and get up with the Impella as well,” Courtner said.

“(The VAD) was literally the only thing keeping

me alive. The left side of my heart had basically stopped working,” Tracey said.

With the VAD, the teens walked the hallways together for physical therapy to keep them strong until transplant. They played online video games against one another from their own rooms.

Allowing a child or teen to develop as normally as possible while waiting for heart transplantation is also extremely important, notes Jaworski.

“We want children to be able to wait in as healthy of a state as possible for their transplant in as normal a childhood kind of situation as possible. We want them awake; we want them eating; we want them playing; we want them moving; we want them breathing on their own,” Jaworski said.

Rob received his heart transplant on Aug. 17, with Tracey receiving his four days later on Aug. 21.

Jaworski said Rob and Tracey exemplify the team’s goals for pediatric patients on VADs.

“Because both of these kids came in at the same time, they have become buddies. It’s awesome. Pre-transplant they actually had gotten together to play cards a couple times, and as they recovered, each one of them made a point each day to walk by the other one’s room to cheer him on or tell the other ‘good job,’” Jaworski said.

Courtner said Rob was a motivator for Tracey.

“It helped encourage Tracey to know that he had a newfound friend going through the same things that he was going through. It also encouraged him to get up and go out to check on Rob to ensure he was doing well too,” she said.

Both Rob and Tracey are on the road to recovery, and they have seen each other during follow-up visits in the clinic.

Rob has a positive outlook and pulls inspiration from quotes, including one that means a lot to him and his situation.

Quoting in part an unknown author, Rob said, “Never regret a day in your life. Good days give you happiness, and bad days give you experience.” 🦋

## Ready, set, ACTION

Monroe Carell Jr. Children’s Hospital at Vanderbilt is a member of the Advanced Cardiac Therapies Improving Outcomes Network (ACTION). There are 58 network sites across the world, according to the ACTION website.

The goal of the network is to “unite and connect the global health care community to improve outcomes for patients with heart failure.”

David Bearl, MD, MA, medical director of the Pediatric

Ventricular Assist Device (VAD) Program at Monroe Carell, says the network allows health care institutions to pool their data and evidence-based practices together to determine best therapies and treatment plans.

“When implanting only about six to eight ventricular assist devices per year, especially of different types, it can be hard to learn from those experiences and create evidence-based guidelines and treatment plans. Through AC-

TION, we can pool our resources for both research purposes as well as quality improvement projects,” Bearl said.

Prior to the recent use in pediatrics of the Impella 5.5 VAD, Bearl, along with Justin Godown, MD, medical director of pediatric cardiomyopathy, reviewed literature on the Impella from collaborations within ACTION, and specifically explored outcomes and survival rates.



Callaway Farkas, 2,  
with her mom, Carina





# SMALL MOMENTS



# IMPACTS

Junior League of Nashville celebrates 100 years of volunteerism and philanthropy to advance children's health.

STORY BY CHRISTINA ECHEGARAY  
PHOTOGRAPH BY DONN JONES

**By 10 months old,** Callaway Farkas had spent much of her life in and out of Monroe Carell Jr. Children's Hospital at Vanderbilt, with several hospital stays lasting 27 to 29 days. Her frequent hospitalizations were a result of an inborn error of metabolism known as methylmalonic acidemia. She had too much methylmalonic acid in her blood because her liver was unable to break down certain fats and protein building blocks, making her sick.

Weary and exhausted from all the pokes, tests and admissions their infant had experienced, Carina and Luke Farkas were saddened during a hospital stay in April 2021

that Callaway, affectionately known as "Calla," needed a peripherally inserted central catheter, or PICC line, to make blood draws and medication administration easier. They also would have to leave the room. It broke their hearts to not be present with Callaway during the procedure.

That's when Certified Child Life Specialist Chloe Flood stepped in. The Child Life team at the hospital works with families to promote a positive medical experience. Through therapeutic play and activities, child life specialists create a friendly environment to help children feel more comfortable, including during medical procedures.

**C**arina fondly remembers how Flood, who had worked with them during inpatient stays, pulled out her cellphone and asked, “What are Callaway’s favorite songs?” Carina rattled off the songs on her daughter’s bed-time music playlist — Ben Rec-tor’s “Extraordinary Magic” and Kacey Musgrave’s “Rainbow,” among others. Flood cre-ated a music playlist and walked back in the room to be with Callaway.

“It goes against every maternal-paternal bone in our bodies to not be with our children during some of the scariest moments of their lives. Knowing that there are people in the room with her that don’t view her as just another patient or just another task provides the smallest bit of comfort and relief when we can’t be there ourselves,” Carina said. “Knowing that Chloe cared about something small enough like that, even for a 1-year-old...the symbolic nature of that was not lost on us. Words fall short, but it was very important and meaningful.”

More than 100 years ago, a group of Nashville women set out to achieve, among many things, impact-ful moments like the Farkas family experienced with Flood. The Junior League of Nashville was formed in 1922, amid the polio epidemic that left thousands of children paralyzed. These women set out to be champi-ions of children’s health care and to help patients and families through a steadfast commitment to service and transformative philanthropy.

Much of the group’s rich legacy features the long-standing partnership with Monroe Carell, in which the two organizations have carried out a collective vision to ensure quality and compassionate health care for chil-dren. Through volunteerism and transformative gifts, the Junior League has helped shape crucial health care

initiatives and established numerous foundational pro-grams at the hospital, which includes significant sup-port for the Child Life Program.

“Starting a century ago and continuing today, the Junior League of Nashville has had a vision of what children’s health care could and should be. Time and time again, the Junior League has come together through special programs, volunteerism and philan-thropy to support the children and families in our com-munity and at Monroe Carell,” said Meg Rush, MD, MMHC, President of the hospital.

## Children’s health care — past, present and future

The Junior League of Nashville’s partnership with Vanderbilt dates to 1923, when the Junior League Home for Crippled Children opened. The “Home,” as it was referred to, provided free convalescent and reha-bilitative medical care for children with polio and other diseases. The idea of the Home was also to make it as much of a homelike atmosphere as possible.

While growing and advancing their mission through the decades, they joined efforts in the 1960s to be a part of conversations for a proposed future Mon-roe Carell. In 1971, the Home relocated to the chil-dren’s floors of Vanderbilt University Hospital.

Through the years, the Junior League’s gifts have helped support the Junior League Family Resource Center, the Child Life Program, the Neonatal Intensive Care Unit Developmental Follow-up Clinic, the Junior League Sickle Cell Disease and Asthma Program and many more programs. Previous gifts also include pro-viding capital to help build the freestanding children’s hospital that opened in 2004, and again in 2016 to help support the hospital’s Growing to New Heights Cam-paign to build the most recent four-floor expansion.

The Junior League also provided the groundwork for comprehensive maternal fetal care programming at

## 100 YEARS OF CARING

**1922**

**Cornelia Keeble Ewing and 46 other young women found the Junior League of Nashville — the 30th member of the Association of Junior Leagues of America.**

**1923**

**The Junior League Home for Crippled Children opens at Ninth Avenue and Monroe Street to help children with orthopaedic illnesses.**

**1929**

**The Junior League purchases five acres at 2400 White Avenue and breaks ground on a new building.**

**1971**

**The Junior League relocates its Home to the children’s floors of Vanderbilt Univer-sity Hospital.**

**1988**

**Junior League support of the Child Life Program’s services begins.**

**1998**

**Junior League pledges \$2 mil-lion to support new free-standing Monroe Carell Jr. Children’s Hospital at Vanderbilt.**

**2007**

**Begins support/expansion of Neonatal Intensive Care Unit Follow-Up Clinic.**

**Junior League Fetal Center formed.**

**2012**

**Junior League gifts \$1.5 million to start the Sickle Cell Disease and Asthma Program.**

**2016**

**Junior league commits \$1.5 million to Child Life Program.**

**2022**

**For 100th anniversary, Junior League gifts \$1.5 million for pediatric rehabilitation.**



Through the years, the Junior League's gifts have also provided significant funding for crucial programs like these:



The Junior League Center for Advanced Maternal Fetal Care



The Junior League Sickle Cell Disease and Asthma Program



The Junior League Family Resource Center



The NICU Developmental Follow-up Clinic



Growing to New Heights Campaign



Child Life



And many more

Vanderbilt more than a decade ago when it made a transformative gift to improve care for pregnant women and their infants. The League enabled programming to get off the ground, expand and set the foundation for what is now The Reed Family Maternal Fetal Clinic.

In June, for the Centennial celebration, the Junior League marked the milestone anniversary and partnership with another \$1.5 million commitment to the hospital. The Centennial anniversary gift, part of the Junior League's ninth supplemental agreement with Monroe Carell, will go to support the hospital's pediatric rehabilitation efforts.

"As the Junior League's partnership with Vanderbilt has evolved, what has remained steadfast is our dedication to addressing unmet needs in our community. Our centennial gift underscores this commitment," said Jenny Barker, Junior League of Nashville President (2021-2022). "In this full-circle moment, we are making a gift that looks to the future, with a focus on family-centered care, while paying tribute to the past."

This gift establishes the endowed Junior League of Nashville Directorship in Pediatric Rehabilitation for a physician, yet to be named, to lead pediatric rehabilitation initiatives at Monroe Carell. It will also be used to create an endowed fund that will help grow the pediatric rehabilitation program and related patient- and family-centered care well into the future.

Over the years, the Junior League has given nearly \$20 million, including the latest gift, and thousands of volunteer hours.

"It is fitting that for the centennial anniversary, the Junior League's latest generosity connects back to its roots in rehabilitative medical care for children by supporting pediatric rehabilitation efforts at Monroe Carell. We are tremendously grateful to the Junior League for its enduring partnership, now and for many more years to come," Rush said.

### The difference makers

Volunteer work is also an important tenet of every gift the Junior League makes to Monroe Carell. Prior to COVID-19, in-person volunteers hosted special events for patients and families and spent time with patients in the hospital playrooms and at the bedside, whether to play a board game or offer companionship.

Behind the scenes they have ensured the hospital has items for the comfort cart, which provides travel-size personal items and snacks for patients' families. During COVID-19, with public health safety measures in place, the Junior League pivoted to ensure their volunteer mission endured with efforts like playing bingo virtually with patients, putting together activity kits and delivering notes to front-line health care workers.

"It was apparent from the beginning of my child life journey that the Junior League of Nashville volunteers would be an integral part of our team at Monroe Carell," said Stephanie Van Dyke, director of Child Life and Volunteer Services. "Their support continues to be a difference maker in how we are able to provide the very best medical and psychosocial care for children, teens and their families."

Carina would agree. The League's impact is not lost on her. During each hospital stay, the Junior League's support of the Child Life Program has helped to fill their time with difference makers, not just for Callaway, but also for the entire family, down to the smallest details.

"Child life specialist Malie Jones learned that I loved doing crosswords, and she just showed up one day and handed me a *Wall Street Journal* crossword with a pen," Carina noted, adding that those personalized touches go a long way.

Callaway, now 2, had a liver transplant in June 2021. While her parents hope she has fewer hospital stays with a new liver that is better able to handle her condition, they know that the Child Life team and groups like the Junior League make a tangible difference for countless families in the hospital.

"Having programs like Child Life genuinely helps families to keep going, and that's all we want to do for our kids. I am extremely grateful," Carina said.

The Farkas family marvels at how far Callaway has come. Each morning, she greets the day with, "Bye-bye bed. Hello day!" She enjoys the small things: like the thrill of being hung upside down and being twirled around; like watering flowers at her grandparents' house or exploring the yard. Even as a toddler, she knows that small moments have big impacts.

"She's just a firecracker. She loves life," Carina said.



Photos from Junior League of Nashville through the years. The Junior League opened the Home for Crippled Children in 1923 to provide convalescent and rehabilitative medical care in a homelike environment for children with polio and other diseases. Photos from the League archives.



## faces of hope

MEET THE PEOPLE WHO BRING HOPE TO FAMILIES EVERY DAY

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

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

STORY BY JILL CLENDENING

### Andrea Hughie, MSN, RN, NEA-BC

ASSOCIATE NURSING  
OFFICER

**W**hen Andrea Hughie, MSN, RN, NEA-BC, joined Monroe Carell Jr. Children's Hospital at Vanderbilt as administrative director of nursing in 2017, she brought with her 15 years of pediatric nursing experience including pediatric critical care, case management, pediatric primary care, and various leadership roles in hospitals in her home state of New Jersey and in New York City.

She quickly put her expertise, including a Lean Six Sigma Black Belt Certification, to use as she worked with Case Management and the Behavioral Health Patient Safety Team to identify and implement process improvements to deliver better patient care.

Hughie helped standardize the work of the Case Management team to ensure every patient had everything required to transition safely home or to another facility for additional therapy or rehabilitation when discharged.

She worked with Behavioral Health to create the Patient Safety Team to more effectively provide one-on-one observation for children with psychiatric needs.

Hughie also worked hard to ensure children on public insurance or who are uninsured with psychiatric needs get connected to needed services in a timely manner.

As a result of that work, in the summer of 2022, three members of the Tennessee State Mobile Crisis Program began working from the Monroe Carell Emergency Department to more effectively assess children experiencing a mental health crisis.

"I enjoy the advocacy part of my role," Hughie said. "I have a passion for populations that don't have a lot of representation or who are underserved. There's a national crisis with kids with psychiatric needs, and I love being able to impact that."

Hughie became a new mother in 2020, while isolated from family and friends due to the pandemic. Her son, Jacob, was born prematurely and spent five weeks in the Neonatal Intensive Care Unit at Monroe Carell. Jacob was diagnosed with a chromosomal abnormality, and he receives therapy and other services both at the hospital and through outside resources.

She and her partner, Jason Hall, gained hard-earned but invaluable insight as they experienced the care of a hospitalized child from a parent's perspective.

Seeing how advocacy was



critical as she sought services for her son, Hughie is energized by recent appointments that will allow her to be a public advocate for children throughout Tennessee.

Hughie was appointed to a task force working with the Metropolitan Nashville Juvenile Justice System to better serve children going through the courts who have psychiatric needs. Hughie was also tapped to serve on the board of the Tennessee Early Intervention System, a program that provides services to infants and young children with disabilities or other developmental delays.

"That's direct community impact," Hughie said. "Care doesn't



**"There's a national crisis with kids with psychiatric needs, and I love being able to impact that."**

— ANDREA HUGHIE



## faces of hope

MEET THE PEOPLE WHO BRING HOPE TO FAMILIES EVERY DAY



**“We’ve spent a lot of time helping families and clinicians realize that we’re not just end-of-life care.”**

— TRACY HILLS, DO

just happen within our four walls. It’s an honor to be able to represent Vanderbilt and extend our impact outside the clinical space.”

### Tracy Hills, DO

ASSISTANT PROFESSOR  
OF CLINICAL PEDIATRICS/  
HOSPITAL MEDICINE  
SECTION HEAD, PEDIATRIC  
PALLIATIVE CARE

**T**racy Hills, DO, assistant professor of Clinical Pediatrics and director of Pediatric Palliative Care at Monroe Carell Jr. Children’s Hospital at Vanderbilt, cites an American Academy of Pediatrics quote that sums up palliative care: “The goal is to add life to the child’s years, not simply add years to the child’s life.”

When she and her team meet

a young patient experiencing a serious illness, they discuss and plan for physical, psychological, social and spiritual needs, and they incorporate the patient’s and family’s wishes to guide the decision-making process as much as possible. Because of this, one of the hardest situations a family can experience can also become a time of empowerment and understanding.

When Hills came to Monroe Carell in 2016, she and a nurse practitioner provided palliative care services. Now the interdisciplinary team has expanded to include a second physician, a nurse coordinator and a social worker. Their patients range from unborn children with serious or life-limiting diagnoses (the team meets with families at the Reed Family Maternal Fetal Clinic at Vanderbilt) to young adults with complex medical conditions.

“We’ve spent a lot of time helping families and clinicians realize that we’re not just end-of-life care,” Hills said. “Palliative care includes so many other things, such

as understanding the patient’s and family’s goals, improving quality of life, pain management and symptom management. We see patients with many different medical conditions, and we’ve established relationships with clinical groups throughout the hospital. Each year we’ve been able to do more.”

During high school in Portland, Oregon, Hills volunteered at a Ronald McDonald House, where families with seriously ill children can stay near the hospital. There she witnessed how a child’s illness impacts the entire family, and, for the first time, she interacted with children who died from their illnesses.

Hills also connects her career path with the year she turned 25. Her mother was diagnosed with lung cancer, and she died just a year later.

“I remember as she got sicker, we had to ask, ‘Should we get hospice involved now?’ Her providers didn’t bring up palliative care or hospice. We were fortunate that we were able to keep her at home and respect her wishes. I’m so grateful for that and to the hospice team that took care of her.”

Hills is keenly aware of the long-term needs of grieving families, and one of her team’s goals is to establish hospital-based grief support for families, with a pilot group that began in the summer.

“For many families — especially those whose children have long-term illnesses — the hospital becomes their second home,” she said. “When they lose their child, family members have shared that they also feel like they’ve lost their second family. They really want grief support that is affiliated with the hospital.” 🦋

SUSAN URBAN



## personal perspective

FIRST-PERSON ESSAY



# From the Heart

*Longtime volunteer reflects on passion for giving back*

STORY BY FRAN HARDCASTLE  
PHOTOGRAPH BY JOE HOWELL

**S**omeone once told me that you have to learn to volunteer from your heart, not just in your head. You can't just talk about it. You have to feel it and have a desire to make an impact.

Over the years, it has been a joy to volunteer for Monroe Carell Jr. Children's Hospital at Vanderbilt in many different ways.

I still can remember my first volunteer role. It was selling papers on Palm Sunday to raise money for the Junior League Home for Crippled Children, a home for children recovering from polio and other diseases. The papers told stories of the children served throughout Middle Tennessee who were cared for at the home.

The paper sale was something I grew up doing. I remember going door to door in neighborhoods all across the area trying to hit every door before families had gone to church. Most people wanted to give because everyone had some kind of connection with someone who'd been treated at the home.

In 1923, the founding Junior League members convinced the Standard Oil Company to let them use a house at Ninth Avenue and Monroe Street — rent-free of course. Doctors donated their services, the Junior League women provided everything else, and the Junior League Home for Crippled Children was born.

As I got older, I started to volunteer with the home more. I helped with lunches, organizing volunteers for transport, reading to children and bringing them outside to play. My involvement only progressed from there. We worked with the medical community at every level to ensure that not only were we providing the best possible clinical care, but that we also addressed all the unique aspects of supporting ill children and their families. This often meant providing insight into areas of day-to-day care that had tremendous impact. The women of the Junior League built a reputation as trusted advisers in this unprecedented endeavor at a time when that was exceptionally uncommon.

It was always very rewarding to feel the difference you could make with your presence and your support.

We tried to create as much of a home-like atmosphere as possible for these sick children who needed us. Everything we did was done with love and care. We didn't know then that the home would go on to become a hospital and eventually evolve into what is known today as our beloved Monroe Carell Jr. Children's Hospital at Vanderbilt.

I was serving as treasurer of the Junior League when the home moved into the children's hospital-within-a-hospital at Vanderbilt. I attended every meeting where the voices of parents and volunteers were heard. It always felt like we were making a real difference in those meetings. That's where we fought for sleeper chairs for parents and telephones in the rooms for them to talk to other family members. We were there to be the voice of the children and their families. That is when I saw the true impact volunteers could have.

Over the years, it has been an honor to give back to help children at Monroe Carell through the Junior League of Nashville, Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt, Iroquois Steeplechase and Canby Robinson Society. These organizations do such great work to give back.

I'm thankful that the passion for giving was instilled in me at such a young age. I always believe the younger the better when it comes to introducing volunteering. That passion can be fostered throughout a lifetime, and the impact can be felt for years and years.







## Getting Patients Like Jordan Back in the Game

When Jordan Johnson was struck by a ball during his baseball game, he was taken to Monroe Carell Jr. Children's Hospital at Vanderbilt to make sure everything was OK. While there, doctors discovered that he had an abnormality of blood vessels inside his brain stem. The lesion had most likely been there since birth, growing over time.

Jordan underwent an eight-hour brain surgery a few weeks later. After recovering in the hospital, he was ready for the next step of his healing journey — rehabilitation. Now a year out from surgery, Jordan is home and working to improve each day. His next goals are to walk on his own and play sports again.



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

*Photo by Susan Urmey*

# HOPE

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