

HOPE

CHILDRENSHOSPITALVANDERBILT.ORG




GROWING PAINS

Autoimmune diseases don't have to sideline youth



SUMMER/FALL 2021



Chloe Lainhart, a
child life specialist,
plays with Gabrielle
Meacham, 4, a patient
at Monroe Carell Jr.
Children's Hospital at
Vanderbilt.

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SUMMER/FALL 2021



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HOPE



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The Children's Hospital 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 Children's Hospital. Learn more at VanderbiltHealth.org/advisoryboards.

Mission Moment



As children age, they achieve developmental milestones. As a children's health care system, we are not really any different and are always striving to achieve new milestones. Together, we celebrate some of these with you.

For the 15th consecutive year, we have ranked in 10 out of 10 specialties by *U.S. News and World Report*; we are the only children's hospital in Tennessee to attain this goal and one of only 22 children's hospitals to do so nationally. And for the first time, we achieved a new designation as the No. 1 children's hospital in Tennessee and in the entire Southeast.

Also, this spring, we opened our third cardiac catheterization room with state-of-the-art monitoring and imaging capabilities — and it is busy. This year, our Child Life program celebrates 50 years of supporting children and families, improving health outcomes along the way. And, as you will see, *HOPE* magazine has a new design as we move into a second decade of sharing our stories with you. None of these achievements would be possible without the incredible collaborative spirit and efforts of our faculty, staff and trainees over many decades.

In this revamped edition, you will still see great features, including a story introducing you to our Family Advisory Council, a committed group of parents and caregivers who make us a better place because of their wisdom. We also highlight our complexity of care through stories of surgical innovation and statewide care for children with rheumatological diseases. And we share the breadth of our programs in our new Spotlight on specialized care, Q&A with program leaders, and a personal essay from patients or families.

In a year-plus of unprecedented challenges, one thing has remained unwavering: our commitment to give hope as we enhance the health and well-being of the children and families we serve through our innovation, education and discovery.

We want to thank you, our community and partners, for your ever-present support of the care of our patients and families as well as the advancement of our missions. We hope you enjoy our new look!

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
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to find out how you can make
a difference.



good to know

NEWS FROM CHILDREN'S HOSPITAL AT VANDERBILT



Seacrest Studio at Monroe Carell Jr. Children's Hospital at Vanderbilt recently celebrated five years of providing programming for pediatric patients. Opened in 2016, the studio marked the 10th broadcast media center the Ryan Seacrest Foundation has opened inside a pediatric hospital. The studio enables patients to explore the creative realms of radio, television and new media that can aid in the healing process for children and families during a visit to or stay in the hospital. Seacrest Studio at Children's Hospital has had many special visitors over five years, including longtime friends and supporters, the Nashville Predators hockey team (shown above). 🦋



Pediatric liver transplant program receives top honors



Monroe Carell Jr. Children's Hospital at Vanderbilt's pediatric liver transplant program was recently named among the nation's best programs by the Scientific Registry of Transplant Recipients.

Named one of five programs with a superior rating for patient survival during a two-and-a-half-year period, the recognition also highlights the program's 100% patient and graft survival rate.

"We knew we were performing well," said program chief Sophoclis Alexopoulos, MD. "Receiving verification through this report is a great indicator that we are moving in the direction we want. We are proud of our progress."

The program was also listed as the eighth busiest deceased donor pediatric liver transplant program and the 12th busiest total pediatric liver transplant program in the nation. 🦋

Personalized Care

Teen cancer lounge at Monroe Carell Jr. Children's Hospital at Vanderbilt unveiled

Monroe Carell Jr. Children's Hospital at Vanderbilt and Teen Cancer America recently announced the completion of a new state-of-the-art lounge to serve the unique needs of adolescent and young adult (AYA) cancer patients.

Together, Kylie Jenner and Teen Cancer America made a \$550,000 gift to build the new lounge space, located on the sixth floor of Children's Hospital. The gift was made in honor of Harry Hudson, singer-songwriter and cancer survivor who was successfully treated for stage 3 Hodgkin lymphoma after being diagnosed in 2013 at age 20. Jenner, CEO/Founder of Kylie Cosmetics and Kylie Skin, has been a longtime friend to Hudson.

In September 2017, Jenner announced that she would celebrate her birthday by raising funds for Teen Cancer America with Hudson. Through the sales of her Kylie Cosmetics Birthday Collection, she raised funds to help improve the lives of teens and young adults with cancer.

The new lounge, designed with input from a focus group made up of Children's Hospital AYA patients, is outfitted with their specific needs and interests in mind. The main sitting area of-

fers electronic equipment (video games, big screen television), a selection of movies and streaming capabilities for favorite television shows, a Wi-Fi connection, and space to interact with peers, which is critically important for the AYA population. Off the main area, there is also a meditation room.

Hudson visited Children's Hospital twice in 2018 and then virtually visited on March 25 to meet with teen cancer patients and tour the newly completed teen cancer lounge.

"I am so grateful for Kylie's friendship and the impact she's had on my life and my cancer journey," said Hudson. "She has always been there for me, and together, we wanted to figure out a way to be there for other young people who are battling this disease. With the help of Teen Cancer America, we were able to contribute the first Hey, I'm Here For You Teen Lounge at Children's Hospital at Vanderbilt — a comfortable space for young people

undergoing treatment to pursue their passions."

Adolescent and young adult cancer patients often have unique needs as they navigate their cancer treatments and long-term impacts after remission.

"The emotional and social support is critical to help them cope through their cancer journey," said Scott Borinstein, MD, PhD, director of the Adolescent and Young Adult Oncology Program and Scott and Tracie Hamilton Professor of Cancer Survivorship. "When they are in the cancer clinic or in the hospital, they crave camaraderie and want to interact with individuals their age so they can talk about their experiences. Our partnership with Teen Cancer America allows us to create a distinctive space for our AYA cancer patients — a place where they can be separate from our younger patients — an area of the hospital all their own, and an environment specially tailored to their wants and needs." 🦋



DOAN JONES

15

For 15 consecutive years, Monroe Carell Jr. Children's Hospital at Vanderbilt has been recognized as a top pediatric facility in the annual *U.S. News & World Report* Best Children's Hospitals rankings. Children's Hospital has ranked every year since the pediatrics rankings' inception in 2007. In the 2021-2022 rankings, Children's Hospital was named the No. 1 children's hospital in Tennessee and in the Southeast. The hospital also achieved a maximum 10 out of 10 nationally ranked pediatric specialty programs. Only 22 pediatric facilities attained this achievement for the 2021-2022 report. 🦋



Patient Eddie Axelson, 9, and mom, Tanya, (left) with nurse Kim Bettis, RN

A first: patient receives new investigational gene editing therapy



A 9-year-old patient of Monroe Carell Jr. Children's Hospital at Vanderbilt is the first in the world to receive an investigational gene editing therapy for Methylmalonic Acidemia (MMA), a rare genetic disorder diagnosed at birth.

On May 29, Eddie Axelson, of Clarksville, Tennessee, received LogicBio Therapeutics' investigational single-administration targeted gene editing therapy, hLB-001, which seeks to correct MMA, an inborn metabolism disorder in which the body cannot properly process protein from food.

Axelson received the dose of hLB-001, administered via IV infusion, as part of LogicBio's SUNRISE multicenter clinical trial. The study will assess the safety, tolerability and effectiveness of this potential gene editing therapy for MMA.

The investigational gene therapy, created by LogicBio Therapeutics, also marks the first-ever such genetic therapy administered for a biochemical disorder at Chil-

dren's Hospital and Vanderbilt University Medical Center.

"This is a gene editing trial in which we use a harmless virus to transport the missing gene into liver cells, so that the liver cells will start producing the deficient enzyme to correct the defect in body chemistry," said Thomas Morgan, MD, associate professor of Pediatrics and Genetics and lead principal investigator for the study at Vanderbilt.

People with MMA have too much methylmalonic acid in their blood because their livers can't break down certain fats and protein building blocks, specifically four amino acids known by the acronym VOMIT (valine, odd chain fatty acids, methionine, isoleucine and threonine).

Currently, the only treatment is to restrict protein in a patient's diet and to provide a special formula without the four amino acids.

"While the current treatment is usually adequate, it's not good

enough to keep kids from getting sick or potentially needing a liver transplant or a combined kidney and liver transplant later in life," Morgan said. "If this works, it could alter the DNA in the liver so that it fixes the problem for the rest of the patient's life, potentially sparing them the need for a transplant in the future."

The hLB-001 gene editing therapy is designed to use an engineered adeno-associated virus to precisely deliver a working copy of the mutase gene to the patient's hepatocytes and integrate it right next to another gene called albumin, the most highly active gene in the liver. In this way, albumin drives the production of the mutase enzyme, with the goal of replacing enough mutase activity to improve the patient's metabolic status.

MMA is diagnosed at birth through the state's newborn screening — a simple heel stick blood sample used to check for numerous diseases. 🦋

Fundraising fun

DANCE MARATHON RINGS UP FUNDS FOR CHILDREN'S HOSPITAL

With many special events around the country suspended over the past year due to COVID-19, students across Middle Tennessee did not let that stop them from helping patients at Monroe Carell Jr. Children's Hospital at Vanderbilt. Recently, students from 12 colleges and high schools across the area teamed up to host one collective virtual dance marathon event, called "Marathon of Marathons."

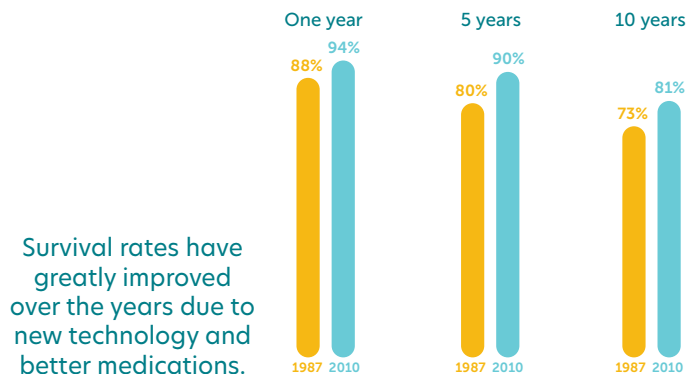
Historically, participating schools have hosted in-person dance marathon events to raise funds and awareness for Children's Hospital. As the culmination of a year of fundraising, the event typically includes a special dance, games and inspirational stories from patient families and hospital leadership.

During the 13-hour Marathon of Marathons, each school had one hour to highlight their individual dance marathon program.

The event concluded with the fundraising total reveal — more than \$300,000. Collectively, dance marathons have raised more than \$3 million for Children's Hospital over the years to fund vital programs at the hospital from discovery research grants, to fellowships in the neonatal intensive care unit to cancer research and capital projects. 🦋

LEADERS IN PEDIATRIC HEART TRANSPLANTS

Monroe Carell Jr. Children's Hospital at Vanderbilt is one of the original pediatric heart transplant programs in the country, and after 30 years, the program is among the top four largest and busiest programs in the United States. For 2019 and 2020, the program experienced back-to-back record years for the number of heart transplants performed. A multidisciplinary team approach, cutting-edge technology and better-than-expected survival outcomes have been key factors in the program's successes.



2005

The first pediatric ventricular assist device (VAD) was performed. VADs have been implanted in 43 patients since that time.

2013

The first Berlin VAD, specifically designed for small children, was placed. To date, there have been 15 Berlins placed.

2013

The first ABO-incompatible heart transplant was performed. There have been 17 transplants in infants since the program began.

Currently, the program has 94 recipients who are greater than 10 years post-transplant and 34 patients who are more than 18 years post-transplant.



94

GREATER THAN
10 YEARS



34

MORE THAN
18 YEARS



The program has **three transplant cardiologists, two nurse practitioners, two nurse coordinators** and has extended the criteria for heart transplant candidates treated at Children's Hospital to include complex and higher-risk groups with stable survival rates.

Addressing psychosocial needs of cardiac patients' families

Ellen and Bo Boyer's first child, a daughter they named Brett, was diagnosed with a congenital heart defect (CHD) while in utero. The couple was told that their beloved daughter would require open heart surgery to survive.

For most, an atrioventricular septal defect is repairable 97% of the time.

For Ellen Boyer, the thought of Brett being in the 3% never crossed her mind.

Despite attempts from the medical team to check on the well-being of the parents after the surgery, the Boyers' sole focus was their daughter.

"We were not expecting for surgery not to go our way," said Ellen Boyer. "I was blindsided and had not let myself go there. When it happened, and people wanted to talk to us, we were not open to it.

"The wheels have been turning ever since," admitted Boyer. "We knew that something was missing in the overall treatment of CHD."

The Boyers hope they have found the missing piece of the treatment plan for families along their cardiovascular journey and that other pediatric hospitals follow suit.

The Brett Boyer Foundation recently made a gift in Brett's memory to support the hiring of a psychologist in the Department of Pediatrics aimed at supporting the Pediatric Heart and Vascular Institute at Monroe Carell Jr. Children's Hospital at Vanderbilt.

"While the team can heal children's hearts, there was still an emotional and mental component that needed to be addressed. We figured that if a rapport with a psychosocial expert was estab-

lished on the front end, perhaps more families would be open to talking about their experiences. It's important to have an expert, someone trained, to provide tools to manage a family's emotions," Boyer said.

In preparation for designating funds to assist with creating this new position, the Boyers asked other CHD parents for input. The responses flooded in with an overwhelming call for emotional support. It was the confirmation the Boyers needed to proceed with their plans.

Discussions with Scott Baldwin, MD, chief of the Thomas P. Graham Jr. Division of Cardiology, have been ongoing for more than a year. While the COVID-19 pandemic slowed down progress, it also heightened the need for psychosocial support of families dealing with serious medical issues.

An estimated 40,000 children are born with CHD in the United States annually.

At Children's Hospital, the teams perform about 475 cardiac surgeries each year. The clinic sees 17,000 outpatient visits a year.

For many cases of CHD, diagnosis of the defect is found in utero. All cases differ, and some require multiple surgeries over a period of time.

"Parents and families of children with congenital heart disease can experience profound stress from the time of diagnosis, through hospitalizations, surgeries, and for years to follow, impacting the child's development and the health of the entire family," said David Bichell, MD, chief of Pediatric Cardiac Surgery. "Recognizing the special emotional toll that heart problems bring to a family, the far-reaching emotional trauma of hospitalizations, and the unfilled need for professional mental health support for congenital heart families, the Boyers have stepped in as a force for positive change." 🦋

Pediatric COVID-19 vaccine trial underway

Monroe Carell Jr. Children's Hospital at Vanderbilt is part of a phase 2/3 clinical trial to study the safety and efficacy of the Moderna COVID-19 vaccine in children.

Researchers in the Vanderbilt Vaccine Research Program enrolled at least 100 healthy children, ages 6 months to 11 years, over the course of one to two months. The trials will follow an age de-escalation, dose escalation approach, where small doses of the vaccine are evaluated in older children first, followed by younger children. This allows the researchers to decide the best dose to use in different age groups. In this case, the study will first look at children 6 to 11 years old; then 2- to 5-year-olds; and finally, ages 6 months to up to 2 years.

"If our children are going to be in school, and grandparents are going to enjoy extended visits with grandchildren, we may have to vaccinate our children. Therefore, we need to evaluate the vaccine in children in order to optimize the use of COVID-19 vaccines," said C. Buddy Creech, MD, MPH, director of the Vanderbilt Vaccine Research Program and associate professor of Pediatric Infectious Diseases.

Creech said age de-escalation is used to ensure the appropriate vaccine dose and effectiveness for each age group, especially since immune system behavior varies among different ages. 🦋



Bo and Ellen Boyer with their daughter, Brett

JUNE STAR PHOTOGRAPHY

New cardiac cath lab opens at Children's Hospital



A new, state-of-the-art cardiac catheterization lab debuted in April at Monroe Carell Jr. Children's Hospital at Vanderbilt to meet the Pediatric Heart Institute's growing volumes.

As the ninth busiest pediatric cardiac surgical program in the country, the expansion includes hybrid cath lab capabilities to allow for collaboration between cardiac surgeons and interventional cardiologists in the cardiovascular procedural suite, which combines all the features of a traditional cardiac surgery operating room with those of a cath lab.

For years, the care team has worked in a space that served both the cath lab and electrophysiology lab. Currently, the cath lab performs about 800 cases annually. The previous space saw a combined caseload of 1,200. The program is on pace to exceed those numbers in 2021.

The expansion brings the number of rooms to three and houses a 10-bed holding and recovery area, with increased staffing.

The space also incorporates video link technology to enable the cardiac ICU and ECHO Lab teams to have direct contact with the cath lab to discuss patient findings. This real-time communication enables a seamless handoff following procedures.

The cath lab diagnoses and treats pediatric and adult patients living with congenital heart disease. 🦋

Tinsley Bellar



ERIN O. SMITH

On the move

CLINIC HELPS CHILDREN WITH CEREBRAL PALSY REGAIN MOBILITY

Seven-year-old Tinsley Bellar loves to dance — her mother describes it as TikTok dancing with cheerleader moves. She also loves to run, completing her school's fun run last year.

But only three years ago, a walk across her living room using her walker warranted a celebration.

Tinsley, who has cerebral palsy (CP), had a three-hour surgical procedure called selective dorsal rhizotomy in 2018 at Monroe Carell Jr. Children's Hospital at Vanderbilt to treat muscle spasticity. Two months after the procedure and daily physical therapy, she ditched her walker. "It completely changed everything," said her mother, Melissa Grove.

CP is the most common motor disability in childhood, ac-

cording to the Centers for Disease Control and Prevention. Caused by abnormal brain development or damage to the developing brain, it impacts a person's ability to move, maintain balance and posture and control muscles.

Children's Hospital is home to the state's only multidisciplinary clinic for children with CP. It's also the only place in the state to offer selective dorsal rhizotomy for children with spastic CP, the most common type (about 80%) of the disability.

People with spastic CP have increased muscle tone — stiff muscles — and as a result, their movements can be more difficult. Symptoms vary from person to person, ranging from mild (walking with some difficulty) to more severe (requiring special equipment to walk or not being able to walk at all).

Tinsley fell into the moderately severe category. Her surgery was performed by Robert Naftel, MD, associate professor of Neurological Surgery. During the procedure, performed under general anesthesia, a 1½ – 2-inch incision is made over the lower spinal cord, and nerves are separated and identified by electrical stimulation. Certain sensory nerve fibers in the spine — the ones that lead to too much muscle tone (spasticity) — are cut.

Following the surgery, patients experience some tingling and weakness in their legs and aren't able to walk right away. It takes months of intensive daily physical therapy to obtain the desired result.

But Naftel said the biggest predictor of success with the surgery is picking the right patient. "We can't make every child walk perfectly normally, but we can make them walk more efficiently, with better endurance and with a less assistive device." 🦋

conversations

INTERVIEW WITH BUDDY CREECH, MD, MPH



C. Buddy Creech, MD, MPH, is professor of Pediatrics in the Division of Pediatric Infectious Diseases, director of the Vanderbilt Vaccine Research Program and holder of the Edie Carell Johnson Chair in Pediatrics.



Q What prepared Vanderbilt University Medical Center and Monroe Carell Jr. Children's Hospital at Vanderbilt infectious disease teams for the COVID-19 pandemic?

A What prepared us? Decades of investment in basic science discovery, vaccinology, immunology, molecular diagnostics, infection prevention, epidemiology and implementation science. Without this type of vision, Vanderbilt would not have been prepared to lead the way we have for the last year.

Pandemic preparation begins well before the first case of disease. For over three decades, the (Mark) Denison Laboratory has been studying the fundamental aspects of coronaviruses in the laboratory. This commitment to basic discovery fueled development of therapeutics (like remdesivir and other antiviral drugs) and provided resources by which to measure the immune response to infection and vaccination. Once the first cases of COVID-19 were seen, we had to identify the best ways to prevent infection and launch a robust testing strategy.

Our infection prevention colleagues worked tirelessly to protect our health care workers and limit the hospital spread of SARS-CoV-2. Our colleagues in the Molecular Infectious Diseases

Laboratory were committed to providing reliable results as quickly as possible — this was essential for not only our patients, but also our providers who were frequently exposed to SARS-CoV-2 and needed a way to evaluate potential COVID-19 symptoms quickly. Once our hospital began to fill with COVID-19 patients, we needed to standardize the way we cared for patients. Our infectious diseases, ICU and hospitalist colleagues took the lead and provided excellent care, sharing best practices, codifying treatment approaches and leading clinical trials. Then, in summer 2020, as vaccine trials launched, VUMC was uniquely positioned to conduct these pivotal studies, conducting numerous trials of vaccines now available under EUA, by leveraging robust clinical research units such as the Vaccine and Treatment Evaluation Unit in the Vanderbilt Vaccine Research Program and the HIV Vaccine Trials Network. Our news and communications team has also played a unique role to help our teams communicate new and vital information about disease activity and vaccines to the public.

Q What are some of the key studies you've been involved in with the COVID-19 pandemic?

A Our group has been principally involved in three areas. Early in the pandemic, we led trials of the antiviral drug, remdesivir, as well as an immune modifying drug, baricitinib, in hospitalized patients. Then, in summer 2020, we launched the Moderna phase 3 vaccine trial, followed by the Johnson & Johnson phase 3 vaccine trial. We recently completed enrollment for a study evaluating a new variant vaccine, made by Moderna, that targets the Beta variant of SARS-

CoV-2, and are actively recruiting children younger than 12 years in a Moderna vaccine trial. Finally, we are actively engaged with the CDC, in a project led by Dr. Kathryn Edwards, to evaluate the safety of vaccines in various populations, recognizing that rare side effects can occur.

Q What have we learned about how COVID-19 impacts children?

A Fortunately, the direct, viral effects of the virus on children have been less than adults; however, we have seen more COVID-19-related deaths this year than we would expect from other viral illnesses, such as influenza. We have seen recent increases in the number of children infected with the Delta variant, and we see some children who develop an inflammatory condition after exposure to COVID, called MIS-C. While the direct impact has been less than in older adults, it is still a virus we want our children to avoid.

Q What advice would you give parents considering vaccination for their adolescent children?

A I would encourage vaccination. Have a conversation with your teenager. Let them know the importance of protecting themselves and those around them. We are social creatures, and we've seen the devastating effects of social isolation on adolescents this year. The side effect profiles of each of the vaccines authorized for emergency use are encouraging, and the significant side effects that have been seen are, importantly, very rare — so rare that an individual is more likely to be struck by lightning than to experience a severe side effect of vaccination. 🦋



A year ago, Jordan Johnson, pictured second from left, underwent a complex eight-hour brain surgery. Today, he reflects with his parents, Ivette and Jeff, and his older brother, Jalen, on how far he's come.

BACK IN THE GAME

After brain surgery, Jordan Johnson is learning to walk and play sports again.

STORY BY PAIGE TURNER
PHOTOGRAPH BY SUSAN URMY

When 15-year-old Jordan Johnson was struck by a ball during his baseball game in June 2020, he never imagined the hit would end up saving his life. After the injury, Jordan's parents, Jeff and Ivette, took him to Monroe Carell Jr. Children's Hospital at Vanderbilt to make sure everything was OK. They were shocked when a scan revealed that Jordan had a giant cerebral cavernous malformation, an abnormality of blood vessels inside his brain stem. The lesion had likely been there since birth, gradually growing over time. By the time Jordan suffered the hit, the lesion had reached a critical size. The options were to continue to let it grow, with the possibility of life-threatening rupture, or to remove it with a high-risk surgery.

Immediately, the Johnsons began exploring the best programs in the country. After much research and prayer, they decided that the neurosurgery team at Children's Hospital, led by Jay Wellons III, MD, MSPH, was the right choice.

The Johnsons scheduled the procedure for July 21, 2020, as "21" is the number Jordan wears on his baseball uniform.

"We were just a typical family with a typical life," said Jordan's dad, Jeff. "Our lives consisted of travel ball, school band performances and family vacations to

spotlight

NEUROSURGERY

Disney World. We would never have believed that our son would ever have to have brain surgery.”

After spending two weeks recovering in the hospital following the eight-hour surgery, Jordan began his journey to rehabilitation. He would have to relearn everything, from how to eat to how to walk. Because the lesion was inside the brain stem, a major concern was Jordan’s ability to move and communicate. His parents say their biggest questions were, “Are we going to get our Jordan back? The Jordan he was before surgery?”

Because Tennessee does not have a pediatric inpatient rehabilitation facility, many young patients must travel out of state for this critical service. Due to Jordan’s age and size, fortunately, he was eligible to stay at Vanderbilt Stallworth Rehabilitation Hospital for adults.

Throughout the healing process, Jordan grew especially close to his surgeon, Wellons.

“Jordan is an inspiring young man,” said Wellons, chief of the Division of Pediatric Neurosurgery. “He has handled a very challenging diagnosis and recovery with grit and determination. His parents and his older brother, Jalen, have been incredible advocates for him during every aspect of his care. When the opportunity came for my own son, Jack, to meet him, I jumped on it. To no surprise at all, Jordan had a profound impact on him too.”

Wellons’ connection with and commitment to care for patients like Jordan has not gone unnoticed. For his work, Wellons was awarded the inaugural Cal Turner Chair in Pediatric Neurosurgery in 2020. The new endowed chair was generously funded by Cal Turner Jr. and his late wife, Margaret, who together with their family have long been committed to the mission of Children’s Hospital.

“The gift from Cal Turner Jr. and Margaret supporting Pediatric Neurosurgery is but one example of the generosity of the Turner family improving lives. Dr. Wellons’ expertise and human touch are shining examples of our mission to personalize health care, and it’s fitting that he is the inaugural holder of this chair. It’s a phenomenal recognition of his impact on his patients and their families,” said Jeff Balser, MD, PhD, President and Chief Executive Officer for VUMC and Dean of Vanderbilt University School of Medicine.

In addition to the new endowed chair, the Turner and Dugas family, including Judy

and Steve Turner and Laura Jo Dugas and the late Wayne Dugas, supports a variety of programs and expansions at Children’s Hospital, such as the telemedicine initiative that connects care to children in rural communities.

And while the Turners have a longstanding connection with the Medical Center, they also have a deep-rooted relationship with Wellons.

Cal Turner Jr. and Margaret were close friends of Wellons’ late parents, and the families have many fond memories together. When Wellons moved to Nashville, he reconnected with Turner, and he says it has been a joy to build that relationship.

“What a gift it has been for me to have Cal and these wonderful stories of my parents and our families’ history together. I miss them both very much, and so many times I’ve wanted to ask their opinion or tell them a story about my own journey,” said Wellons. “This bond with Cal has been such an important relationship to me. He has a great deal of wisdom, and I am definitely in need of that! Being awarded the chair was such a wonderful surprise, as I cannot imagine a more meaningful name to my family.”

The opportunity to reconnect has been equally significant to Turner.

“I am so honored to have a small part in the medical ministry of Dr. Jay Wellons. He embodies everything that a great physician should be,” said Turner. “Our family always identified Nashville as our city and Vanderbilt as our medical center, and they always served us well. It is a great privilege to give back to an institution that has blessed us and will continue to bless others in the future.”

This new gift will help Children’s Hospital continue to serve as a hub for excellence in diagnosis and treatment for children like Jordan.

Now a year out from surgery, Jordan is home and receiving outpatient physical ther-



“This bond with Cal has been such an important relationship to me. He has a great deal of wisdom, and I am definitely in need of that!”

– JAY WELLONS



Jay Wellons III, MD, MSPH

apy. He is rating a 37 out of 56 on the Berg Balance Scale, a clinical test for balance, a vast improvement from his post-surgery rating of nine.

“I think I’m doing great because after surgery, I couldn’t even brush my teeth, and now, I can solve my Rubik’s cube,” said Jordan. “My goal is to walk on my own and play sports again, and I know that with hard work, I can do anything.”

Today, Jordan loves playing the saxophone and hanging out with his friends. Together with his family, he even shares his story to raise funds and awareness for rehabilitation efforts at Children’s Hospital.

“We are so thankful that we had this world-class hospital and surgeon right in our backyard,” said Jordan’s mom, Ivette. “Because of that, we have our Jordan back. We were recently able to celebrate his 16th birthday, and we’ll get to watch him graduate, go to college and be whatever he wants to be.”

Always reaching for the next milestone, Children’s Hospital is looking to expand rehabilitation services for children in the region. Offering inpatient rehabilitation closer to home with access to the services at Children’s Hospital would improve long-term outcomes for patients. 🦋

Visit ChildrensHospitalVanderbilt.org/give to make a difference for more patients like Jordan.

GROWING PAINS

Pediatric rheumatology division treats youth
sidelined by autoimmune diseases.

STORY BY **NANCY HUMPHREY**
PHOTOGRAPH BY **DONN JONES**

NYLA WRIGHT wants to live the carefree life of a 16-year-old. Her family and close-knit group of friends want that for her too. But Nyla, who has suffered from the chronic autoimmune disease lupus since she was 9, has days where she hurts so badly, she can't get out of bed, wash or dress herself.

On those days "my pain is a 10," she says. "It's terrible. I'll be having a normal day, and the next day my friends are like, 'where's Nyla?' And I'll be gone for two weeks, three weeks," she said.

When she has a flare (an unpredictable eruption of the disease), "she hurts all over," says her mom, Sarha. "Her body hurts. Her throat hurts. She can't swallow. It's like her body goes into attack. That's the way she explains it to us."

And that's exactly what's happening.

Systemic lupus erythematosus (commonly known as lupus) is a disease that causes the body's immune system to attack its own cells and tissues. It results in episodes of inflammation to various parts of the body and can af-

fect the joints, tendons and skin. It can cause rashes, fatigue, pain and fever, and also affect blood vessels and organs such as the kidneys, heart, lungs and brain.

Nyla, who lives in Meridianville, Alabama, a suburb of Huntsville, is one of hundreds of children and teens treated by the Division of Pediatric Rheumatology at Monroe Carell Jr. Children's Hospital at Vanderbilt for autoimmune diseases that affect multiple organs, including lupus, juvenile idiopathic arthritis, dermatomyositis and vasculitis.



“The diagnosis of many of these conditions can be difficult because symptoms can be similar to other disorders,” said Brent Graham, MD, associate professor of Pediatrics, director of the Division of Pediatric Rheumatology and Nyla’s physician. There’s a good bit of medical detective work involved in a diagnosis, as physicians take a thorough medical history of the patients, then do a head-to-toe exam to collect clues.

“Basic science advances have improved our ability to diagnose and treat our patients in a more precise way,” Graham said. “The most important thing is to get accurate and early diagnosis and treatment and have the ability for good follow-up.”

‘Lupus looks very different in different people’

Nyla was 9 when she complained that her chest was hurting. Sarha took her to her pediatrician who thought she might have reflux and prescribed a reflux medication. That night, she felt worse and began to run a fever. The fever climbed to almost 104 degrees as her mom alternated ibuprofen and acetaminophen to try to bring it down. Nyla fell asleep, then got up and had a seizure. Her mom called 911, and she remained in the hospital in Huntsville for three days where she was diagnosed with lupus.

She was sent to a pediatric rheumatologist at another center, but the family wanted a second opinion, and she was able to see Graham at Children’s Hospital the next day.

“We heard what they both had to say, then we asked Nyla who she was most comfortable with, and she said Dr. Graham,” said Sarha. Graham has been Nyla’s physician for the past seven years.

“Lupus looks very different in different people. It’s a very heterogenous disease,” said Alaina Davis, MD, a pediatric rheumatologist and assistant professor of Pediatrics at Children’s Hospital. “A lot of the symptoms are very non-specific, which makes it challenging to recognize and diagnose. Kids present with persistent fevers, rashes triggered by the sun and true arthritis. They can get muscle inflammation that results in aches and weakness and get sores on the roof of their mouth. Oftentimes, liver and kidney effects are not something the patient can feel, so you need bloodwork to look for that,” she said.

Davis said there’s not a single blood test or X-ray that can provide a diagnosis.

“You might see ulcers in the mouth, and you can get blood tests and X-rays to help support the diagnosis of lupus, but it’s a combination of things that results in a diagnosis,” Davis said.

Children with lupus have more aggressive disease than their adult counterparts, and often present with organ damage, she said. It requires timely and aggressive immune suppression medication to get the inflammation under control and protect organs. Sarha said that Nyla had heart and lung involvement early in her disease, and

it’s a constant readjustment of therapies to make sure that her organs are not impacted during a flare.

Lupus occurs most often in young women in their late teens (usually older than 15) and adult women younger than 45. It also affects more African Americans, Asian Americans, Hispanics and American Indians than whites.

The cause of lupus isn’t known, but experts think it may be a mix of genes and other factors, including being exposed to the Epstein-Barr virus (which causes mononucleosis) and other environmental factors that aren’t yet known.

It’s treated with steroids during the acute phases. “They work really quickly, and they’re very strong, but they have a lot of side effects, especially in the long term, in terms of metabolism and bone health. So, we try to use the lowest dose possible for the shortest period possible,” Davis said, adding that in the early phases of treatment, higher doses, both oral and intravenous, may be necessary.

“We can control inflammation to prevent complications from the disease, but that requires the patient being adherent with a complex medical regimen and frequent doctors’ appointments. The disruption of having to come to recurring appointments and the responsibility of taking a medication two, and up to three, times a day can be really challenging,” Davis said. “Some of the complications of lupus are things you can’t see or feel (silent organ involvement). By the time a patient realizes it’s there, it’s too late. The damage is done. We can control inflammation, but we can’t reverse damage. Having lupus requires taking a medication every day, even if you

“The diagnosis of many of these conditions can be difficult because symptoms can be similar to other disorders.”



Brent Graham, MD

Lupus occurs most often in young women in their late teens (usually older than 15) and adult women younger than 45. It also affects more African Americans, Asian Americans, Hispanics and American Indians than whites.



feel OK, and that can be hard for a teenager to do when they want to fit in with their peers.”

Most patients with lupus take hydroxychloroquine, a drug commonly used to treat malaria. It has been shown to reduce flares in people who have lupus. “It’s really important they stay on hydroxychloroquine for life. If they stop it, they’re at an increased risk for their disease activity increasing again,” Davis said.

Nyla, one of about 100 young patients with lupus treated at Children’s Hospital, has been treated with steroids, both oral and intravenous, as well as hydroxychloroquine and other steroid medications that change based on whether her disease is stable or flaring.

Patients may also need to see other specialists when organs like the heart and kidneys become affected.

“Even though we don’t have a true multidisciplinary clinic, we work really hard to make sure the patient can see everyone they need to see in one day,” Davis said. The rheumatology team works closely with nephrology and other teams due to the multisystem nature of lupus.

And the team helps when it’s time for teens to transition from pediatric to adult care.

There are about 1.5 million cases of lupus reported in the United States. Childhood cases (those diagnosed before age 18) represent about 15-20% of patients. Davis said the disease may be present in childhood but not diagnosed until adulthood, so it’s hard to be certain how many cases are actually diagnosed during childhood and adolescence.

Juvenile Idiopathic Arthritis

Most of the patients seen in the Pediatric Rheumatology clinic (about 500) have juvenile idiopathic arthritis (JIA), the most common type of arthritis in children and teens. There are about 200,000 cases reported each year in the United States. JIA, formerly called juvenile rheumatoid arthritis, typically causes joint pain and inflammation in the hands, knees, ankles, elbows and/or wrists. But it may affect other body parts too.

JIA occurs when the immune system, which is supposed to fight invaders like germs and viruses, gets confused and attacks the body’s cells and tissues, causing the body to release inflammatory chemicals that attack the synovium (tissue lining around a joint).

The word “idiopathic” means unknown, and researchers aren’t sure why children develop JIA. It’s believed they have certain genes that are activated by a virus, bacteria or other external factors. But there is no evidence that foods, toxins, allergies or lack of vitamins cause the disease, according to the Arthritis Foundation.

Research is also an important component of the Division of Pediatric Rheumatology, which actively collaborates with the Childhood Arthritis and Rheumatology Research Alliance (CARRA) and the Pediatric Rheumatology Collaborative Study Group (PRCSG) to study multiple rheumatic diseases. There are active clinical research programs in systemic lupus and medication adherence and musculoskeletal pain as well as active

Comprehensive Care

Tending to the mental and physical well-being of children with lupus

Being diagnosed with lupus, a chronic and debilitating disease which sometimes causes life-threatening complications, can be devastating for children and their families.

The disease occurs when the immune system attacks healthy tissue instead of fighting infections and requires lifelong immune suppressive therapy and countless doctors’ visits.

At Monroe Carell Jr. Children’s Hospital at Vanderbilt, the Division of Pediatric Rheumatology team focuses on both the physical and mental health of children with lupus.

“We work really hard to take care of the whole patient, not just the patient’s lupus,” said Alaina Davis, MD, a pediatric rheumatologist and assistant professor of Pediatrics at Children’s Hospital. “We pay attention to mental health. Not only can lupus affect the brain and perhaps contribute to psychiatric illness, but the effects of having a chronic disease and managing a complex medical regimen can affect mental health as well. And we know that mental health can have negative effects on medication adherence, quality of life and disease outcome.”

The first step in taking care of patients’ mental health is identifying if they need help, Davis said. So, patients with lupus are screened at every visit for depression in a standardized, formal fashion. “That’s something that’s not being done at most rheumatology centers,” Davis said.

The Division of Rheumatology at Children’s Hospital is part of an international network, Childhood Arthritis and Rheumatology Research Alliance (CARRA), an investigator-led collaborative research network of clinicians focused on pediatric rheumatic diseases, including lupus. Children’s Hospital is part of several workgroups within that alliance, including ones on mental health and transitioning from pediatric to adult care.

Peer support is also a unique aspect of the care provided to patients with lupus by the Children’s Hospital team.

quality improvement initiatives in juvenile idiopathic arthritis, lupus, mental health and transition care.

Basic research is also important. Anna Patrick, MD, PhD, assistant professor of Pediatrics, is establishing a program to improve the understanding of lymphocytes in JIA, a type of immune cell that is made in the bone marrow and found in the blood and lymph tissue.

Like lupus, there's no single test that can confirm a diagnosis of JIA, because symptoms may be similar to other conditions. It's confirmed by taking a thorough history and examination.

But a quick and early diagnosis and the ability to get good follow-up care can make a difference in the trajectory of the disease, Graham said.

"At this point, debilitating juvenile arthritis is extremely rare, but access to care is critical," Graham said. "There are numerous treatments, and not all patients respond to first-line or second-line treatments, but there are options."

Most patients with JIA will have to stay on medicine for many years, sometimes for life, Graham said. Medications range from nonsteroidal anti-inflammatory medications to powerful disease-modifying antirheumatic drugs (DMARDs) and other immunosuppressive medications.

"Medicines have really advanced, so we have multiple biologic medicines that are effective and have low side

effects, prevent damage and help patients have a really good quality of life. Many of our patients play sports, dance, are active and do whatever they want to do."

Siblings Chase and Allie Borregard of Owensboro, Kentucky, are great examples of that, Graham said.

In 2017, Allie was 10 when she was diagnosed with oligoarticular arthritis, the most common and mildest form of JIA. Chase, now 12, was diagnosed later that year with polyarticular arthritis, affecting multiple joints. He was 8.

Both play youth hockey. Allie, now 14, attends Selects Academy, a residential hockey program located at Bishop Kearney High School in Rochester, New York. Her 16U division team won the New York state championship in April and went on to compete in the USA Hockey Nationals. Chase, a sixth grader, plays for the Tri-State Spartans AAA hockey team.

Allie's arthritis, which began with a swollen knee, has been managed well with medication; Chase's has been a little more of a struggle to manage, says their mom, Andrea Borregard. It's also likely that Chase had JIA for a couple of years before he was diagnosed. He

"Many of our patients play sports, dance, are active and do whatever they want to do."



Allie, 14, and Chase Borregard, 12

ERIN O. SMITH

500

Most of the patients seen in the Pediatric Rheumatology clinic (about 500) have juvenile idiopathic arthritis (JIA), the most common type of arthritis in children and teens. There are about 200,000 cases reported each year in the United States.

had been seeing a specialist for about two years, who had not been able to pinpoint what was wrong.

Allie was already a patient of Graham's when Chase was diagnosed. Chase became his patient as well.

She takes two medications to keep her arthritis under control — methotrexate, a DMARD, and an oral anti-inflammatory drug. "Everything that's worked for Allie has not worked for Chase. Allie's was so easy to treat. Chase's was not. We're dealing with a different beast here," Andrea said.

After trying several medication combinations that didn't work, or caused too many side effects, Chase's arthritis is currently being managed with an injection of tocilizumab and an oral medication, leflunomide, both DMARDs.

"Chase has gone from hurting when he walks to playing the highest level of youth hockey. Both of my kids are very active and get to go and do. They're not pain free all the time, but they know how to manage it and live with it. They know when to push and when to rest. They wouldn't be doing any of that if it weren't for the care they've gotten from Dr. Graham and Children's Hospital," Andrea said.

"For me, as a mom trying to manage two very different cases of arthritis, having complete confidence in the wonderful physician caring for my kids has made a huge difference. I trust him, and he's been great."

Helping fill the need

The Borregards travel about two hours to Nashville to see Graham. Patients in other parts of the country may have to travel longer distances to see a pediatric rheumatologist.

Finding one close by isn't always easy, said Alisa Gotte, MD, a pediatric rheumatologist at Children's Hospital, associate professor of Clinical Pediatrics and director of the Pediatric Rheumatology fellowship program. Most pediatric rheumatologists are located at larger academic medical centers, she said.

In the most recent analysis available, a 2015 American College of Rheumatology study, there were only 287 pediatric rheumatologists offering clinical care in the United States. The projected need was 382. "So, we were already working at deficit," Gotte said, adding that the gap is estimated to keep widening. In 2025, the projected workforce is 243 (down from 287 due to the fact that pediatric rheumatologists tend to be older and many may be retiring), and the projected need is 434. In 2030, the workforce is expected to be down to 231, with 461 needed.

To help fill the need, Vanderbilt began a three-year accredited fellowship program in 2014. Alaina Davis, MD, now on the faculty, was the first graduate of the program.

"Our training program emphasizes the importance of training new people so maybe our workforce numbers will improve instead of going down," Gotte said. The Children's Hospital program has four fellows during

the current academic year. Recent fellowship graduates from Vanderbilt have opened practices in Kingsport, Tennessee, and in Columbia, South Carolina.

The first year of the program is a clinical year where the physician takes care of patients. During the second and third years, they continue their clinical education but add a scholarly activity. "Pediatric rheumatology is a field where we need lots of research to explore diagnosis and find better treatments," Gotte said. Recent research by fellows at Vanderbilt includes a project with medical students to expose them to pediatric rheumatology early in their medical education; basic research in a lab; and a clinical research project looking at depression and mental health disorders in patients with lupus.

Nine states, mostly in the West, have no pediatric rheumatologists. If you don't live near one, it raises the chance that a child goes undiagnosed, Gotte said. The average number of miles a patient must travel to see a pediatric rheumatologist is 57, about twice the distance to see other specialists.

'You have to keep pushing'

Nyla, who travels about an hour and 45 minutes for her appointments at Children's Hospital, says having lupus, frequent medical appointments, and a complicated regimen of medication is hard on her academically and socially.

"I'll be gone for two weeks, three weeks (when her disease flares) and there's a boatload of schoolwork to do. Everything is piling up, and all I can do is blink. It sucks to be 16, and I can't drive anywhere and go and have fun. Sometimes it's hard to explain to my friends what happens to me, but they understand, and they still love me."

The COVID-19 pandemic has added an extra layer of complexity to her life. She has had to wear a mask at school and in public for years during flu season, but last year had to switch to remote learning and to always wearing a mask when outside her home.

Her mom gives her this advice: "It's been a rollercoaster for us, but I always say, you can deal with a lot of things given to you, and you have to keep pushing." And Nyla does.

She tries to accomplish a lot on the days she is feeling well. Prior to the pandemic she joined a group of teens with lupus to visit members of U.S. Congress in Washington, D.C., to lobby for more money for lupus research. She hopes to do it again. "It was awesome," she says.

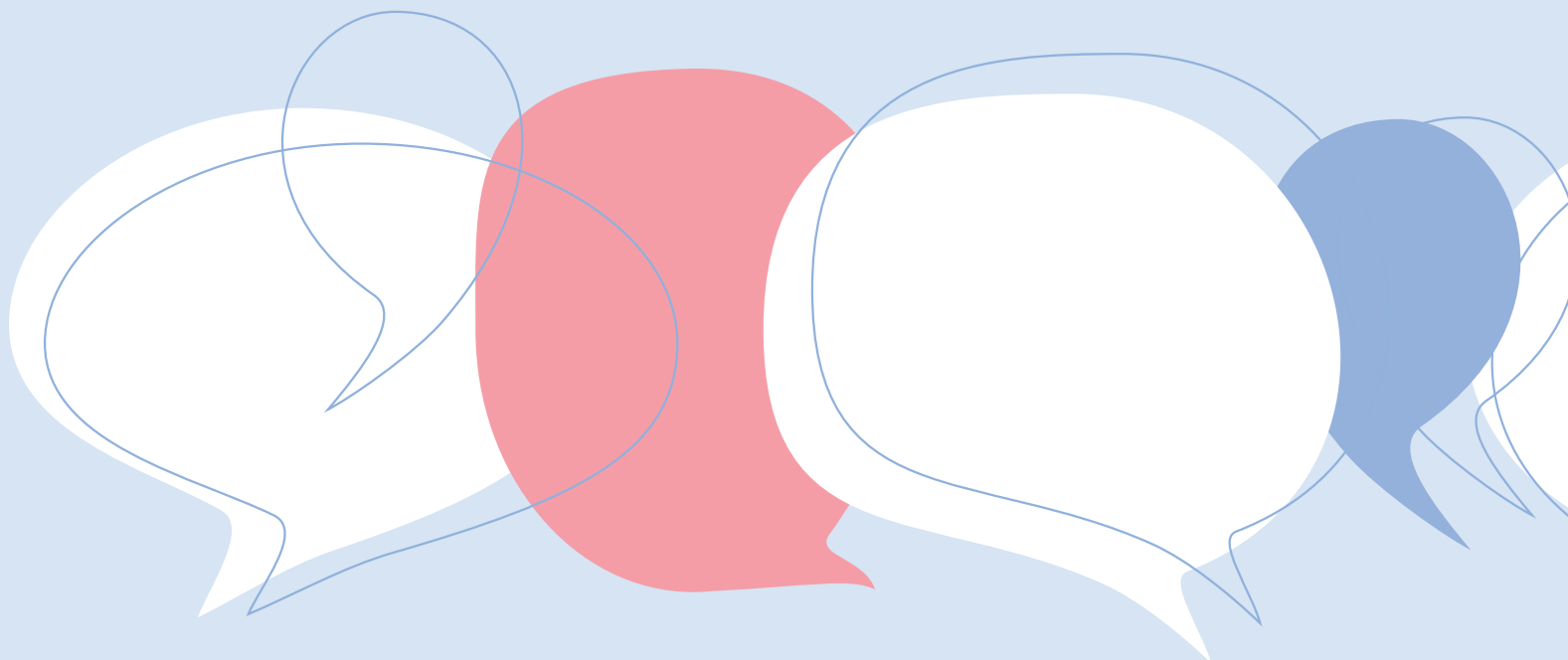
And over the last year of quarantine, she taught herself to crochet. "I got bored and needed something to keep my mind off my schoolwork and having lupus," she said. She's accomplished in amigurumi (the Japanese art of crocheting tiny dolls and animals), has an Instagram account devoted to her art, and plans to open an Etsy shop.

"I really love it," she says of her new hobby. 🐰

Nyla crochets amigurumi animals, which she learned how to make over the past year.



DONN JONES





Family Focus

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Family Advisory Council's mission puts children and families at the center of the care team.

PARENTS OF CHILDREN who have chronic illnesses are often experts in their own right. They attend doctors' appointments, receive frequent diagnoses and updates and do their own research to become extremely well-informed about their children's conditions. Coupled with a strong spirit of advocacy, these parents are an invaluable resource.

Monroe Carell Jr. Children's Hospital at Vanderbilt recognized the power of these caregivers in 1995, when the Family Advisory Council (FAC) was established. Previously, hospitals were operating under an institutional-centered approach, which did not allow for much input from patients and families about their own care. At the recommendation of child psychologists, over time hospitals began implementing a more patient- and family-centered approach to care.

The most prominent example of this approach at Children's Hospital is the FAC, which is still active today. The FAC includes parents and hospital staff who identify concerns and priorities, offer input in planning programs and policies and create education and support resources for medical providers.

For Brittany Swanson, chair of the FAC at Children's Hospital, the necessity of family-centered care was voiced by her son, Coben, who was diagnosed with T-cell acute lymphoblastic lymphoma when he was 7, while the Swanson family was living in California. After two years of continuous inpatient care, the Swanson family decided to research oncology teams in other states.

STORY BY **EMILY STEMBRIDGE**
ILLUSTRATION BY **ADOBE STOCK**



“Children’s Hospital at Vanderbilt won hands down,” Swanson said. When the family got to Nashville in 2016, Coben, who has autism, was overwhelmed with changes. Coben, now 13, asked his mother to find a way to voice his difficulties. From there, Swanson knew she had to seek out the Children’s FAC. She has served since 2017, becoming the chair in January.

Swanson first realized the FAC’s impact on patient care early in her family’s time at Children’s Hospital. At Coben’s previous hospital, Swanson was responsible for keeping track of her son’s medications, dosages, MRI and CT scan results, dates to change his nasogastric feeding tube and anything else related to his care.

One week before Coben was due for his first chemo infusion at Children’s Hospital, Swanson received a call from his care team. She was pleasantly surprised that someone else was coordinating Coben’s care. His care team coordinated and arranged his specialty doctors’ visits, allowing him to see them all in a single day. They also appealed to the pharmaceutical company on the Swanson family’s behalf for Coben’s medications that insurance did not cover.

“At the time, I wasn’t aware of the Vanderbilt Patient and Family Promise, but as I began to work with the FAC, it became clear that it was not only a great idea, but that it was actively being put into practice every day. ‘Coordinating care’ is a huge help to parents like me, and I do not take it for granted. After having experienced it firsthand, we are aiming as a family council to ensure all families feel that their care is coordinated, taking a weight off their shoulders like it did for my family.”

Who is the FAC?

To join the FAC, parents must have a child actively receiving care at Children’s Hospital. Usually, the child has a chronic illness or condition, which calls for parents to be at the hospital frequently for their child’s treatment. The goal is to put the most deeply involved parents at the forefront of the council’s decisions. Other requirements are attendance at 75% of the council’s meetings and a willingness to provide constructive feedback to hospital staff and leadership. To protect parents’ emotional well-being, the FAC recommends they wait until the initial crisis of their child’s diagnosis has passed before joining. The FAC currently has 25 members.

“To be able to put the family and patient at the center of care, you have to understand who they are,” said Janet Cross, MEd, administrative director of Patient- and Family-Centered Care at Children’s Hospital. “We want to get to know them and understand their beliefs and culture, what’s important to them, what their resources are and what their strengths are. Their perspective has to be at the table.”

Swanson is a great example of the seasoned perspective the FAC looks for. She has spent countless days

in hospitals and as a result, is able to accurately represent the family experience. As chair of the council, Swanson’s goal is to continue utilizing real families to learn what is working well and identify opportunities for improvement. She does not shy away from sharing her open and honest opinions with hospital leadership and encourages other families to do the same. “If we don’t know something’s broken, we can’t fix it,” says Cross, in agreement with Swanson’s approach.

The parents who make up the FAC are so valuable to Children’s Hospital that a rule has been implemented to allow parents whose children age out of pediatric care to stay on the council for three more years. Parents are now able to offer their valuable perspectives on the sometimes challenging transition to adult care.

When these three extra years end, patients have the opportunity to transition to the Vanderbilt Univer-

“We want to bridge the gap between medical providers and parents unable to speak up for the best care.”

Brittany Swanson, shown with son, Coben, joined the Family Advisory Council to be an advocate and voice for families like hers who navigate health care for their children.



The Council includes parents and hospital staff who:

- Identify family concerns and priorities
- Offer input in planning programs and policies
- Create education and support resources for families and medical providers

If you are interested in joining, please email familyadvisorycouncil@vumc.org

sity Adult Hospital family council. The FAC is one of three family councils at Vanderbilt University Medical Center. Vanderbilt University Adult Hospital and Vanderbilt Behavioral Health also have one. Hospital leaders across all three areas and their respective family councils collaborate and share strategies for success, as well as ideas for problem-solving.

The FAC Experience

Parents join the FAC as volunteers, undergoing background checks and orientation like VUMC employees. From there, they attend monthly meetings with FAC members and hospital staff, sharing their perspectives about patient- and family-centered care. “I see it as a place where my opinion matters, where I get to be an adult and reimmerge myself with the kind of work life I had prior to becoming a full-time caretaker of a child with critical health needs,” Swanson said.

When the tasks at hand feel laborious, Swanson chooses to focus on the greater purpose of the FAC. “I remember why I wanted to be part of the council in the first place — to speak on behalf of the families who may not have a voice, or don’t know what to ask for when it comes to the care of their child. We want to bridge the gap between medical providers and parents unable to speak up for the best care.”

Before the COVID-19 pandemic, all FAC meetings were held in person. Now meetings are held via Zoom, but Cross does not see this as a hindrance. “Zoom meetings have given us the ability for more participation. Our members who live nearby are able to conveniently join us without needing a babysitter, and we’ve been able to add families from farther away who normally wouldn’t be able to commit to monthly trips to the hospital.” Virtual meetings also allow Children’s Hospital administrative team leaders, who are present at every council meeting, to join more easily. In the future, the FAC plans on implementing hybrid meetings, so every member can still easily share their valuable input.

Advising and Improving the Hospital

The FAC advises Children’s Hospital on big decisions, such as building redesigns and restructuring, as well as smaller decisions, such as minor, but necessary, changes to the Children’s website. Many parents serve on the Quality Committee, which evaluates mistakes and near mistakes made by the hospital.

“Our Quality Committee looks at areas where we could improve,” said Cross. “Some hospital staff were nervous about airing mistakes to families, but the reality is our families are so passionate and committed to making care better that they understand we’re human. The Quality Committee never judges mistakes. Instead, they offer constructive feedback to help us improve things in the long run.”

The Quality Committee recently took action when a child of a member of the council received an

incorrect after-visit summary. The council member was able to share this experience with the Medication Safety Committee. Hospital staff analyzed the mistake and put actions into place to prevent it from happening again. “This is just one example of our council members bringing issues to our attention before they affect other patients,” said Cross.

The FAC is involved in many steps of the hospital’s operations, including training new Children’s Hospital employees. Every new Children’s Hospital employee has an orientation session with parents from the FAC, where the parents offer a true patient perspective and guidance. In 2020, the FAC provided orientation to 4,662 new hires at Children’s Hospital.

“The most impactful work we do as members is attending new employee orientation, where we are invited to share our child’s story in a very personal way,” Swanson says. “We instill in each employee just how important their job is. It takes a special kind of person to work at a children’s hospital, and I think we’re able to give them some insight to the reality of those little faces they see each day.”

In addition to new employee orientation, the FAC has also worked with the Emergency Department to evaluate teen suicide prevention strategies, met multiple times with the Children’s Hospital dietary team to evaluate in-hospital food for children, worked with anesthesiologists to standardize NPO (nothing by mouth) guidelines across the hospital and offered advice for various communications scenarios, such as the best way to send a message about a child’s procedure being rescheduled. The FAC even helps Children’s Hospital decide the best furniture and room layouts for newly opened hospital floors.

Swanson is most proud of the FAC’s efforts in designing an upcoming award, the Patient and Family Choice Award, that honors any staff member at Children’s Hospital who positively impacts care. “The award could go to the valet staff who cheer you up each time you visit or to the hardworking mom who comes in late at night to clean your child’s room. We want to better recognize all of these essential people and their roles.”

Shared Experiences and Support

By listening to patients’ needs, incorporating their ideas, partnering in their safety and educating them to advocate for their own care, the Children’s FAC is at the forefront of patient- and family-centered care at Children’s Hospital. It offers an opportunity for parents to give back and create action and change. It’s a healing experience for those involved.

“We’re only snapshots in a family’s life, and our goal is to figure out how to help them be successful,” said Cross. “What better experts than patients and families to help us understand their perspectives?” 🦋

Carter Ray, 21 months old,
at home with his mom,
Lacey, dad, Chris, and big
brother, Jackson, 3.





NEXT-LEVEL CARE

Surgical innovations help children heal faster,
with less pain.

FOR THE FIRST 18 months of his life, Carter Ray lived at Monroe Carell Jr. Children's Hospital at Vanderbilt.

After several innovative, minimally invasive surgical techniques used over a year to improve his health — including a first-of-its-kind procedure performed in the United States — Carter finally went home, to Lynchburg, Tennessee.

Minimally invasive surgery (MIS) is exactly what it sounds like — the least intrusive pathway to performing a wide range of medical procedures and surgeries. This allows children to recuperate faster and with less pain.

The innovative technique allows a surgeon to use telescopes and operating instruments through small incisions. Surgeons at Children's Hospital have extensive experience and expertise in MIS, which has been performed at Children's Hospital since the 1990s.

Depending on the type of surgery, there are several minimally invasive surgical methods that may be utilized (robot-assisted surgery, laparoscopy, endoscopy, arthroscopy, bronchoscopy, gastroscopy, among others) across many pediatric specialties.

"We have a fantastic group of surgeons who have been doing this for a very long time," said Irving J. Zamora, MD, MPH, assistant professor of Pediatric Surgery and director of Advanced Minimally Invasive Surgery. "It continues to evolve, and we are learning more advanced technology and approaches to offer our patients."

"We are building a program that is allowing us to do high-level, advanced surgical operations and meet the needs of some of the most critically ill, medically complex patients, like Carter."

STORY BY JESSICA PASLEY
PHOTOGRAPH BY MICHELLE BARNETT PHOTOGRAPHY

First-ever use in the U.S.

Carter, born Nov. 3, 2019, was diagnosed with a very rare form of esophageal atresia (EA), trans-esophageal fistula (TEF) Type B and tracheobronchomalacia (TBM), conditions that ultimately required reconstruction of the esophagus to allow secretions and nutrients to reach his stomach.

Seen in 1 in 4,000 U.S. births, EA is a rare birth defect where part of the esophagus isn't developed properly and sometimes has a connection to the airway. TEF caused secretions to collect into Carter's airway and lungs and led to several bouts of pneumonia, while TBM resulted in excessive weakness and near collapse of his windpipe wall. These conditions interfere with breathing and can cause significant lung issues.

The complexity of the case required the specialized care of a surgical team at Children's Hospital, led by Zamora, who put together a group of experts including surgery partners Harold Lovvorn, MD, and Nathan Novotny, MD, as well as colleagues from Otolaryngology-Head and Neck Surgery, Christopher Wootten, MD, and Lyndy Wilcox, MD.

Together, they focused on repairing the esophagus and airway using minimally invasive surgery techniques — all with the ultimate goal of getting Carter home.

What would have been a potentially daylong, high-risk, open-chest and abdominal surgery was shortened to a 38-minute endoscopic procedure.

The multidisciplinary team focused on repairing Carter's esophagus and airway, which required the use of special magnets to connect the two ends of a congenitally separated esophagus. Zamora collaborated with Michael Harrison, MD, and a team at University of California San Francisco (creators of the magnet device) and Oliver Muensterer, MD, PhD, in Munich, Germany (the only other surgeon in the world to use the magnets).

Given the novel nature of this approach, the procedure required a compassionate use approval from the Food and Drug Administration. The team spent months preparing for the first use of the Connect EA - Magnamosis device in the U.S.

"Not many institutions are doing this, and even fewer are using a minimally invasive surgery approach to perform these innovative procedures," said Zamora. "While this was a milestone for the institution and others interested in such innovations, most importantly, we saved Carter's life."

Small incisions, big impact

One of the surgeons partnering with Zamora on Carter's care, Christopher Wootten, MD, associate professor and chief of Pediatric Otolaryngology-Head and

Neck Surgery, has long used minimally invasive surgical techniques in his practice.

In addition to extensive use in the airway, Wootten uses MIS for procedures including endoscopic ear surgery and tympanoplasty (repair to the eardrum). The practice has allowed for better outcomes and reduction in the number of incisions or need to drill behind the ear for access, which ultimately lessens the chance of postoperative complications.

"We have a fairly large patient population with congenital anomalies," said Wootten. "Having the ability to work in very small spaces has enhanced our ability to perform very intricate procedures that are difficult to do microscopically."

Wootten's team has several goals for the use of minimally invasive approaches, which include repairing abnormalities of the skull base; enhancing cochlear implants; and eventually managing disorders of the eustachian tube.

"Over time, we have been able to enhance our reputation through the creation of the endoscopic ear course, which is a CME (continuing medical education) offering," said Wootten. "It's brought us national attention. This course holds professional importance and shows people on the national level that we have become experts. They learn from us and take these novel techniques to their patients all over the country."

MIS also serves as an invaluable teaching tool, allowing images to be viewed on giant screens (both live and recorded) to better instruct future surgeons.

Children's Hospital offers MIS for a wide range of



Irving Zamora, MD, MPH, hugs patient Carter Ray, who was finally able to go home after 18 months at Children's Hospital.

DOAN JONES

Depending on the patient's diagnosis, there are several minimally invasive surgical methods that may be utilized such as:

robot-assisted surgery



laparoscopy



endoscopy



arthroscopy



bronchoscopy



gastroscopy

complex conditions with the goal of providing equal or superior clinical outcomes as well as reducing surgical risks, use of pain medications and hospital length of stay.

3D models aid precision image-guided surgery

To assist with providing optimal surgical views, the hospital offers a unique opportunity to the surgeon: 3D images of the anatomy.

Sumit Pruthi, MD, professor of Radiology and Radiological Sciences and Pediatrics and chief of Pediatric Neuroradiology, spearheaded and led the establishment of the 3D Printing Center to assist with both pediatric and adult cases.

Begun in 2016, the program has grown in capacity and scope, recently adding a Stratasys J735 printer, which allows for the creation of highly complex models.

A print or 3D model may require between two to 24 hours to complete, depending on complexity, and typically uses multiple materials, colors and textures for a more lifelike replica of the internal structure of the patient.

"Better information leads to better outcomes," said Pruthi. "Having the ability to hold the model to manipulate, turn and study in a three-dimensional space, allows the surgeons and teams to conceptualize and develop a strategy on how best to treat patients.

"While most of the anatomy can be seen using two-dimensional imaging, the model affords the ability to see the anatomy from multiple angles and perspectives, giving the surgical team a greater advantage," he said.

Since the creation of the 3D Printing Center, approximately 825 models have been printed to assist in decision-making and serve as a practice tool prior to surgery. In some cases, the models have helped to detect other abnormalities, and in others, have prompted teams to review additional approaches to a procedure because of what they see.

The model also plays a role in medical education/teaching for both residents and parents.

"Another piece of this is sharing images depicting their child's anatomy and the surgical procedure with the parents," said Pruthi. "Patients' families appreciate our models as their physicians walk them through the surgical process. I can only imagine how difficult it can be to try to comprehend what the teams are saying when a parent is focused on their child; our images help the parents direct their attention to the procedure being described."

Areas utilizing the innovative printing technology include craniofacial, orthopaedics, cardiology, cardiothoracic surgery, ENT, urology, gastroenterology, oncology and pediatric surgery.

According to Harold Lovvorn III, MD, professor of Pediatric Surgery and medical director of Pediatric Trauma at Children's Hospital, the 3D images make understanding the anatomy more accurate, resulting in a safer procedure for the patient.

"The use of image-guided tools will allow us to ex-

tend the MIS program to more challenging conditions," said Lovvorn.

While every condition is not suitable for MIS, the ever-growing list of diagnostic and therapeutic uses and rapidly expanding programs offers a glimpse into the future of medicine for pediatric patients.

MIS has revolutionized many surgery techniques in both chest and abdominal procedures and is more commonly becoming the standard approach for many of the conditions treated at Children's Hospital, proving that the smallest of incisions have a big impact.

"Our commitment is to provide the latest technologies and innovative tools when performing surgery on children, whether for birth anomalies, tumors or trauma," said Lovvorn.

Within this age of innovation, the patient is the ultimate winner as the newest techniques provide multiple benefits, including: less pain and the use of fewer opioids; shorter recovery and hospital stays; and the ability to stay on track with continued treatments in the case of cancer therapies.

"Although we tout and marvel at all the innovation that minimally invasive surgery offers in the surgical care of children and newborns, when you get right down to what's most important, we ultimately are doing what is best for our patients," he said. "We want our patients and their families to be able to return to their normal activities sooner rather than later."

A chance for many firsts

Carter went home for the first time on April 27, where he joined his big brother, Jackson, 3.

"It's not like this has been easy, and we have all had to take risks, but without them, we wouldn't have learned how to repair his esophagus," said his mom, Lacey Ray. "Sometimes you have to take chances to make improvements, and you have to have someone willing to be the first."

Although tracheostomy- and ventilator-dependent, Carter, now 21 months old, no longer requires tubes coming from his mouth and nose to suction secretions and help him breathe.

With the help of physical and occupational therapy, the team is hopeful that he will learn to swallow, walk and begin experiencing many firsts.

"We are all home together, and he loves being here," said Lacey Ray. "He has come out of his shell. He is smiling a lot, laughing and even rolls to his belly," she said, giving credit to Zamora and his team. "I'm glad there are teaching hospitals like this. It's why they can try new things that will hopefully help others in the future who will need this kind of procedure."

"I've heard people say that once a child comes home, they thrive. It is so true. He is a miracle, and we are looking forward to our future together." 🦋

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 Children's Hospital — 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 Children's Hospital is equipped to handle any issue a child may face — no matter how complex.

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STORY BY EMILY STEMBRIDGE

Nancy Jaworski, APRN, DNP

VAD COORDINATOR

Nancy Jaworski, APRN, DNP, oversees some of the most complex procedures pediatric patients can undergo: implantations of portable ventricular assist devices (VADs), which help circulate blood throughout the body and serve as the first step in the journey toward heart transplantation for the sickest of transplant candidates.

Four years ago, Jaworski came to Vanderbilt as a pediatric cardiac intensive care unit nurse, and then joined the pediatric transplant and VAD team two years ago. She now serves as the VAD coordinator overseeing all aspects of VAD implantations for children. Jaworski, who has been a nurse for 20 years, finds joy in witnessing medical advances that allow sick children to recover from illnesses and conditions that would have been impossible to recover from years ago.

"When I get to send a child

home with their parents, it's a good day at work," she said. "Getting the chance to walk a family's journey with them and be there for them is the best part of what I do. I get to help them process what's going on and be there with them every step of the way. It's about the patients — it's always been about the patients."

As the VAD coordinator, Jaworski helped turn the VAD program from an evolving team of health care providers into a polished, well-oiled machine with plenty of resources to offer families. She formed a VAD-focused advisory committee, reached out to national transplant programs, collaborated with pediatric specialists and studied VAD guidelines from other institutions. With all of the information she gathered, Jaworski successfully established standard operating procedures for all future pediatric VAD implantations.

The operating procedures are constantly being evaluated, ensuring the most up-to-date standards are always in place. Every day, the VAD team meets to streamline its communication, with the goal of limiting patients' days spent in the ICU and hopefully allowing chil-



ERIN O. SMITH

dren to go home while they wait for their transplant. By successfully doing these two things, the VAD team saved close to \$500,000 in medical expenses in its first year of operation.

Since beginning her efforts to establish a coordinated pediatric VAD program, Jaworski has always placed preserving patients' childhood and parents' sanity above all. "I look at every single kid, and I think if this were my kid, this is what I would want someone to help me with. We give them a future and we make it one worth living."



"When I get to send a child home with their parents, it's a good day at work."

- NANCY JAWORSKI

faces of hope

MEET THE PEOPLE WHO BRING HOPE TO FAMILIES EVERY DAY

Erin Boyd, MD

ASSISTANT PROFESSOR OF
PEDIATRICS

Erin Boyd, MD, assistant professor of Pediatrics in the Division of Adolescent and Young Adult Health, tackles mental, social and emotional complexities with her patients, serving as their one-stop resource for all things in adolescent health. As an expert in adolescent HIV/AIDS, transgender health, childhood obesity, contraception, puberty, healthy relationships and more, Boyd relies on the coveted trust of adolescents in order to best treat them.

A Vanderbilt University graduate, Boyd was drawn back to Monroe Carell Jr. Children's Hospital at Vanderbilt because it provided her an opportunity to pursue her interests, which specifically include HPV vaccination implementation and PrEP (pre-exposure prophylaxis, a medication for people at

risk for HIV), with a large support system around her. She also has a passion for training residents and medical students in these complex topics.

"Adolescents are an underserved population who have their own unique challenges in growth and development. My interest in adolescent health allows me the opportunity to change and influence this population as they become adults," she said.

Boyd realizes that trust plays a large part in providing the best care for her adolescent patients, and she frequently draws on her own life experiences to build rapport.

"I try to establish a relationship with my patients by connecting on something that they are also interested in. I fully focus on the

patient when I'm in the room — I let them know that this is their visit. I give them an opportunity for one-on-one time where we can talk and ask questions about things they may not feel fully comfortable talking to their parents about just yet. Connecting with them and letting them know that, within reason, our conversation is confidential, is the best way to establish trust," Boyd said.

Positively influencing the next generation is the reason Boyd is interested in adolescent health, as adolescents are at a vulnerable crossroads in their transition from childhood to young adulthood. Boyd uses her expertise to be an ally for young patients as they grow up, teaching them how to take ownership of their health.

Teaching not only her patients, but also residents, something new each day that can be carried forward in their daily lives or future practice is what Boyd considers the most important aspect of her job.

"I can't expect to make a huge change right away, but if I can give them one solid take-home point each time I see them, that's a win for me," Boyd said. 🦋



"Adolescents are an underserved population who have their own unique changes, growth and development. "

— ERIN BOYD



SUSAN URBAN



The little things

Family, friends, nurses, music, cookies and card games help teen on cancer journey

STORY BY AVA PAIGE
PHOTOGRAPH BY SUSAN URMY

My name is Ava Paige. I'm a 16-year-old singer/songwriter born and raised in Nashville. I've been around music all my life, and I have played guitar since I was 7. When I was 10, I decided to pursue music as a career. I started writing songs, performing wherever I could and learning about the industry. By the beginning of 2019, I was writing twice a day, five days a week with co-writers, meeting with people in the industry and performing more than 150 shows a year. Everything was going well, until July 1, 2019. My life changed forever.

I was doing a small music tour in Texas, playing at local venues in Fort Worth as well as at a children's hospital there. I wasn't feeling right, and my mom, being a retired nurse, knew something was wrong. I couldn't walk from terminal to terminal at the airport without being incredibly winded.

We went to my pediatrician when I got home. She sent us to Monroe Carell Jr. Children's Hospital at Vanderbilt. They ran my blood counts. Six doctors walked in to tell us the news: I had cancer. The diagnosis was acute lymphoblastic leukemia (ALL for short), and I had to start chemo immediately. I was put into a hospital room for a month and a half straight and had chemo every day. It was incredibly intense. I was faced with a lot of road bumps along the way.

I like to say when people are fighting cancer, we aren't just fighting cancer, we are also fighting the side effects of chemotherapy. For me, I had medically induced diabetes, water retention/fluid on my lungs, pancreatitis, heart/liver damage and a fungus that ate half my nose. I had five surgeries to remove the fungus, and I lost the septum in my nose as a result.

The treatment was rough, but I was so lucky to have an amazing support team around me! Everyone on the care team at Children's Hospital was so kind and understanding. I remember one night, I ordered cookies at 2 a.m. and played UNO cards with the night nurses. To this day, I can't walk around the sixth floor of Children's Hospital without someone saying "hi."

My family/musical family also stepped up in a big way! I moved to an online school to pursue music, so instead of having school friends, I was busy creating music with my musical friends. They surrounded me with so much love and support! People would stop by and bring food and gifts, share stories, sing songs and just spend time with me. If I had a rough morning, my mom would call someone to stop by. And by the end of the day, I would be singing and smiling, sometimes forgetting I'm in a hospital room. After surgeries, my favorite sandwich would be sitting on my bed, or someone would bring a fuzzy blanket. Even the "little things" like sending a text or card made a huge difference. By the end of my stay in the hospital, we had to pack two cars full of gifts and bags.

The overwhelming amount of love and support makes it easy to stay positive and keep fighting. Today, I'm on my seven-month chemo countdown, and still writing, singing and performing! If you want to follow my story, you can find me on social media @AvaPaigeMusic. 🦋



A brighter future for the next generation

In their time of greatest need, families turn to the place they trust — Monroe Carell Jr. Children's Hospital at Vanderbilt. As one of the nation's leading pediatric hospitals, Children's Hospital has been caring for our region's smallest patients for years. Treating a full range of health issues from colds and broken bones to heart diseases and cancer, Children's Hospital sees nearly 1,800 children each day. Your support makes this life-changing care possible. Help impact the future of health care for generations of patients and families to come.



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Ranked #1 in Tennessee and the entire Southeast.

Because of the excellence of our staff, providers and support from the community and beyond, we have been named the #1 Children's Hospital in Tennessee and the entire Southeast by *U.S. News & World Report*.



[ChildrensHospitalVanderbilt.org](https://www.ChildrensHospitalVanderbilt.org)

Kailani, age 5

