

# hope

CHILDRENSHOSPITALVANDERBILT.ORG

WINTER 2021



## Puzzle Pieces

Solving the mysteries of  
COVID-19 in children



## cover story

### 02 Puzzle Pieces

Investigators at Children's Hospital are highly engaged in local and national research efforts aimed at unpacking the mysteries of COVID-19 and a rare complication of coronavirus called multisystem inflammatory syndrome in children. The stories of patients like Kailani Brown, 4, (on the cover and above), help researchers understand ways the disease affects children.

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**B**Y THE TIME YOU READ this edition of *HOPE*, we will be into the new year, with the true hope that we will soon put the COVID-19 pandemic behind us. This will not be immediate and will come with some prolonged need to practice public health measures.

Over the past 11 months, our wonderful teams of physicians, nurses, trainees and all other team members have adjusted to so many new routines in the 'how' of delivering care, with a 1,000% dedication to maintaining the 'what:' a commitment to excellence. As leaders of our teams, we are so grateful for the speed of pivoting, the generosity of spirit and collaboration, and the innovation that we have witnessed — actions that will continue to be called upon in the coming year.

We would be remiss if we did not recognize the many contributions of our research teams in the coronavirus fight. From understanding the virus and how it infects, to therapies, to the recently approved vaccines that we are slowly but surely deploying, our teams have been at the forefront of discovery and leading the science.

As you read these pages, you will learn about just a few of our stories, seen through the eyes of our patients — from tiny to teen. You will learn more about our amazing teams, to be sure, but you will also hear about how our patients' journeys were supported by some of our COVID-19 pivots. And we will formally introduce you to one of our new employees, who joined us just before the pandemic started. His commitment to our mission of patient-centered, personalized care is exceptional and unique.

More than ever, we are grateful to our community for partnering with and supporting us through this journey. As we start 2021, we thank you for your many messages and creative ways you have continued to ensure our discovery, training and patient care moves forward. Even as we offer hope and healing every day to those who need us, you have reminded us of the hope in connection and community.

Wishing you wellness as we start this new year.

Sincerely,

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Kailani Brown, 4

# PUZZLE PIECES

*Solving the mysteries of COVID-19 in children*

## Kailani Brown was too quiet.

The normally spunky 4-year-old wasn't talking her mother's ear off or dancing through the house like usual after she finished her virtual pre-K classes. Her mother, Nicole Brown, found Kailani balled up under a blanket on the couch, asleep.

"It was a Friday, and I figured maybe she was just really tired at the end of the week," Brown remembers.

Kailani slept fitfully through the rest of the day, and when her mother checked on her later, her temperature was just over 100 degrees.

It was the start of an illness that would send Kailani to the hospital, where she was diagnosed with a puzzling new disorder called multisystem inflammatory syndrome in children, or MIS-C.

written by Leigh MacMillan  
photograph by Erin O. Smith



IS-C is a rare complication of COVID-19, and it's part of a growing list of things we don't yet understand about how COVID-19 is impacting children.

Here's what we do know.

"In children, COVID-19 disease is much less severe than it has been in adults," said Ritu Banerjee, MD, PhD, a pediatric infectious diseases specialist at Monroe Carell Jr. Children's Hospital at Vanderbilt. "Of the first 900 or so COVID-infected children we've seen at Vanderbilt, 95% of them have remained outpatients who have recovered from their infections without any complications. A very small percentage, less than 5%, have required hospitalization, and among those only one patient who had multiple medical problems required mechanical ventilation."

Despite the comforting news that most children and adolescents who become infected with SARS-CoV-2, the virus that causes COVID-19, have mild disease and recover quickly, it is clear that some children develop severe disease and rare complications like MIS-C, and researchers don't know why.

"We continue to be surprised by COVID-19 every day. Just when we think we understand something, a new study comes out and we realize maybe we really don't understand anything," Banerjee said. "Why are some people completely asymptomatic and some get extremely sick? How susceptible are children to infection and how infectious are they? Are young children less infectious than older children? We really need more studies to answer those questions."

Investigators at Children's Hospital are highly engaged in local and national research efforts aimed at unpacking the mysteries of COVID-19. For example, they are entering cases of COVID-positive children into a national registry, collecting samples — nasal swab, saliva and blood — from pediatric patients and their family members to follow the disease, and collecting information to assess transmission in schools.

"There's a lot of data gathering going on to try to learn more about this infection in children," Banerjee said.

### Sick for a month

Sarah Cook didn't hesitate to enroll her family in studies at Vanderbilt after her son, Harrison, tested positive for SARS-CoV-2.

"I'm trying to teach them that it's their civic duty, and this is how we learn about this disease," Cook said.

Cook's children, 15-year-old twins Harrison and Hallie and 13-year-old Janie, attended a two-week summer camp in Texas during July.

"We hesitated letting them go to the camp because of the infection rates, but we made an exception because the camp is so close to my heart — I went there — their cousins were

going, and it's essentially all outdoors, including the sleeping areas," Cook said.

When she and her husband picked up their children, Cook knew with one look that Harrison wasn't well. He told her that he'd had a sore throat and snotty nose, but no fever, for a couple of days. The girls felt fine, and the family completed the 13-hour drive home to Brentwood, Tennessee.

The next day, Harrison continued to blow his nose constantly and complained about being tired.

Sarah Cook got nervous. She had heard of some adolescents with only a runny nose having positive COVID tests, so she took Harrison to Vanderbilt for a test. It came back positive.

Harrison's extreme fatigue and cold symptoms persisted for days, and then he developed weakness and pain in his legs, vomiting and severe diarrhea. In the meantime, Hallie started having cold symptoms and lung congestion, but her COVID test was negative, and she recovered after about 10 days. No one else in the family had symptoms.

After two weeks, Harrison started running a fever.

"It was bizarre," Cook said. "The fever would come and go. He had extreme fatigue and could barely walk. I made him walk down the street and he complained of chest pain."

Harrison, a water polo player who swam for two hours a day before he went to summer camp, was out of commission for a month. He's back to practicing now and is lifting weights to regain his lost strength.

"Is he back to where he was? No. I think it takes a while to get back to normal after something like that," Cook said.

Harrison says his friends were surprised that he couldn't keep up his day-to-day activities.

"They didn't realize how COVID can keep you in bed; that you can be really sick with it even if you don't have to go to the hospital," Harrison said. "It's a real thing; I was sick with it for a month."

Cook recognizes that most children and adolescents have mild disease, but "not everyone's a two- or three-day cold type of thing," she said. "It's a weird virus; you can't assume that someone's not going to get hurt from this," she added. "I saw it with my own eyes. Harrison's at the peak of his health, has no

**"We continue to be surprised by COVID-19 every day. Just when we think we understand something, a new study comes out and we realize maybe we really don't understand anything."**



underlying health conditions, was exercising every day...and he was barely able to stand up for a little while.”

### **Mostly mild disease...why?**

The striking differences in response are intriguing to Natasha Halasa, MD, MPH, a pediatric infectious diseases specialist at Children’s Hospital.

“We would love to know and be able to predict how someone will respond,” she said. “Most children may get a slight fever or not feel so well for a few days. Of those that have severe disease, about half have an underlying medical condition. Like adults, if a child has asthma or obesity, they’re more likely to have more severe disease. But that leaves half of those who have severe disease without any underlying condition. Why is that?”

Investigators are exploring potential genetic differences that may put some people at risk for more severe disease.

Children who develop severe disease are treated with the same approaches and medications used for adults, which include steroids, supplemental oxygen, respiratory support and the antiviral remdesivir, Banerjee said. Researchers at Vanderbilt, including Mark Denison, MD, director of the Division of

Pediatric Diseases and an international authority on coronaviruses, played a key role in the development of remdesivir, the first drug approved by the U.S. Food and Drug Administration for the treatment of COVID-19.

Halasa is leading a study aimed at the question of why children have mostly mild disease.

“This virus is fascinating because other respiratory viruses like RSV and influenza are most severe in children and the elderly, but this virus is mostly sparing the children,” Halasa said.

There is some evidence, she noted, that the cells lining the nasal passages in children have less of the receptor for SARS-CoV-2, called ACE2, compared to adults, making the virus less able to latch onto and infect cells in children. That might explain why only about 8% of COVID cases are in children, but it’s not the whole story, Halasa believes.

“We still see severe disease in children; children have died from COVID; children have suffered complications,” she said.

*After a monthlong illness with COVID-19, Harrison Cook, 15, is working to regain his strength.*



ERIN O. SMITH

**“People are having long-term complications — pulmonary, cardiac, neurological — most of the complications we’re seeing associated with this virus are not what we see with other respiratory viruses.”**

She and her team are enrolling children and adults with confirmed SARS-CoV-2 infection and their close contacts to follow over time. They are collecting nasal swab and blood samples to determine virus levels and immunological responses — both antibody responses and, in collaboration with Vanderbilt immunologist Spyros Kalams, MD, cellular immune responses. It is possible, Halasa said, that children and adults have different immune responses to SARS-CoV-2, which could help explain differences in disease severity.

So far, they have enrolled more than 700 individuals who have had confirmed or suspected infection and their household contacts in the study, called COPE (COVID Outbreak Pandemic Exploration). About one-third of the study participants are children, including 43 with confirmed SARS-CoV-2 infection.

Another study, funded by the Centers for Disease Control and Prevention (CDC) and led by Vanderbilt investigators Carlos Grijalva, MD, MPH, and H. Keipp Talbot, MD, MPH, enrolled some of the same families to examine the transmission of SARS-CoV-2 within households in Nashville. The team reported recently in the CDC’s Morbidity and Mortality Weekly Report that 51% of others living in a home with someone who was positive for COVID-19 also became infected, and quickly — within five days of the first person experiencing symptoms.

### **A scary complication**

Although SARS-CoV-2 is a respiratory virus, it’s causing problems beyond the lungs and respiratory system, Halasa said. She noted that the ACE2 receptor is present throughout the body, which allows the virus to infect a wider range of tissues and organs.

“People are having long-term complications — pulmonary, cardiac, neurological — most of the complications we’re seeing associated with this virus are not what we see with other respiratory viruses,” Halasa said.

She notes that children are also suffering from similar complications, findings that have not yet been widely appreciated.

And then there’s the rare and unsettling inflammatory complication, MIS-C, which appears to be a dysregulation of

## **HEROS study probes COVID-19 infection in children and families**

Every two weeks, families across the country pull out surveys and nasal swab kits. They are participating in HEROS (Human Epidemiology and Response to SARS-CoV-2), a study that aims to understand the transmission and impact of the coronavirus that causes COVID-19 in children and families.

Enrollment in HEROS is complete, with 1,913 families, including 5,599 participants and nearly 2,000 children from infancy to college age across 12 cities and regions in the United States. Families are being followed for six months.

“The study is novel in asking families to do all of the sample collections remotely to avoid what would have otherwise been frequent interaction with research staff or the health care system,” said Tina Hartert, MD, MPH, Lulu H. Owen Professor of Medicine at Vanderbilt University School of Medicine. Hartert is leading the nationwide HEROS study, which is funded by the Na-

tional Institute of Allergy and Infectious Diseases.

The HEROS study will provide insight into how many children up to age 21 have been infected, the percentage of those infected who develop symptoms of COVID-19 and any differences in immune responses to the virus between children and adults within the same household.

“It’s not known whether children are more resistant to the virus or whether they are infected by the virus just as frequently as adults but don’t get symptoms. Children don’t appear to become as critically ill compared with adults, but this doesn’t equate to children not getting infected,” Hartert said. “Settling this debate requires large, high-quality population studies that include longitudinal sampling, like HEROS.”

Hartert noted that HEROS differs from most current transmission studies by starting with healthy families, rather than with an acutely ill or hospitalized participant —

study designs that miss an asymptomatic family member as the initial household infection.

The HEROS study team rapidly enrolled families that were already participating in NIH-funded pediatric research studies of asthma and other allergic conditions. The study population will allow investigators to also examine whether infection rates differ between children who have asthma or other allergies and children who do not, including the impact of topical steroids used to treat asthma and allergies.

In addition to biweekly questionnaires and nasal swabs, families collect baseline stool samples and periodic blood samples using a capillary blood self-collection device. If someone in the family shows symptoms of a viral illness, the family completes additional questionnaires and sampling.

Results from the HEROS study are expected in early 2021.

— by Leigh MacMillan



the immune response that occurs two to four weeks after COVID-19 infection, even in children who were completely asymptomatic — like Kailani Brown.

Kailani hadn't been ill before she started running a fever that Friday in late August 2020.

A rapid strep test at her pediatrician's office was negative on Saturday, and results from a COVID-19 test wouldn't be back for a few days. By Sunday, Kailani's fever was so high that her mother took her to the Emergency Department at Children's Hospital, where the clinicians suspected Kawasaki disease — an inflammatory syndrome with clinical symptoms of fever, rash, redness of the eyes, swollen lymph nodes and inflammation of the mouth, lips and throat.

But Kailani's fever waned while she was in the emergency department, and Nicole Brown was advised that she could take Kailani home and bring her back for bloodwork and treatment if the fever persisted for two more days. The fever did persist, and on Tuesday, Kailani was admitted to the hospital with clearly swollen red lips and red eyes, Brown said.

"She didn't want to eat or drink or get out of the bed. It was like she was off balance and didn't want to put her feet to the ground," Brown said.

Although her COVID-19 virus tests were negative, Kailani had antibodies in her blood, suggesting previous infection — a surprise to Nicole Brown, who said the family had been vigilant in staying at their Hermitage, Tennessee, home, not seeing other people and wearing masks when running errands. Brown's husband, a delivery driver for Frito-Lay, even went so far as to strip off his clothes and go straight to the shower when he returned home from work each day, she said.

The evidence of COVID-19 infection and other clinical and laboratory features make MIS-C distinct from Kawasaki disease, despite overlap between the two syndromes, Banerjee explained. The treatment is similar and involves intravenous medications to modulate the immune system and calm the hyper-inflammation.

Kailani recovered and went home after one week. She will continue to be followed for a year through a multidisciplinary MIS-C clinic at Children's Hospital where specialists from pediatric infectious diseases, rheumatology and cardiology monitor patients and look for complications.

"It was so scary, and it took her a while even after we came home to get back to being herself," Brown said.

Banerjee stresses that MIS-C is rare. Tennessee has reported at least 50 cases of MIS-C to the CDC, while the state has had more than 110,750 cases of COVID-19 in children and youth up to age 20 as of early January. Children's Hospital has treated 19 children for MIS-C since mid-July.

More than three-quarters of the 1,659 MIS-C cases in the United States, as of early January, were in children who are Black or Hispanic, according to the CDC, a troubling number

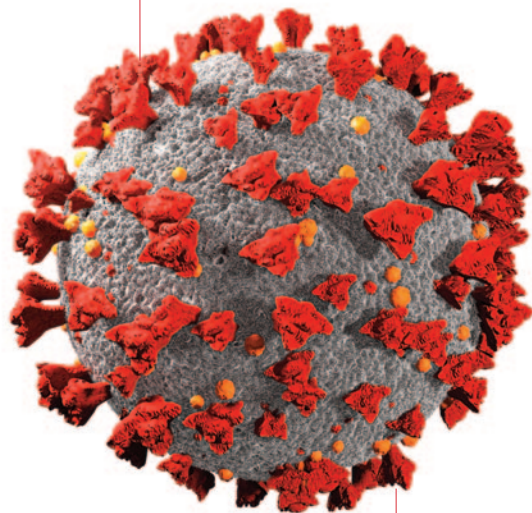
that mirrors the racial and ethnic disparities of the pandemic overall, Banerjee noted.

"We have a lot of work to do to understand COVID-19 and complications like MIS-C," Banerjee said. "Of course, the best way to prevent these complications is to prevent COVID-19 infection in the first place. We all need to be masking, physically distancing, washing our hands and avoiding large gatherings."

hope

## What is coronavirus?

This is SARS-CoV-2. It's called coronavirus because under a microscope, the little spikes make it look like it's got a crown; "corona" is the Latin word for crown or halo.



SARS-CoV-2, also known as COVID-19, is a respiratory disease. The virus is thought to spread mainly from person to person through respiratory droplets produced when an infected person coughs, sneezes or talks.



# PAWTNER IN CARE

**Children's Hospital's newest employee  
and first facility dog, Squid, helps comfort patients**

Squid, an inky-black Labrador retriever mix, walks slowly through the halls of Monroe Carell Jr. Children's Hospital at Vanderbilt, surrounded by a chorus of "awww."

Wearing his work vest and his own Children's Hospital photo ID badge, he occasionally glances up and over his leash at his handler, Leslie Grissim, MA, CCLS, watching and listening for her instructions.

Squid, Children's Hospital's first facility dog, is on his way to the sixth floor to visit Camille Adkinson, 8, who is getting inpatient treatment for acute myeloid leukemia. Over the next year, she'll have five hospital stays lasting three to four weeks each session, time she will spend away from most of her family and without her three dogs.

But her smile is wide on a gray and drizzly late September afternoon as she welcomes Squid and Grissim to her neat and festively decorated hospital room.

written by Nancy Humphrey  
photograph by Donn Jones



*Camille Adkinson, 8, found comfort in spending time with Squid during a recent hospital stay for treatment for acute myeloid leukemia.*







# G

rissim asks Camille what she'd like to do with Squid, and she asks to take him for a walk around the unit. She can't leave her area of the sixth floor because the normal germs outside

the unit are a threat to her small body. So, for about 20 minutes, Camille holds a short leash and walks Squid in a circle around the unit.

Camille talks about her pets to Grissim, who says she's heard Camille has written a book about her experience so far at Children's Hospital. Camille says that Squid is mentioned in her book. "That's awesome," Grissim says. "You'll have to show me sometime." Camille stops, smiles and rubs Squid's silky ears.

After many laps, Squid barks, indicating that he needs a bathroom break, but before he and Grissim leave, Camille blows bubbles through a wand to Squid, who hilariously jumps and pops them. Then she tosses a colorful beach ball to him, which he bounces back to her with his nose.

"You were a good team today," Grissim tells Camille, promising they'll be back soon for another visit.

Squid has performed his job well, providing some valuable emotional therapy to a child in the hospital. He receives ear rubs and praise — "Good Work, Squid!" — from Grissim.

"Facility dogs are trained to engage patients to help them achieve a specific treatment goal," Grissim said. "Engaging a patient using an animal who can decrease anxiety and increase motivation to meet a therapeutic goal is just another tool in our toolbox. Maybe if something else hasn't worked, Squid's presence and the task he will do will be enough to get a child to smile or get out of bed.

"Squid is a very hard worker," Grissim said. "He loves children. He loves people. His presence, overall, brings a level of calm. He brings stress and anxiety down a level. Animal-assisted interventions offer both patients and staff the ability to talk without barriers and the opportunity to express themselves in a way that may not be possible with another human. Connecting with an animal can break down walls."

Camille is one of four patients Squid visited on Sept. 24, 2020. He works Monday-Friday from 10 a.m. to 3 p.m., visiting up to six children a day. Grissim receives requests each weekday morning for Squid visits and she prioritizes them based on the reason for the visit and when it needs to occur.

Also, on this day, Squid and Grissim stop by the nurses' station on the 10th floor pediatric cardiology unit. Caring for children with heart issues, some critically ill, is tough and often emotional for the staff. For those who are interested, Grissim gives the release command and Squid takes turns putting his

front legs over the laps of nurses sitting in chairs. They bend down to hug and talk to him. Grissim gives each nurse who asks time with Squid, never hurrying them.

"We do informal check-ins with the nurses, along with visits to patients," Grissim said. "He's helpful to our staff if they've had a hard week."

## Bringing the program to life

Squid is a member of the Patient- and Family-Centered Care team. He joined the staff in February 2020 thanks to the generosity of Mars Petcare. The Facility Dog Program at Children's Hospital was established through a collaboration with Mars Petcare to support a full-time facility dog and a staff position for coordination of the program, with the overall goal of showing the positive impact a facility dog can have on patients, family and staff.

"In the past year, we've seen more people than ever before turning to pets as a source of comfort, and we've loved seeing the positive impact Squid has made for the children, families, and staff at Monroe Carell Jr. Children's Hospital at Vanderbilt," said Craig Neely, vice president of Marketing at Mars Petcare North America. "We're thrilled to partner with the team at Vanderbilt to bring this facility dog program to life."

The work to bring Squid to Children's Hospital began almost three years before Squid came to Nashville.

The Children's Hospital team, led by Janet Cross, MEd, CCLS, CPXP, administrative director of Patient- and Family-Centered Care, first contacted Vanderbilt University Medical Center's Development Office, to help identify potential funding. Through its Better Cities for Pets program, Mars Petcare North America enthusiastically agreed to fund the project for three years.

Once funding was secured, Grissim and Erin Munn, Child Life Specialist 3, were chosen as the dog's handler and secondary handler, respectively, before the application was submitted to Canine Companions for Independence (CCI), a nonprofit organization that provides highly trained assistance dogs.

Children's Hospital was placed on a waiting list for acceptance into the program. The acceptance came one and a half years later, just as Squid was completing an extensive two-year training regime.

Squid and his siblings (a litter of eight), born in Santa Rosa, California, were delivered to different regions of the country for training about eight weeks after they were born.

**"Squid is a very hard worker. He loves children. He loves people. His presence, overall, brings a level of calm."**

Canine Companions puppies are raised by volunteers who take them to puppy classes to teach them basic obedience and house manners. When they are old enough to enter the organization's professional training program, the dogs come to one of six regional training centers.

Squid, sent to Orlando, Florida, was raised under the Canine Companions Prison Puppy Raising Program, which partners with the Gadsden Correctional Facility in Quincy, Florida.

Squid spent nearly one year under the care of a female inmate, then was transferred to another puppy raiser, called a finisher, for more socialization, then back to the CCI campus in Orlando. Professional trainers teach the dogs the advanced commands they need to obtain treatment goals — which for Squid as a facility dog are engaging patients in their treatment and providing comfort and affection to support families and hospital staff experiencing the impact of a child's intense medical situations.

*Squid celebrated his 3rd birthday Nov. 7, 2020, with a virtual party with patients and families.*



DOWN JONES

After graduating from the program (dogs must be evaluated for their temperament and must be highly proficient in their skills), Squid completed an intensive two-week instruction in Orlando in early February with Grissim and Munn. On Feb. 14, 2020, after his graduation, the trio took an airplane back to Nashville. Three days later, Squid began easing into his job at Children's Hospital.

Squid is owned by CCI. Grissim must be re-assessed periodically by CCI, and she frequently updates the organization about Squid's weight and veterinary visits. Grissim, Cross and Munn have calls with Mars Petcare every other month to update them on Squid's progress. Facility dogs work about eight years. After that time, they retire and spend their golden years just being a pet.

"Over the years, the positive impact that facility dogs have on children in hospitals has been well documented," Cross said. "I can't say enough good things about the work that Leslie and Squid are doing. They recently helped with a school-age patient in intensive care who needed to be extubated. The child was very anxious about it and Leslie and Squid stayed with the child during the extubation and she did very well. You can tell just by watching Squid that he's so well trained. He knows what he's doing."

Cross said the COVID-19 pandemic has probably helped Squid to acclimate more quickly to his new hospital surroundings. "They tell you in training it probably takes four to six months for the dog to acclimate to a new hospital, but with COVID-19, Squid came in February, and we pretty much shut down in March (limiting visitors), so Squid didn't have to get used to all the distractions of having a lot of people around. We think, because of that, he probably had an easier time acclimating."

## Home life

Squid lives in Brentwood, Tennessee, with Grissim, her two adult sons (when they are home from medical school and college) and German Shepherd mix Sasha, cat, snake and tarantula. "The lid's secure," Grissim jokes.

In addition to becoming comfortable in his work environment, Squid also needed to acclimate to living with Grissim. If she goes on vacation or somewhere she can't take Squid, Munn, who lives close to Grissim, steps in to care for Squid.

Grissim has been at Children's Hospital as a Child Life Specialist for 27 years. When the opportunity came up to apply for the position of Squid's handler, she jumped on it.

"I've had dogs since I was a youngster. The routineness of taking care of a dog and being with a dog is not new for me. But the excitement of starting this new program, in addition to being able to bring this furry, fun guy to work with me every day to do amazing things, was very attractive to me. I'm bringing the skills of working with patients and families in a



family-centered environment with me (to this new role). Bringing this very highly trained professional dog into this setting is very, very exciting.”

At home, Squid needs to remain in his crate for rest and sleep while he’s adjusting to his home and to Grissim. He can’t go to dog parks or run free with other dogs (besides Grissim’s Sasha, Vanderbilt University Medical Center’s other facility dog, Norman, housed in the Department of Hearing and Speech Sciences in Medical Center East, and other CCI graduate friends in Nashville).

Grissim inserts three to five short (5- to 15-minute) training sessions into Squid’s day so he can maintain his skills and work on new ones as well.

*Patients get to choose what they would like to do with Squid during a visit, like play fetch or get a “hug.” Patient D.J. Townsend, 17, took Squid to the Children’s Hospital outside koi pond. \*note: Squid’s handler Leslie Grissim wears a face shield on this day to communicate with patients and families who need to read lips.*

Before his workday begins, Squid must be groomed (hair and teeth brushed and nails and ears checked). And he gets at least an hour of exercise a day, including two walks and playing fetch. He gets a professional bath every three to four weeks with a spot bath in between.

And even though he’s a dog, he’s a working professional, just like any other staff member at Children’s Hospital. So, there are expectations for those who encounter Squid at work.

It’s not OK for bystanders to pet or distract him while he’s working, and staff know not to interrupt a Squid visit at the bedside unless it’s for timely medications or vital signs that can’t wait. “Ultimately, it’s the patient’s choice,” Grissim said. “If the patient wants to invite a nurse in to see Squid, sure that’s OK, but the patient needs that total time with Squid.”

Unless “released” to play, Squid must maintain control, a task that he’s becoming better at as he gets a little older, Grissim said. So, no jumping on or rushing at people. And he can’t accept treats from anyone other than Grissim — his treats are

DOWN JONES





the tiny pieces of kibble extracted from Grissim's fanny pack that he gets for a job well done.

Squid can perform more than 40 commands, including basic ones like "sit" and "stay." They include "visit" (Squid rests his head on a child's lap if they're sitting, or nose to nose for a child who is in bed); "lap" (he puts his front paws up and into someone's lap for a hug); "cover" (Squid places his legs gently over the top of a patient's legs, like a weighted blanket); and "nudge," often used for a sedated child, (he gently nudges the child's hand with his nose).

Grissim carries a set of laminated flip cards showing the commands with her, so children can visually select what they want to Squid to do. He can tug a wagon or basket and pull it along, open a refrigerator door and drawers and turn light switches on and off.

Cross said that Children's Hospital hopes to soon add more facility dogs to its team. Texas Children's Hospital has three; Children's Hospitals of Atlanta has over a dozen.

"Squid is only able to see at most six children a day, but there are models out there with each service having its own dog — cardiology, oncology, etc. We could certainly put more dogs to work. We just have to find the funding."

On a September afternoon, Squid and Grissim stop by 17-year-old D.J. Townsend's room for a much-needed distraction for D.J. who is recuperating from a complicated spinal surgery.

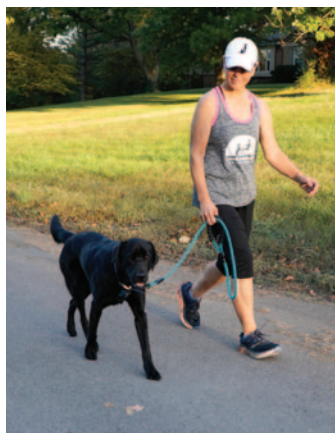
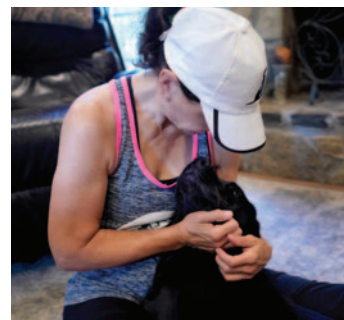
Already in the hospital for several weeks with about six weeks left to go, D.J. wears a "halo," a medical device used to stabilize the cervical spine after spine surgery. He is limited as to what he can do and where he can go.

When Grissim asks D.J. what he'd like to do with Squid, he already has something in mind — he wants to take Squid from his room, on the eighth floor of Children's Hospital, down the elevator to the main entrance and outside to the pond filled with beautiful orange, white and black koi — a first for Squid, but not for D.J.

"I like to stand back and let the patient interact with Squid," Grissim said before the visit with D.J. "It gives them control and lets them guide the interaction."

D.J. sits down carefully in a wheelchair outside his room and Grissim hands him a short leash designed just for patients. She holds Squid's longer leash attached to a prong collar designed for training. "You show us the way, D.J.," Grissim says. "We'll follow you."

D.J. smiles as he, Squid, Grissim and his mother walk out of the unit. When they return to his room after about 10 minutes at the koi pond, Grissim directs Squid to gently put his legs onto D.J.'s lap. D.J. puts his left arm around Squid's neck and scratches his silky ears with his right hand. "He's awesome," D.J. says. 🐾 hope



## A day in the life of Squid

- 6:15 a.m.** – Wake up, stretch; go outside and hurry back inside for breakfast
- 6:30 – 9 a.m.** – Rest in kennel; 10 minutes of training; walk; grooming; hair and teeth brushed
- 9 a.m.** – Car ride to work
- 9:45 a.m.** – Arrive at Children's Hospital
- 10 a.m.** – Leslie gathers information in her office about patients to see for the day. (Squid stays in a kennel while in Leslie's office to make him feel safe, secure and relaxed before he meets people.)
- 10:30 a.m.** – See first patient
- 11 a.m.** – Bathroom break and 10-minute training session
- 11:30 a.m.** – See another patient or staff member
- Noon** – Playtime! Squid gets to play in open spaces like the playroom or Children's Hospital foyer and with Norman (another CCI dog based in Medical Center East).
- 1-3 p.m.** – See more patients; interspersed with short training sessions on new techniques and tricks that help amuse our patients
- 3 p.m.** – Head home with Leslie
- 4 p.m.** – Playtime with Sasha (Leslie's dog) at home; rest; more playtime
- 5 p.m.** – Dinnertime!
- 6 p.m.** – Evening walk
- 7 p.m.** – Playtime with Sasha; grooming
- 8 p.m.** – Bathroom break
- 9 p.m.** – Bedtime



*Cary Nicks Jr. was born at 22 weeks' gestation and spent six months in the hospital. He is now thriving.*



# A Fighting Chance

*Tiny Baby Team provides dedicated care for  
the smallest premature newborns*

Mary Nicks remembers frantically typing in a Google search from her home in Linden, Tennessee, desperate to find the nearest hospital equipped to care for her twins who were about to arrive far too soon.

Her search for a medical center that could provide intensive care for infants born at 22 weeks of gestation led her to Monroe Carell Jr. Children's Hospital at Vanderbilt, two hours away in Nashville. She read that the Mildred Stahlman Division of Neonatology at Children's Hospital is ranked one of the top programs in the nation for the care of critically ill newborns and premature babies. The Level IV NICU was one of the first hospital programs in the world to care specifically for preterm infants, and the Children's Hospital is the Regional Perinatal Center for Middle Tennessee.

"We were terrified," Nicks said. "I remember having just a big fear of the unknown. I had an incompetent cervix, and I already knew that I wouldn't make it to term. I just didn't know I would deliver my twins as early as I did. When my doctor here confirmed that I was dilated, and they sent me home, I Googled 'what hospital would try to save a baby at 22 weeks?'"

She and her husband, Cary, began driving toward Nashville.

written by [Jill Clendenen](#)  
photograph by [Susan Urmy](#)



## More than 1,400 babies are admitted to the Children's Hospital's Neonatal Intensive Care Unit (NICU) each year.

What the Nicks family didn't learn from that quick internet search is that the hospital also has a specialized Tiny Baby Team to provide the best evidence-based care to improve survival and long-term outcomes for infants born extremely prematurely.

This multidisciplinary group includes approximately 50 health care professionals — physicians, nurse practitioners, nurses, physician assistants, respiratory therapists, occupational therapists, physical therapists, child life specialists, medical receptionists and others — who manage the complex, intensive care of these tiny newborns as well as support and educate their families.

Amazing advances have been made over the past decade in premature infant intensive care, and now the survival rate for infants born in the United States at just 28 weeks is more than 90% with excellent neurological outcomes. However, the survival rate for babies born before 25 weeks' gestation is lower. And when a baby is born before 23 weeks' gestation, that survival rate drops dramatically.

The average survival rate at U.S. hospitals for an infant born at 22 weeks' gestation is less than 20%. At Children's Hospital, the survival rate for infants born this early at the hospital is now 50%, a significant increase due to the efforts of the Tiny Baby Team. Additionally, the survival rate at Children's Hospital for infants at 25 weeks' gestation is 87% and at 24 weeks, survival averages 64%. Unfortunately, if a severely premature infant is born at another hospital and transferred to Children's Hospital, their survival rate is significantly lower.

"Some pediatric hospitals around the country with centers of excellence dedicated to the care of extremely low gestational age neonates have achieved a 78% survival rate at 22-23 weeks, and that's why we formed the Tiny Baby Team in the summer of 2019," said neonatologist Maria Gillam-Krakauer, MD, MEd, the team's physician leader.

"We have a huge number of people here who are dedicated to improving things for this group of patients and families in Middle Tennessee. There is great humility in these team members as they put aside their individual pride to develop a shared expertise and put patient care and outcomes first. No matter who is on that infant's care team that day, they get the same, high-quality care."

Infants born extremely prematurely face a cascade of critical health issues. Severely underdeveloped lungs result in respiratory distress, often requiring at-home oxygen due to chronic lung disease. About 10% of micro preemies develop moderate to severe cerebral palsy. Micro preemies also often have immature digestive systems that lead to poor nutrition absorption as well as the potential for long-term digestive complications. About 20% of micro preemies are diagnosed with severe cognitive disabilities by school age, and another 20% have mild to moderate cognitive problems. Between 2% and 3% of micro preemies have permanent vision or hearing impairment.

For nearly a year, the Children's Hospital Tiny Baby Team pored over published medical studies for the most current research related to the care of extremely premature infants. They used this to develop an evidence-based care strategy designed to protect the babies' vulnerable neurological systems.

For the first two weeks after birth, the team follows strict care guidelines, including minimal handling to reduce stimulation, carefully positioning the head to reduce the risk of brain bleeds and stringent management of the infants' fluids and respiration.

"Hands-on care times are scheduled every six hours to allow the babies uninterrupted sleep," said Jennifer Cortez, RN, nursing lead for the Tiny Baby Team. "Limited stimulation is really what's important for these little ones. If you do anything that increases their blood pressure even a little bit, it can affect those fragile little blood vessels in their head. A lot of times, bleeding in their head is what leads to just devastating outcomes."

In addition to very real medical issues, a clinician's implicit bias might also negatively impact the care of premature infants, Gilliam-Krakauer said. Studies have shown that when providers complete questionnaires related to patients with different ages and conditions, they more often select to offer intensive care to older children and adults with lower survival prognoses over offering intensive care to an extremely premature baby.

"We also see this bias in the language clinicians use to describe premature infants; it's often not patient-first language," she said. "It's hard to understand why this happens, but it's thought to be because when a baby is born extremely premature, that baby is unable to show personality, wants and desires. This needs to be addressed and requires a reset in the medical community."

The Tiny Baby Team also hopes to improve communication with community-based hospitals and providers who care for expectant mothers before they arrive at centers specializing in neonatal care such as Children's Hospital. For example, if an obstetrician believes a woman is likely to deliver prematurely, giving the mother a steroid injection aids maturation of the infant's lungs and skin as well as reduces the infant's risk of bleeding in the brain.



Mary and Cary Nicks Sr. with their son, Cary Nicks Jr., 1, the first baby born at 22 weeks to survive at Children's Hospital. Cary Jr. had a twin, Adalynn, who did not survive.

"Our referral base is north to Bowling Green and Paducah, east to Cookeville and south to Fayetteville," Gilliam-Krakauer said. "The challenges we face are delays in transfer of the mother because providers don't realize that the survival at 22-23 weeks is improving, or failure to give the mother steroids as soon they realize she has preterm labor."

Over two days as Children's Hospital clinicians managed Mary's labor and administered steroids, the Tiny Baby Team also talked to the Nicks about the immediate and long-term prognosis for micro preemies. While the detailed information was appreciated, processing everything was understandably tough, Mary said.

Because of the decreased chance of their twins surviving if delivered at 22 weeks of gestation or of having a good quality of life due to extensive health challenges if they survived, the couple made the hard choice to not take extraordinary measures to save their infants. They told their care team they would hold the babies when they were born and allow them to die naturally.

Then, on Nov. 29, 2019, just 30 minutes before Mary was taken back for an emergency C-section, they changed their minds.

"We were in a really hard spot," Mary said. "But even with the horrible odds we had been given, we decided we wanted them to try everything they could to save our babies."

When Cary Nicks Jr. and Adalynn Nicks were born, the Tiny Baby Team immediately began lifesaving care. The infants were struggling through every moment, and their son Cary, seemed to be the sickest.

"We thought we would lose him and not her," Mary remembered. "They were just so tiny that they couldn't draw blood samples. When Adalynn passed, it was very sudden. The team was able to run cultures from her to find out what was wrong and use that information to treat Cary. In reality, she saved her brother's life. Adalynn was his little angel."

Cortez was caring for Adalynn on the night the twins' condition quickly deteriorated, and she drew the blood sample that ultimately charted the direction for Cary's care.

"Often, with tiny babies like these, it's just the most minute changes in their vital signs that signal something is wrong," she said. "You see how much these little ones are fighting."

Adalynn's test results showed she had developed *Escherichia coli* (*E. coli*) sepsis, a blood stream infection. The Tiny Baby Team used this information to quickly intervene with antibiotics for Cary.

As he was fighting this infection in the Neonatal Intensive Care Unit (NICU), Cary also developed necrotizing enterocolitis or NEC, a serious disease that causes infection and damage to the bowel lining. Pediatric surgeon Irving Zamora, MD, MPH, performed emergency surgery to place an abdominal drainage tube.

Over the next five months — during which time a pandemic began — Cary continued to receive intensive care at Children's Hospital, growing and meeting critical milestones. His parents were also educated by the team about how to feed him, how to position him properly for sleep, warning signs to watch for, and other important caretaking skills for when they returned home.

Cary became the first baby born at 22 weeks who survived since the Tiny Baby Team was formed, a significant milestone for the team, and they are emphatically determined to build on this success.

"This is a story of hope, but it also emphasizes how much work we have to do," said Gilliam-Krakauer. "This shows there can be survival, and there can be good outcomes, even at this very early age. But one of their children died. We were only able to save one of their twins. That shows how much room for improvement we still have."

When the COVID-19 pandemic began in March 2020, hospital visitation was limited and only one parent could be inside the facility with their son at a time. Thankfully, when Cary was well enough, he was moved into a patient room with a bed for one parent to stay close to him overnight. That made the challenges caused by the pandemic a bit easier, Mary said.

On May 5, members of Tiny Baby Team and the NICU said happy goodbyes to Cary, as his parents settled him in a car seat for the first time and drove home.

And he's doing well. He turned 1 year old in November 2020, but adjusting for how early he was born, developmentally

he's considered to be 7 months old. Ready to explore everything, he's beginning to 'army crawl.' He's had two teeth come in, and his once-fragile lungs are doing so well he no longer has to be seen by a pulmonologist.

"By the time we brought him home, he weighed over 9 pounds," Mary said. "He came home on oxygen, but just three months after being home, we completely weaned him off. As of right now, he just has chronic lung disease and bronchopulmonary dysplasia. And he has some development delays. That's all."

Cary recently underwent surgery at Children's Hospital, again with Zamora, to successfully repair three hernias, and his parents were grateful to already have a strong relationship and connection with the surgeon.

"The Children's Hospital at Vanderbilt is a great hospital, and that's why we continue to do most of our care at Vanderbilt," Mary said. "We trust them, and they were just so wonderful. And we love Dr. Krakauer. She was absolutely amazing, and she always took the time to explain in detail everything that was happening and what we could expect moving forward."

Although the risks of a negative outcome were extremely

high when their twins were born so early, the Nicks said having experts there non-stop to explain everything so they could make informed decisions made them feel empowered. The Tiny Baby Team also gives the family a lot of credit.

"These parents showed tremendous resilience and strength," Gillam-Krakauer said. "They gave that to him, and that's why he survived the odds."

"Every baby is different, but you just have to have faith and take it day by day," Mary said. "These little miracle babies — they're strong. Now Cary, our baby, is just a baby. He really has no significant, ongoing problems that will impact his long-term quality of life."

Hearing about how well Cary and other once-tiny infants are doing gives the Tiny Baby Team affirmation that their efforts are significant and can transform the lives of these families, Cortez said.

"As a team, we've had a lot of victories, and we've had a lot of losses, too, which is terrible. When you see a baby turn the corner, and there is a positive outcome, it makes it all worthwhile." 🦋 hope

## Unplanned extubations in preterm infants studied

Unplanned extubations (UEs) in adult and pediatric populations have long been associated with poor clinical outcomes and increased costs to health care systems.

A very common adverse event in intensive care unit settings, the long-term outcomes of UEs in critically ill, preterm infants have never been studied until now.

UEs are defined as any removal of the endotracheal tube that the medical team did not plan in advance.

These include breathing tubes dislodged by the patient, removed accidentally during routine nursing and medical care and those intentionally removed during an acute resuscitation event.

In a retrospective matched cohort study, a team of investigators at Monroe Carell Jr. Children's Hospital at Vanderbilt led by Dupree Hatch, MD, MPH, assistant professor of Pediatrics, Neonatology Division, was the first to describe the impact that UEs have on preterm infants.

"While our findings were congruent with the adult and pediatric intensive care unit populations, we discovered preterm in-

fant outcomes after UE were worse and the magnitude was more severe," he said.

The study, published in *Pediatrics* this month, documented that neonates experienced worse inpatient outcomes, extended length of stay and increased hospital costs.

"Our study was the first to describe what these UEs mean for the baby as well as what impact it has on the Neonatal Intensive Care Unit (NICU)," said Hatch, "The findings are helpful for those working to lower rates of UEs and gives us the ammunition to continue to do this important quality improvement work."

"Spending money on prevention will help save lives and costs. If teams have more resources to deal with unplanned extubations, they can not only improve patient care, but save money."

The research team looked at a cohort of very low birthweight infants, born less than 3.3 pounds, who required mechanical ventilation. The short-term results of UEs includes reintubation, oxygen desaturation and the need for CPR.

The study was able to determine that

UEs in preterm infants are associated with significantly poorer hospital outcomes and increased financial costs.

According to study results, exposure to one or more UEs was associated with a nearly one-week increase in the duration of mechanical ventilation, an additional 10 days in the hospital and nearly \$50,000 increase in total hospital costs.

UEs were also associated with worsened respiratory outcomes, which could also prolong the need for mechanical ventilation.

Conservative estimates show direct hospital costs of about \$60 million as a result of UEs in babies less than 28 weeks at birth, said Hatch.

With national efforts to decrease the rate of UEs drawing more attention by quality improvement teams, Hatch hoped evidence-based interventions to prevent UEs, such as using multi-person teams for re-taping the breathing tube and transferring or moving patients, will become standard practice in the NICU.

— by Jessica Pasley



# Tiny Baby Team



The Mildred Stahlman Division of Neonatology at Monroe Carell Jr. Children's Hospital at Vanderbilt is ranked No. 17 in the nation as a top program for the care of critically ill newborns and premature babies.

**50**

number of health care professionals on the Tiny Baby Team

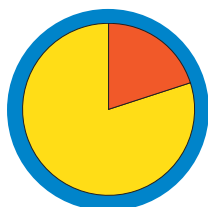


**1,400**

number of babies admitted to NICU each year

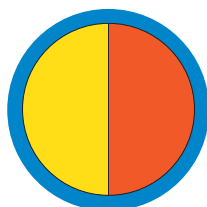


The Tiny Baby Team's intervention and evidence-based care is improving survival and long-term outcomes for extremely premature infants.



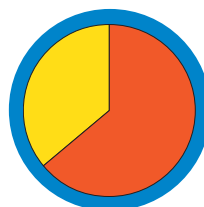
**20%**

average survival rate at U.S. hospitals for infants born at 22 weeks' gestation



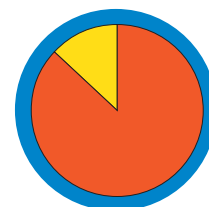
**50%**

average survival rate at Children's Hospital for infants born at 22 weeks' gestation



**64%**

average survival rate at U.S. hospitals for infants born at 25 weeks' gestation



**87%**

average survival rate at Children's Hospital for infants born at 25 weeks' gestation

Micro preemies are at increased risk for developing severe health issues.



**2-3%**

number of micro preemies that are diagnosed with permanent vision or hearing impairment



**20%**

number of micro preemies that are diagnosed with severe cognitive disabilities by school age



**10%**

number of micro preemies that develop moderate to severe cerebral palsy

Carliyah Taylor, 10



# Back in Action

*Carliyah Taylor is hitting home runs again after a major car accident, which led to the discovery of a rare abdominal cyst.*

written by Christina Echegaray

photograph by Donn Jones

**O**n March 3, 2020, shortly after 7 p.m., Ashley Cash got the phone call no parent ever wants to get. There had been an accident.

Her three daughters, Kanaiah Taylor, 15, Zakaiah Taylor, 12, and Carliyah Taylor, then 9, had been passengers in a motor vehicle accident while in their grandparents' car. They were en route from Lewisburg, Tennessee, to nearby Shelbyville for travel team basketball practice when another car swerved into their lane causing a wreck.

Kanaiah, Cash's oldest daughter, called her mom. "She told me, 'Mama, there's been a wreck,'" Cash said, adding that Kanaiah wasn't sure Carliyah was alive. Cash drove to the crash site arriving nearly the same time as emergency medical personnel. The other girls were in shock and scraped up. Their grandfather had been able to get out of the car. Their grandmother had to be extricated from the car by firefighters and had several injuries, requiring hospitalization.

Unconscious with injuries unknown following the crash, Carliyah was brought by Life-Flight helicopter to Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville.

Children's Hospital is the only comprehensive regional pediatric center within a 150-mile radius to be verified by American College of Surgeons, the country's leading surgical care organization, as a Level 1 pediatric trauma center. The certification recognizes the hospital's commitment to provide the highest level of care for injured pediatric patients from Alabama to Kentucky and throughout Tennessee.

Only 63 children's hospitals in the country have ACS Level 1 pediatric trauma center status, and Children's Hospital is only one of two hospitals in Tennessee to earn the verification. Children's Hospital is equipped to treat patients with a wide range of injuries resulting from incidents like all-terrain vehicle accidents, motor vehicle crashes, falls, gunshot wounds, and bicycle wrecks, among other mechanisms.

Also, as a larger comprehensive pediatric center, Children's Hospital has the ability to fully evaluate and treat pediatric patients for their injuries and beyond, pulling in board-certified medical and surgical pediatric specialists from more than 30 specialties.

“Our trauma program has broad outreach, and we get children from all over Tennessee, into northern Alabama and south-west Kentucky. When children are brought to us, parents can be assured their children are coming to one of the top institutions in the country for trauma care and comprehensive pediatric care,” said Harold “Bo” Lovvorn III, MD, medical director of the Pediatric Trauma Program at Children’s Hospital and associate professor of Pediatric Surgery. “We look over these children in every detail. We have the expertise as an institution to take care of a child from the physicians, surgeons, nurses, radiologists, anesthesiologists, and beyond.”

Children’s Hospital’s Pediatric Trauma service admits more than 1,200 pediatric trauma patients each year. The collaboration across multiple disciplines, care units and behind-the-scenes staff helps patients get the quality, compassionate care they need.

That cross-section of expertise also helps in unique cases like Carliyah’s. Her trauma injuries didn’t tell the full story of what was happening inside her body.

When Carliyah, who was intubated at the scene, arrived at Children’s Hospital, Lovvorn said, both her lungs were bruised, consistent with trauma, and she had a swollen eye and abrasions on her face. She had a concussion from hitting her head during the accident. Evaluations revealed she should recover fully from the accident.

Her blood work, however, showed that she had elevated lipase levels, an enzyme in the body related to the function of the pancreas. A CT scan of her abdomen didn’t show any trauma injury. But it revealed something that the doctors and radiologist never expected to find — a complex choledochal cyst in her bile duct, completely unrelated to the accident.

Choledochal cysts are congenital — present from birth — and are a developmental abnormality of the bile duct. They occur in about one in every 100,000 people. While they are congenital, most are never detected until later in adulthood, when there is increased risk for pancreatitis and even bile duct cancer.

“Here this family has just been through a major accident — one that could have been really tragic — and you’re telling them, your daughter is going to recover, but she has another major problem we have to sit down and talk about,” Lovvorn said.

“(These cysts) can cause a lot of issues — chronic pancreatitis, poor bile flow into the intestine, bile duct infection, chronic ab-

dominal pain. Removing the cyst can resolve the chronic pancreatitis, help with better digestion, reduce risk of colon dryness or bile duct infection. Removing it later in life increases that chance for bile duct cancer. About 40% of adults with these will develop cancer.”

Carliyah’s cyst was about 22 millimeters in size, when that area of the bile duct known as the biliary tree should be about 2-3 millimeters in size.

When Cash found out about Carliyah’s cyst, she said it made sense. Carliyah, an active athlete who plays travel softball and basketball, has always had a healthy appetite. But many times, she has complained of abdominal pain.

“He told me they found something else not related to the wreck — a cyst. He told me this could cause problems for her own the road, and when she’s 40 or 50 years old, it could cause cancer,” Cash said. “I just thought she was eating so much. I had told her ‘you’re complaining your stomach hurts because you’re eating so much.’”

Just as Cash was told Carliyah had a cyst, the COVID-19 pandemic hit. Additionally, all non-emergent surgeries were put on hold. Lovvorn wanted to remove the cyst but knew the procedure would have to wait.

After a few days in the hospital following the accident, Carliyah was sent home.

She returned to Children’s Hospital in May to have an MRI to give Lovvorn a better sense of the size and scope of the choledochal cyst. Remaining “visits” were virtual via telehealth because of the pandemic until surgery could be performed.

At the end of August, Lovvorn performed a four-hour surgery to carefully separate the cyst, dissect part of the liver and reconnect the intestine.

“I’ve done a lot of these operations before, and the typical stay is about four or five days. Carliyah went home in two days,” Lovvorn said. “Then I see her a couple weeks later, and she was totally fine — you wouldn’t have known anything was wrong with her. She is one Tennessee-tough kid.”

In October 2020, a little more than a month after her surgery, Carliyah, now 10, was back on the baseball field, playing outfield and second base for her team, the Dirt Divas. In one weekend, she hit three home runs.

“This child is a go getter. She is loving all the time — just full of life, full of energy and all turning flips,” Cash said. “Nothing keeps that child down.”  hope

“When children are brought to us, parents can be assured their children are coming to one of the top institutions in the country for trauma care and comprehensive pediatric care.”



# pioneers hope

*At Monroe Carell Jr. Children's Hospital at Vanderbilt, our work extends beyond patient exam rooms. We are also searching for discoveries to offer better treatments, provide quality care and train the next generation of clinicians. The profiles here represent only a sampling of the tireless work performed daily to make Children's Hospital a place of unwavering hope. In each issue, we also include a profile to highlight our longstanding partnership with our community pediatricians who help ensure all children receive the best care each and every day.*

**Wagma Dorani, RN**, was born and raised in Afghanistan, but to her, Nashville — and more specifically Monroe Carell Jr. Children's Hospital at Vanderbilt — is home.

Twenty years ago, at the age of 20 and newly married, she left all that was familiar to her and came to the United States to settle in Nashville with her husband. She did not speak English and within three years she had three children. She recalls fondly taking them on sightseeing tours to Children's Hospital where they would visit the butterfly garden and eat in the food court of the brand-new facility (built in 2004).

"This is the world of opportunity. It was a big change for me at the beginning," she said. "Afghanistan is a Third World country, so to me Children's is beautiful. Everything is just amazing here.

"I never thought I'd have an office here and work here one day. It's a huge privilege to work here," said Dorani, the senior program manager for the patient safety team at Children's.

When her children started attending school, Dorani enrolled in Nashville State Community College and set about learning English.

"My husband made sure I got an education because he couldn't go to school because he had to work a lot. As a child I wanted to be a doctor. When I got here (to the U.S.), I felt it was too late for that, but I could be a nurse and help others because I always wanted to help somebody in need."

Dorani earned her bachelor's degree in nursing from Tennessee State University and during her psychiatry rotation, she discovered a passion for caring for children and adolescents with mental health issues.

"That patient population just touched my heart. Coming from Afghanistan where no one even understands mental health — they don't acknowledge it and there's not a lot of treatment — here I just felt like I could make a difference. I could put myself in that situation, coming from a different background and facing a lot of difficulties. With this vulnerable population, this would be the best fit."



DONN JONES

Dorani started as a nurse in the Vanderbilt Psychiatric Hospital on the child/adolescent unit where she worked from 2014-2019. She was given the opportunity to be a clinical staff leader for two years, and then in 2019, a position opened at Children's Hospital.

"Vanderbilt is like — I've never felt like an outsider, like an immigrant. I feel like I'm always home. Having my family away from me, this is my family. I cannot be grateful enough. I've always been protected."

In her role as senior program manager for the patient safety team, she manages 44 mental health specialists and technicians

who take care of Children's Hospital patients with mental health illnesses who present through the Emergency Department.

"The staff that are providing care for these kids are well trained. Those on the staff have compassion for this population so they can provide safe care. Safety for me is the main priority for this population. At the end of day, they are kids. They still need that help and are still vulnerable."

Her three children who used to tag along with her for fun outings to Children's Hospital are now 17, 18 and 19. Two of them are studying pre-med. She and her husband also have a fourth child, 8. Dorani is working toward her master's degree in Nursing Management and Administration from Aspen University's online program.

— by Kathy Whitney



When COVID-19 swept into the United States in March 2020, **Michael DeBaun, MD, MPH**, was ready.

That month the Vanderbilt-Meharry Sickle Cell Disease Center of Excellence he directs shifted to telemedicine. Thanks to a generous private donation, DeBaun and his colleagues distributed iPads and other technology so the families they served could access medical care safely and remotely.

Two months later, when the death of George Floyd at the hands of Minneapolis police sparked a national movement to confront systemic racism, DeBaun was asked to support VUMC leadership.

As co-chair of the newly established Racial Equity Task Force at Vanderbilt University Medical Center (VUMC), his goals are to help improve upward mobility for all employees, increase the community's access to health care and encourage diversity among trainees and other recipients of educational and research opportunities.

Being ready is nothing new for DeBaun, JC Peterson Professor of Pediatrics and Medicine and vice chair for Clinical and Translational Research in the Department of Pediatrics.

Born in St. Louis, Missouri, in 1960, DeBaun grew up in a family of teachers and doers. "I came from a family tradition where the focus on social justice and activism — specifically taking action to improve the lives of others — was part of our ethos," he said.

DeBaun attended Howard University, where he graduated with honors. He earned his MD and master's degree in Health Sciences Research from Stanford University in 1987.

At St. Louis Children's Hospital and Washington University School of Medicine, DeBaun served as a pediatric resident, chief resident and hematology-oncology fellow. There he began his career-long focus on sickle cell disease (SCD), which afflicts Blacks disproportionately, causing severe pain, stroke, disability and premature death.

After earning a master's degree in public health from the Johns Hopkins School of Public Health and Hygiene, he joined the faculty at Washington University School of Medicine, where he earned accolades for his research and mentorship of area high school students.

In 2010, DeBaun and his family moved to Nashville, where he founded the Sickle Cell Disease Center of Excellence jointly run by VUMC and Meharry Medical College. The center was one of the first to employ a medical care home model for children and adults.

DeBaun is internationally known for his work to treat and prevent strokes in children caused by blood vessel narrowing and sickle-shaped red blood cells, which can obstruct capillaries.

Three years ago, he and his colleagues reported that a multidisciplinary approach reduced by nearly 90% the maternal death rate among pregnant women with sickle cell disease at a major teaching hospital in Ghana.

With Adetola Kassim, MD, MS, clinical director of the Adult Stem Cell Transplant Program, and a "learning collaborative" of clinician-researchers from Germany, the Netherlands, United Kingdom, Nigeria, Saudi Arabia, India and Brazil, DeBaun is evaluating a modified form of stem cell (bone marrow) transplantation to cure sickle cell disease.

The technique is haploidentical nonmyeloablative, meaning it does not require the same amount of toxic chemotherapy as other techniques. Equally as important, the donor only has to be a half-genetic match (haploidentical) with their relative,



which dramatically improves access to the procedure to more than 90% of children and adults with SCD.

Preliminary results from the learning collaborative are encouraging, particularly for adults. “We have cured over 30 children and adults with SCD,” DeBaun said.

For his significant contribution to advancing the care of children and adults with SCD, he received the prestigious international 2014 Ernest Beutler Prize and Lecture in Clinical Science from the American Society of Hematology.

When asked how he juggles all of it, DeBaun answered, “The secret is faith and home. Home is my wife ... She’s the anchor. She’s the compass.”

DeBaun and his wife, Sandra, have been married for 33 years, and they have two grown children.

– by Bill Snyder



As a high school senior in Brentwood, Tennessee, **Toni-Ann Wright, MD**, had the opportunity to shadow a pediatrician, and it was after that experience she decided that she would become one too.

That fateful day at the Matthew Walker Comprehensive Health Center in Nashville, Tennessee, showed her that a pediatrician could impact the immediate and long-term health of a child. A few simple words like “eat your broccoli,” had a different meaning when uttered by a pediatrician.

“I was just blown away by how much not only the parents

respect the pediatrician, but how the kids listen to them, too,” Wright said. “So, the parent could say the exact same thing. But once the pediatrician said it, the kids were like, ‘Oh, well, the doctor says I have to eat broccoli.’”

Medicine wasn’t initially her intended career choice. Despite being surrounded by the medical field her whole life, Wright, the oldest of three daughters, planned to study marine biology. Her dad, Wycliffe Wright, MD, is an infectious disease doctor in Nashville, and her mom, Marie Wright, is a nurse. Her parents met while in school in their native Jamaica.

Born in the Bahamas, Wright’s family moved to the United States when she was 4 years old, first in Philadelphia, and later settling in Nashville when she was in eighth grade and where she and her family have remained since, with the exception of schooling. Now, as a pediatrician at Rivergate Pediatrics in Goodlettsville, Tennessee, she takes pride in caring for the community where she grew up.

After that day at Matthew Walker, where she shadowed Ida Michele Williams, MD, Wright decided to study pre-med at Oakwood University in Huntsville, Alabama. She went on to earn her medical degree at Loma Linda University School of Medicine in California.

Entering medical school, she knew she wanted to care for children.

For a brief time, she thought she might want to be an OB-GYN. While she liked caring for women, she was more drawn to the infants. “I realized that after the baby was delivered, I was over at the warmer looking at the newborn baby.”

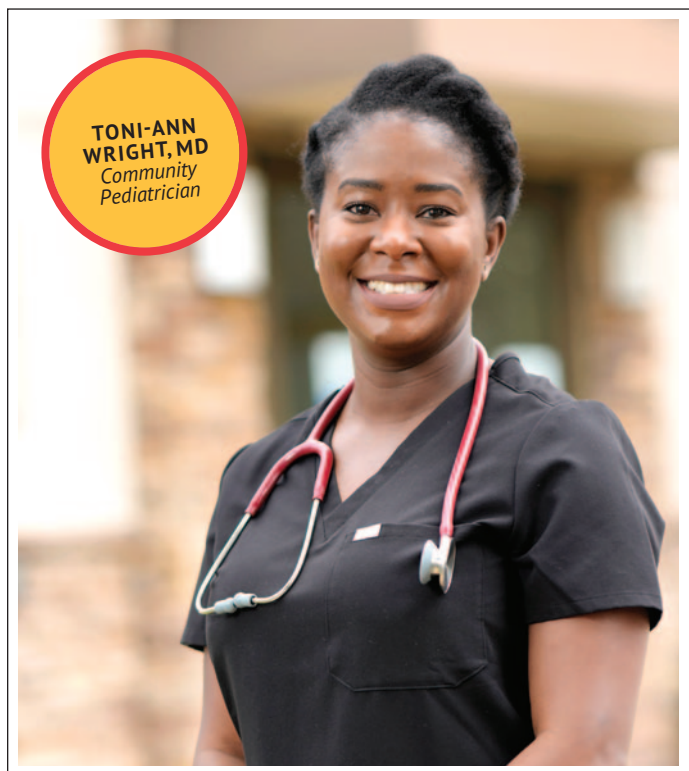
Wright returned to Tennessee to do a residency at University of Tennessee Health Science Center in Memphis, and subsequently stayed on there to work at the Memphis Children’s Clinic, while also moonlighting at Le Bonheur Children’s Hospital Emergency Department.

“My goal was ultimately to come back, which is why I did my residency in Tennessee and then came back to Nashville. I like Nashville. I like my family; we’re pretty close knit. And so, to me, it was a no brainer to come back here.”

She returned to Nashville in 2016, working for two and a half years at the Vanderbilt Children’s After-Hours Clinics, where children and adolescents can be seen outside of their pediatricians’ normal business hours for non-life-threatening illness or injury. She stayed there until joining Rivergate Pediatrics in 2018, where she became the first African American physician partner at the practice.

Having worked with Children’s Hospital as an employee and now as a community pediatrician, she values the partnership between the two.

“I feel comfortable sending my patients there at night if they call and they need immediate care and our office is closed because I know the doctors that I worked with are wonderfully trained and are going to be very compassionate. And I’ll get a note the next day about what happened,” Wright said. “I think





it makes a difference — the kind of care your child gets from someone who's trained specifically to take care of kids. They're not little adults, which is what I try to tell all the parents."

When she is not seeing patients, Wright spends time with her fiancé, Matthew McCartney, and enjoys salsa dancing, hiking, cycling and virtual book club.

— by Christina Echegaray



For **Wallace "Skip" Neblett III, MD**, a five-decade career in Pediatric Surgery was, quite literally, the result of an accident.

Neblett was a biology major at Sewanee: The University of the South in Sewanee, Tennessee, and was making a little money during the summer break before his junior year. He was doing maintenance work for a natural gas company when his tractor flipped over and stranded him on the side of a hill with serious internal injuries.

Neblett was rushed to a hospital in Holly Springs, Mississippi, where his spleen was removed, then transferred to a hospital in Memphis, Tennessee. He spent 10 weeks recovering from an injury to his pancreas and spleen.

"That was really my first significant exposure to medicine and I would say undoubtedly is the reason that I ended up deciding that I wanted to go to medical school," he said.

Neblett, a native of Greenville, Mississippi, was accepted into Vanderbilt University School of Medicine, where fate intervened again his first year, in a very good way. He took a number of classes with graduate students in other majors. One student assigned to sit across from him, Margaret, would become his wife the following summer.

"That was a big year for me to get accepted to and attend the first year of medical school and then to find the person that I was going to spend the rest of my life with," Neblett said.

Neblett received his medical degree from Vanderbilt in 1971 and completed an internship there the following year. He then served as a major in the U.S. Air Force Medical Corps in Elmendorf Air Force Base, Anchorage, Alaska.

He completed his VUMC general surgery residency in 1978 and left briefly to complete a general and thoracic pediatric surgery residency at the Children's Hospital Medical Center in Cincinnati. In 1980, he returned to VUMC as a clinical instructor in surgery, becoming chairman of Pediatric Surgery four years later, a position he held for 27 years.

When Neblett began his surgical training at Vanderbilt, there was no such specialty as Pediatric Surgery. That began under James O'Neill, MD, who joined VUMC as the first pediatric surgeon in 1971 and brought Neblett under his wing.

"The combination of my interest in caring for sick and injured children and being exposed to what pediatric surgery involved by working with Dr. O'Neill during his first two years on the faculty here at Vanderbilt led me to subsequently decide that pediatric surgery was what I wanted to do in my ca-



DONN JONES

reer," Neblett said. "I could not have chosen a more gratifying career or a better place to serve. Our team of caregivers and support personnel is exceptional and work continuously to improve care for our patients and support for their families."

As chair of Pediatric Surgery, Neblett was key to establishing a pediatric surgical residency program in the Department of Pediatric Surgery, one of a select few accredited residencies at that time. In 2004, he received the prestigious John L. Sawyers Award for outstanding contributions to surgical education.

Neblett continues to be active on the Pediatric Surgery faculty, continuing his longtime clinical practice and mentoring surgical residents. When he's not practicing medicine, he's spending time with Margaret, his three children (Jennifer, Sandy and David) and 11 grandchildren.

Neblett has seen colleagues come and go from Vanderbilt over the years, but he never considered leaving.

"For me I always felt like being at Vanderbilt was like being at home," he said. "I trained in general surgery here. I had my first job here. I was chairman of our group for a lot of years and have a very vested interest in ensuring that we continue to be clinically excellent in taking care of patients and providing for the educational needs of our students and residents."

— by Matt Batchelor



Demario and Tamela Davis, with their children (from left) Bailey-Grace, Roman-Parker and Summer-Joy, welcomed their new addition, Carly-Faith, in July 2019. Inspired by Carly-Faith's journey with retinoblastoma, the Davis family now gives back to raise awareness and funds for the disease.

## 2020 Vision

New Orleans Saints linebacker Demario Davis and his wife, Tamela, are used to splitting their time between New Orleans and their home in Nashville. But just as the Davis family was scheduled to be in New Orleans, the COVID-19 pandemic hit, and stay-at-home orders required them to stay put in Nashville for a while. They are so thankful that they did.

Demario and Tamela, along with their children Bailey-Grace, Roman-Parker and Summer-Joy, had recently grown to a family of six with the addition of their youngest daughter, Carly-Faith, in July 2019. When she was just 10 months old, Carly-Faith was diagnosed with retinoblastoma, a type of cancer affecting the retina.

Her parents say that no one can prepare your heart to hear that your child has cancer.

Fortunately for the Davis family, Monroe Carell Jr. Children's Hospital at Vanderbilt was right in their backyard.

"Had we been in New Orleans, the closest place for treatment would have been Houston," Tamela said. "Thankfully, we were home in Nashville, where Monroe Carell Jr. Children's Hospital at Vanderbilt is located. This was a huge blessing and meant we could immediately see a specialist. Carly-Faith was placed

under the care of one of the top research doctors and surgeons for this particular cancer, and this care team quickly became an extension of our family."

With much discussion and prayer, the Davis family decided to move forward with surgery to remove Carly-Faith's left eye only two days after her diagnosis. They then received the good news: Carly-Faith's cancer was removed in time and had not spread outside of the eye or through the nerve from the eye to the brain. They were thrilled to learn that no chemotherapy would be needed.

"We know that there's nothing more difficult for families than hearing that your child has cancer. We've made it our mission to ensure the best possible outcomes for families," said Anthony Daniels, MD, MSc, assistant professor of Ophthalmology and Visual Sciences, Cancer Biology and Radiation Oncology, and Chief of the Division of Ocular Oncology and Pathology at the Vanderbilt Eye Institute. "Through collaboration across teams, we are able to offer the full spectrum of cutting-edge treatments for retinoblastoma, and we can create a tailored treatment plan based on the specific needs of each individual patient. Because of support from those like the Davis family, we can continue to develop newer and more effective treatments in retinoblastoma."

Thankful for the care they received, the Davis family has made it their mission to advocate for patients with retinoblastoma and other childhood cancers.

"This cause is extremely important to our family because all of our lives have been drastically transformed forever by Carly-Faith's diagnosis," Tamela said. "We understand that some families' journeys present more challenges than even we endured. That's why we desire to be a voice to educate."

The Davis family created their own personal fundraising page to encourage their friends, family members and networks to donate to the cause, and they even made a generous donation to kickstart the campaign and match donations dollar for dollar.

"The support and advocacy from the Davis family will make a real difference in our mission to improve the lives of children with retinoblastoma through research, clinical care and training," said Debra Friedman, MD, who holds the E. Bronson Ingram Chair of Pediatric Oncology and is director of the Division of Pediatric Hematology/Oncology. "Support like this provides us the resources to help detect early signs of the disease and provide education to parents and family members navigating a child's diagnosis."

Carly-Faith continues to progress each day and has responded well to her customized prosthetic eye. She is a happy girl who rarely fusses and is always learning new things. Tamela says that even though Carly-Faith is so young, she has a fighting spirit and won't let anything hold her down. Visit [Give.VanderbiltHealth.org/CarlyFaith](https://Give.VanderbiltHealth.org/CarlyFaith) to learn more.

— by Paige Turner

## Lifting Lives

ACM Lifting Lives, the charitable arm of the Academy of Country Music, has made a generous gift to Vanderbilt University Medical Center for programs and research demonstrating the healing power of music to improve the lives of children with autism spectrum disorder.

This gift creates the

ACM Lifting Lives Autism Lab at Vanderbilt Kennedy Center and will establish autism as one of ACM Lifting Lives' signature initiatives while enabling Vanderbilt to expand the reach and impact of its expertise in the field.

The contribution will support the TRIAD (Treatment and Research for Autism Spectrum Disorders) program, Sense Theatre, Music Cognition Lab

and the expansion of telehealth, enabling professionals to provide long-distance education, intervention and monitoring.

"The timing of this gift could not be more advantageous," said Jeffrey Neul, MD, PhD, director of the Vanderbilt Kennedy Center. "The COVID-19 pandemic has made the expansion of telehealth vitally important in treatment of people with developmental disabilities,

as in all areas of health care. Previously, we used remote technologies mostly to provide teachers with tools to use in the classroom. More recently, we have demonstrated that we can use telehealth to accurately diagnose children with autism, monitor their progress and coach parents in best practices. Now we can apply that knowledge to serve far more families."

## Friends Press On

Since 1972, Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt has been supporting the hospital through fundraising, outreach and patient and family programs. Friends members were not going to let a novel coronavirus derail that steadfast commitment.

With social distancing, public health safety measures and limited visitors allowed at Children's Hospital, the group, which has a roster of 3,800 members, knew it had to get creative and pivot to maintain its mission.

A typical year's support from Friends includes lunches for families whose children are in the hospital; art and music supplies for patients to engage in therapeutic activities; sensory supplies for the Emergency Department; bingo for patients; sponsored visits of Disney characters; and more.

Friends has also made several large philanthropic gifts over the years to support programs like care for premature babies, diabetes research, palliative care, pediatric cancer and care for children with complex medical conditions.

With large gatherings cancelled due to COVID-19, Friends' fundraising and recruitment events like Friends & Fashion, An Evening with Friends and the annual kickoff luncheon all went virtual. And members didn't let the new online format hinder their support, as they continued to donate to these new initiatives, further bolstering the group's commitment to keep doing its work from outside the hospital walls.

The 2,000-plus meals that Friends provides monthly to families at the hospital also did not stop. While the group couldn't come into the building to deliver meals, volunteers wearing masks have dropped off meals in the garage of Children's Hospital to a staff member to be distributed to families

inside. Individual members also made and donated cloth masks to Vanderbilt for doctors, nurses and staff to wear during the pandemic.

"Friends support adds a special touch for patients, families and staff in the hospital, and even though we're not able to be inside the hospital walls during the pandemic, we're hoping our presence can still be felt," said Friends President Wendy Gatto. "Amidst COVID when hospital visitors and activities are limited for health and safety, we know that the mission of Friends is even more crucial to advance."

— by Christina Echegaray

Abigail Leggio, 2, is one of the many patients being helped by Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt.



SUSAN URMY



### ID of 'stomach flu' culprit

Norovirus is a major cause of acute gastroenteritis, with at least 49 different norovirus genotypes. GII.4 genotype is responsible for the majority of norovirus epidemic outbreaks. The genotypes associated with medically-attended sporadic acute gastroenteritis are less clear.

Zaid Haddadin, MD, Einas Batarseh, MD, and colleagues compared the clinical characteristics and distribution of norovirus genotypes in children who sought medical care for acute gastroenteritis in three clinical settings (outpatient, emergency department, inpatient) over three years.

In 2,885 children, norovirus was detected in 22% of stool samples. Nearly 90% of the norovirus-positive samples were GII-positive, and GII.4 viruses were detected in 51% of the genotyped GII-positive samples. Seasonal variations were noted among different genotypes, and children with GII.4 infections were younger and had more severe symptoms requiring more medical care compared to children with non-GII.4 infections.

The findings, reported in *Clinical Infectious Diseases*, highlight the importance of continuous norovirus surveillance and could guide strain selection for candidate norovirus vaccines.

This research was supported by the Centers for Disease Control and Prevention and the National Institutes of Health (grant TR000445).

– by Leigh MacMillan

### Post-transplant complication

Hematopoietic stem cell transplantation (HSCT) is a curative treatment for many children with both malignant and non-malignant conditions. Pericardial effusion — excess fluid around the heart — is a recognized complication following HSCT, but its incidence, risk factors and impact on mortality are not well defined.

Carrie Kitko, MD, Justin Godown, MD, and colleagues used the Pediatric Health Information System, an administrative database including more than 50 tertiary hospitals, to assess incidence, risk factors and outcomes of children with pericardial effusion following HSCT.

They found that of 10,455 included patients, 7.1% developed pericardial effusion a median of 69 days post-transplant. Allogeneic transplant patients who developed pericardial effusion (9.1%) had worse survival than those without the complication.

The researchers identified risk factors associated with post-transplant pericardial effusion, including thrombotic microangiopathy and other cardiac symptoms.

The findings, reported in the journal *Pediatric Transplantation*, may help guide screening practices for pericardial effusion to improve outcomes for children following HSCT.

This research was supported by the National Institutes of Health (grant CA068485).

– by Leigh MacMillan

### Nearly one-third of Tennessee parents are worried their child has an undiagnosed mental health condition

One-third of Tennessee parents with children ages 6-17 are worried their child has an undiagnosed mental health condition, a poll from the Vanderbilt Center for Child Health Policy found.

The findings in the poll, released in summer 2020, led by researchers at Monroe Carell Jr. Children's Hospital at Vanderbilt and Vanderbilt University Medical Center, also found that about 30% of parents said their child had been diagnosed with a mental health condition, such as attention deficit hyperactivity disorder (ADHD), anxiety or depression.

"Mental health conditions are common among children and adolescents," said S. Todd Callahan, MD, MPH, associate professor of Pediatrics and director of the Division of Adolescent and Young Adult Health. "Mental health symptoms can be a serious threat to a child's health, growth and development. The good news is that these symptoms usually improve with intervention and treatment."

The findings were collected before the COVID-19 pandemic interrupted children's academic and social lives in unprecedented ways. This underscores the importance of addressing and understanding mental health challenges in children to better keep them healthy and safe, said Stephen Patrick, MD, MPH, a neonatologist and director of the Vanderbilt Center for Child Health Policy.

"COVID-19 disrupted the routines of children across the state, creating stress for parents and children alike. Now more than ever, parents should not be afraid to talk to their kids about mental health and well-being," Patrick said.

The Vanderbilt Child Health Poll asked a statewide sample of 1,100 Tennessee parents about their concerns related to children and mental health (social, emotional and behavioral health) before coronavirus began to spread in the state.

Attention deficit disorder/hyperactivity disorder (16%), anxiety (11%) and depression (8%) were the most common mental health diagnoses, often in combination with another of these three conditions. Nearly 20% of parents reported that their child had been diagnosed with two or more mental health conditions.

Additionally, 10% of parents reported they were unsure how to talk to their children about suicide and couldn't identify warning signs. Parents were mostly afraid that talking about suicide would lead to more thoughts of suicide (16%), were worried others would judge them (13%) or didn't know how to help (13%).

– by Jake Lowary

# A celebration that makes a lasting impact



Want to make the most out of your special occasion while making a difference for patients and families at Monroe Carell Jr. Children's Hospital at Vanderbilt? You can create your own personal fundraising page to share your story and rally those in your community to make a collective impact.

Whether it's donating your birthday or special milestone, hosting a virtual fundraising event or simply paying it forward, creating your own fundraising page is a fun way to give back.



**Get started now: [ChildrensHospitalVanderbilt.org/fundraise](https://ChildrensHospitalVanderbilt.org/fundraise)**



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



## Top-ranked pediatric care close to home

Specialists from Monroe Carell Jr. Children's Hospital at Vanderbilt have made it their mission to make quality health care more convenient for children and families across Tennessee. In addition to the main Nashville campus, Children's Hospital now has more than 20 speciality clinic locations, including in Jackson, Murfreesboro, Cookeville, Hendersonville, among others.