

hope

CHILDRENSHOSPITAL.VANDERBILT.ORG

SUMMER 2017



A Chance
at Life





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Families, like Nicole and Edward Reed and their twin daughters shown above, come from all over Middle Tennessee and beyond to the Junior League Center for Advanced Maternal-Fetal Care where specialists give their unborn babies a chance at life.

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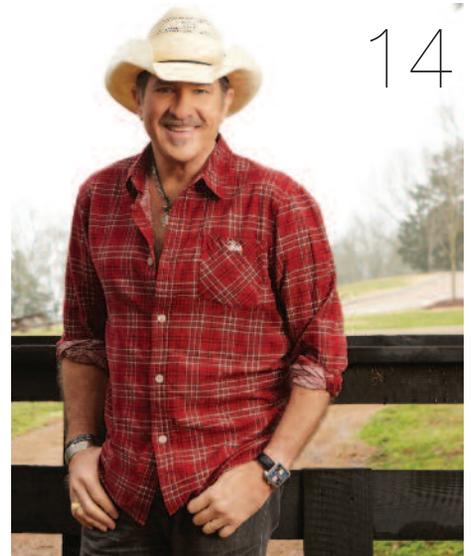
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IN THE BUSY, DAY-TO-DAY ROUTINES OF LIFE, WE SOMETIMES FORGET TO PAUSE AND reflect upon all the good that surrounds us every day. We recently had the opportunity to celebrate the great work that the faculty and staff of Monroe Carell Jr. Children's Hospital at Vanderbilt and Vanderbilt University Medical Center do every day to make a difference in the lives of our patients and families. The stories shared at April's Celebrate the Difference YOU Make Every Day event reminded us of the hope we offer through our innovative clinical programs, our commitment to discovery research and our teaching of the next generation of pediatric providers.

As the region's only comprehensive pediatric health care provider, we are in the unique position to be able to establish programs that reach specialized groups of patients. Through the telling of stories, we share the great work of two of our specialized programs, both of which lead to improved care for our patients but also simplification of the day-to-day routines of patients and their families.

The Complex Care Program, led by David Hall, M.D., and supported in part by the Friends of Children's Hospital, functions as the "team quarterback" to facilitate the development of care plans across multiple specialties and more importantly gives families one point of contact when a health care need arises.

Similarly, the Junior League Center for Advanced Maternal-Fetal Care, a multidisciplinary program supported by the Junior League of Nashville, and led by Kelly Bennett, M.D., John Pietsch, M.D., William Walsh, M.D., and recently, Melinda Markham, M.D., is a nationally recognized program that supports both mothers and babies who have problems detected during pregnancy. Both of these programs draw patients from our Middle Tennessee region but also from neighboring states and beyond because of the expertise and support offered through exemplary coordination of care.

Another story for us to share and celebrate with you is the completion of the Growing to New Heights Campaign, a capital endeavor led by Kathryn Carell Brown. We feature a patient and family, and we highlight our truly amazing community of generous individual, business and entertainment industry partners. They believe in our mission to serve all children with state-of-the-art facilities and to recruit the best and brightest faculty, trainees and staff. We are so fortunate to have these people as true friends of Children's Hospital. Construction is underway for the new floors, which will enable us to continue to develop high quality, innovative clinical and discovery programs to improve the health and well-being of the children in our community, well into the future.

So as the slower days of summer settle upon us, we invite you to celebrate with us. We are so very grateful to live in a community where generous partners support us every day as we provide hope to children and families through the efforts of our dedicated and outstanding faculty, staff and trainees.

Sincerely,

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Chief of staff and Executive Medical Director

John W. Brock III, M.D.
Senior Vice President of Pediatric Surgical Services, Monroe Carell Jr. Professor and Surgeon-in-chief

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A Chance at Life

Caring for mothers and infants, before and after birth

Nicole and Edward Reed were excited to learn at an eight-week ultrasound that they were having twins. But an ultrasound four weeks later left them uncertain they would ever get to meet those babies or experience the same joys and milestones they had with their first child, now 5.

The ultrasound revealed the twins were Monoamniotic-Monochorionic (Mono Mono).

Mono Mono twins are very rare—occurring in about one in 10,000 births and in only about 1 percent of monozygotic (identical twins) pregnancies.

They share the same amniotic sac and placenta, which places this kind of twin pregnancy at high risk due to the risk of cord entanglement, cord compression, twin-to-twin transfusion syndrome (TTTS) and premature birth. Twins with this condition have an in utero mortality rate of about 50 percent.

Time and odds were against them.

written by Jessica Pasley
photograph by Daniel Dubois

Nicole and Edward Reed delivered their twins, Olivia and Alice, with care from the team at the Junior League Center for Advanced Maternal-Fetal Care.



Armed with a diagnosis, the Reeds discovered the Junior League Center for Advanced Maternal-Fetal Care at Monroe Carell Jr. Children's Hospital at Vanderbilt in hopes of giving their babies the best shot at life. Nicole had delivered their older son at Vanderbilt, but until she was referred she was not aware of the maternal-fetal center.

The maternal-fetal at Vanderbilt features a multidisciplinary team approach and offers a customized evaluation in a single setting. The unique collaboration involves a team of pediatric specialists from cardiology, genetics, maternal/fetal medicine, neonatology, neurosurgery, perinatal nursing, radiology, social work, surgery, plastic surgery, palliative care, otolaryngology and urology.

Nicole was 14 weeks pregnant when she first met the team at Vanderbilt.

"When we walked into the clinic, we were panicked," admitted Reed. "We had very little faith that this would be a successful pregnancy based on the previous ultrasound and information we received from our previous clinician. When we walked in we had almost given up."

Nicole said the minute she saw Kelly Bennett, M.D., perinatal director of the center, everything changed.

"She gave us confidence and comfort. Not only was she knowledgeable, but encouraging, calm and compassionate. I knew right then that I, that we, were in the care of someone who was very passionate. The entire team was that way and it made a huge difference," Nicole said.

The maternal-fetal center team meets weekly to discuss diagnosis, delivery plans and birth results while keeping in mind the need to focus on innovative research as well as provider education that could positively impact patients' lives.

With a patient load of nearly 2,500, the center continues to grow and attract families from all over the country.

"We are very patient-centric," said Bennett. "We want our families to know we care about them as people. They are not just patients to us. We are able to provide personal care to each and every family and situation. They are all different with various needs.

"All of the specialties that make up our center come together in one space to offer support and care for our families. It is a collaborative effort to ensure every single family receives the specific attention required. Every single team member is incredibly important to the success that we all share when a baby leaves our care," Bennett added.

Most women whose twins are diagnosed Mono Mono enter inpatient care for regular and aggressive fetal monitoring

until a planned cesarean section. Usually Mono Mono twins are delivered no later than 32 weeks and five days to improve the babies' chances of survival.

Preparing for birth—and beyond

Nicole was admitted at 29 weeks to await the girls' arrival. Three days later, due to frequent drops in their heart rates, Olivia and Alice were delivered on July 14, 2016, weighing 2.3 pounds and 2.9 pounds respectively. Both required a seven-week stay in the Neonatal Intensive Care Unit (NICU) at Children's Hospital.

Melinda Markham, M.D., neonatology director of the center, said the care provided in the unit as well as in the clinic itself is driven by the patients and their specific needs.

"We are truly a unique machine," said Markham. "We have so many subspecialties involved in our center to ensure that our patients, both mom and baby, receive the absolute best care possible, and we all work together to make that happen.

"Our clinic intentionally positions all of our providers and services in one place. It makes a big difference that we all come to our patients and not the other way around. We hear that a lot, and our families are appreciative of that fact."

When Markham joined the staff at Vanderbilt in 2007, the Fetal Center operated two days a week. Now the center has its own dedicated space and is at full capacity seeing families five days a week.

"The important piece to remember about our center is that every patient coming through those doors has a heavy heart," said Markham. "No one wants to be a patient in the

"All of the specialties that make up our center come together in one space to offer support and care for our families. It is a collaborative effort to ensure every single family receives the specific attention required."

maternal-fetal center. But we are here to help relieve some of their burden. There are lots of unknowns on that first visit. From the first appointment and often prior, we are working on the best plan for that particular patient.

“We diagnose the same conditions, time and time again. But each time it’s a different family which requires individualized care and attention. It’s what we do.”

As their first birthday quickly approaches, the Reed twins are thriving and their parents are still in awe of the world-renowned center just minutes from their home.

“I cannot say enough good things about everyone at the clinic. We would not be where we are today without their experience and good will. During pregnancy, mental health is very important and the team was a big part of that for me,” said Nicole.

The Currys’ story

Like the Reed family, Bridgett Curry wasn’t completely sure she’d be returning home with a newborn for her second child. Even as she prepared a diaper bag for the delivery of her son in November 2015, she packed only four outfits, a few pairs of socks and one pack of diapers.

These were all of the baby items that Bridgett had besides the crib and changing table that sat in a bare room back at home in Panama City, Florida.

It was a far cry from the overfilled drawers, stockpiled diapers, baskets of toys and books, a decorated nursery and a host of family and friends that greeted her first baby’s arrival two years prior. Everything was different this time.

During a routine ultrasound at her first obstetrics visit, Bridgett and her husband, Jake, were told their baby had about a 50 percent chance of survival.

The baby had an abnormal opening in the diaphragm. The condition allows some of the baby’s abdominal organs—stomach, small intestine, spleen, part of the liver and kidney—to move into the chest cavity. Called congenital diaphragmatic hernia, or CDH, the life-threatening condition pushed the baby’s heart to the right side of his body and crowded his lungs.

CDH is rare. It is seen in one in 2,500 births.

Bridgett and Jake were given a laundry list of concerns.

“There was a suggestion that I should terminate,” said Bridgett. “But I am a ‘If the good Lord brings me to it, then He will see me through it’ kind of person.

“I started doing my research and found Dr. (John) Pietsch at Vanderbilt. There were other (fetal) centers we could have chosen, but his expertise brought me here and I am so thankful for this group.”

At 32 weeks pregnant, Bridgett made her first visit to meet the team that would care for her and her baby at the maternal-fetal. She would make three subsequent 16-hour round trip drives before having to relocate to Nashville, just two weeks prior to Marshall’s birth.

Improving outcomes for mothers and babies

The Junior League Center for Advanced Maternal-Fetal Care provides the most advanced diagnostic evaluation and care for mothers whose unborn baby has a congenital problem. The maternal-fetal center coordinates care and emotional support throughout the pregnancy as well as after delivery and includes a clinical program in fetal diagnosis and therapy along with clinical and basic research programs.

Some of the conditions that are treated at the center include:

- Cleft lip and cleft palate
- Congenital cystic lung abnormalities
- Congenital heart disease
- Genetic abnormalities
- Intestinal abnormalities
- Myelomeningocele and hydrocephalus
- Other complex prenatal abnormalities

Members of the fetal surgery team at Vanderbilt pioneered the innovative surgical procedure to repair myelomeningocele, the most serious form of spina bifida. Surgeons at Vanderbilt performed the first-ever in-utero repair for this condition in 1997. Internationally recognized for its expertise in the field, The maternal-fetal center has performed more than 300 in-utero repairs of myelomeningocele.

“It was during my first visit at Vanderbilt that I received the first bit of good news since I learned I was pregnant,” said Bridgett. “They did an ultrasound and gave him a 75 percent survival rate. They discussed all aspects of our care. Not just for our baby, but for me too.”

On Nov. 20, 2015, Marshall Curry was born weighing 9 pounds, 11 ounces. Both mom and baby had a full team at the ready for the planned cesarean section. As soon as Marshall was born, his team rushed him to a waiting bed and stabilized him. Bridgett was able to kiss him briefly before he was whisked down the corridor to the NICU at Children’s Hospital.

“I ran right alongside of them that whole quarter of a mile,” said Jake. “I sat outside of the unit and looked through the glass doors. There were so many people around him that I couldn’t see him. It was a very emotional time. Thinking back on it, I still get worked up.

“With Lily (the Currys’ first child), I was able to walk her to the nursery. I could hold her. This was hard because we were so happy about Marshall’s arrival, but we felt a bit helpless,” he said.

“It’s tough because you can’t fix it and you can’t do anything to really help him,” added Bridgett. “You want to do something, but you can’t. But we knew he was in good hands.”

“No one wants to be a patient in the maternal-fetal center. But we are here to help relieve some of their burden. There are lots of unknowns on that first visit. From the first appointment and often prior, we are working on the best plan for that particular patient.”

Marshall was placed on ECMO (Extracorporeal Membrane Oxygenation), a method of temporary lung and/or heart support for infants, children and adults experiencing severe pulmonary and/or cardiac failure. It is used to treat some newborns with CDH—the primary reason Bridgett was attracted to Vanderbilt.

Established in 1989 by John Pietsch, M.D., the ECMO program at Vanderbilt was the first in the state and is one of the largest services of its kind in the nation. It has been used to treat more than 1,000 patients.

ECMO is a life-support system that oxygenates the blood through a machine that has an artificial lung and returns the oxygenated blood back into the body. It is particularly effective in term- and near-term infants with respiratory failure or congenital heart disease, by providing a crucial interim

cardiopulmonary support both before and after surgery is performed.

“We have a solid reputation,” said Pietsch, co-director of the maternal-fetal center and surgical director of the ECMO program. “ECMO has allowed survival rates in CDH babies to improve. But it is just one piece of the treatment plan. We have a team of people here working to solve the puzzle.

“When I think of what we are able to do for these families,” said Pietsch, “when they go in for their first ultrasound, they are so full of excitement and joy. And then, they are told there is something wrong with their baby. Then they come to see us.

“We are a team,” Pietsch said of the multitude of specialists. “We work together to educate, comfort and develop a plan. Families come to us on pins and needles. All of us work together to help them navigate the road home.”

For that the Currys are grateful.

On Thanksgiving Day, Marshall, then 6 days old, was removed from ECMO. It was three days after a successful CDH repair surgery.

At 2 weeks old, Marshall finally opened his eyes. A few days later, his mom held him. He was allowed to go home at 39 days old. He returned to Vanderbilt for his 3-month checkup and again at 6 months. It was at the last appointment that his mom could finally exhale, she said.

“He was given a clean bill of health,” Bridgett said. “To look at him, you’d never know anything was ever wrong. He fought hard from day one. And now he is your typical 1-year-old

with just a few scars and a little different breathing (the CDH caused one of his lungs to underdevelop, but it will grow).

“He is talking, walking and running around. He is full force and we are blessed. I look at him now and I still cry just knowing what all he went through and how far we have come.” 

Jake and Bridgett Curry with their daughter, Lily, and son, Marshall, who had a 75 percent chance of survival at birth.



LANA WILLIAMS

VUMC team helps launch fetal surgery program in Australia

Vanderbilt University Medical Center (VUMC) made history in 1997 when two surgeons pioneered fetal surgery to treat spina bifida, or myelomeningocele, the most common birth defect in the central nervous system.

Almost two decades later, armed with overwhelming evidence from a seven-year study that confirms the effectiveness of the complicated surgery, and with more than 300 cases already performed at Vanderbilt, the institution made history again when a team traveled to Australia last year to help launch that country's first-ever fetal surgery program for spina bifida and guide the first surgery.

The maternal-fetal center team members traveled to Brisbane, Australia, to take part in the historic moment at Mater Mothers' Hospital—Kelly Bennett, M.D. (Maternal-Fetal Medicine); Jay Wellons, M.D., MSPH (Neurosurgery); Stephane Braun, M.D. (Plastic Surgery); Ray Paschall, M.D. (Anesthesiology); Ann Kavanaugh-McHugh, M.D. (Cardiology); Alicia Crum, RDMS (fetal sonographer); and Melissa Broyles (surgical tech).

"We are very collegial and as an academic medical center we believe in that collegial spirit," said Bennett, director of the Division of Maternal-Fetal Medicine. "Surgery has been always taught with the idea of mentorship. To describe something to someone is one thing, while to be at the table with them is another. We could tell the (Australia team) how to do a procedure, but to work with them at the table was really superior," Bennett said. "At the end of the day, we were able to

provide a critical surgery to a baby who desperately needed it and will have a better life as a result. It was a very rewarding experience."

That collegial spirit also would have been what the late Noel Tulipan, M.D., former chief of Pediatric Neurosurgery at Vanderbilt, would have wanted. Tulipan, who died in late 2015, paved the way, led the research and helped pioneer the first fetal surgery for spina bifida in the 1990s, along with Joseph Bruner, M.D. Tulipan believed in collaborating to do what was best for families.

"Noel's and the Vanderbilt group's view was 'sure, come on down, and we'll take you to dinner too,'" said Wellons. "We've taken the Vanderbilt experience gained over time and we've imparted it to another part of the world. Research clearly shows the surgery helps outcomes. There is no doubt that every part of the world needs this as a surgical option for their patients. Glenn (Gardener, M.D.) and his team (in Brisbane) worked hard to make this happen. For us to be asked to be a part of this was a tremendous honor."

In spina bifida, the layers of tissue and bone that normally cover and protect the spinal cord fail to close during development, leaving delicate nerves exposed to the intrauterine environment.

Children often suffer severe disabilities, including paralysis below the waist and lifelong bladder and bowel problems. Nearly 90 percent of children with this disorder develop hydrocephalus, a fluid build-up within the brain, which requires

surgical placement of a shunt to drain fluid. A shunt, while necessary to save a child's life, can impact intellectual development. Surgery in utero closes the "myelo" to reduce the likelihood of shunt placement and to improve the chances of walking.

The Vanderbilt team knew when the Brisbane hospital asked for help in launching a program, it was important to help make this surgery available to families in a part of the world where it hadn't been established. Following a long trip, the team members went to a specially convened meeting with Australia's medical licensing board to get temporary

permission to operate.

Mater and Vanderbilt team members evaluated the two candidates for the surgery, and due to the findings of an updated ultrasound, had the difficult job of telling one family they did not meet criteria for a successful surgery. The day before the surgery for the other family, the teams performed a simulation of the procedure as a dress rehearsal. This brought together more than 45 members of the Australian and Vanderbilt teams in order to work through the next day's procedure.

The surgery was successful, with the Vanderbilt team guiding their Mater counterparts.

— by Christina Echegaray

Members of the fetal surgery teams from Vanderbilt University Medical Center and Mater Mothers' Hospital in Brisbane, Australia, pose for a photo during the Vanderbilt team's 2016 visit.



SUBMITTED PHOTO



Pearl Brown, 5

ORCHESTRATING CARE

*Bridging the gaps for children
with complex health care needs*

Five-year-old Pearl Brown, a tiny girl with flaming red hair, was born two weeks early with a brain abnormality so severe that she was sent home from the hospital on hospice care.

Receiving most of her care at Monroe Carell Jr. Children's Hospital at Vanderbilt, Pearl has been hooked to a ventilator connected to a tracheostomy tube in her airway since 2016. She has multiple seizures a day and is on five different medications to help control them. She has been fed by a feeding tube since she was 7 months old.

She has trouble breathing due to facial deformities (a cleft lip and flat nose) and frequent respiratory infections because she's immobile and has a hard time coughing up secretions.

Pearl is a patient in Children's Hospital's three-year-old Program for Children with Medically Complex Needs, the first in the state.

written by Nancy Humphrey
photograph by Eric Brown

She

sees five specialists regularly—ear, nose and throat, pulmonology, ophthalmology, urology and neurology—and three others as needed, in cardiology, endocrinology and for sleep disorders. She also sees a dietitian, physical therapist, occupational therapist and a dentist.

Children who are considered medically complex typically have a longstanding medical problem involving multiple organ systems and see several subspecialists. They are often dependent on medical technology such as feeding tubes, tracheostomy tubes and ventilators and have high health care use and functional limitations.

Although specialists are apt to treat the problems that relate to their specialty, it's difficult for parents to find a provider who is willing to take ownership and provide oversight for all of their problems. In that sense, they could be considered "medical orphans" in the health care system because there's often no place to go, or it isn't clear where to turn, to unify their care.

Diagnosed in utero with holoprosencephaly, an abnormality of brain development in which the brain doesn't properly divide into the right and left hemispheres, Pearl was born two weeks early to Ruth and Eric Brown of Nashville. The condition also affects development of the head and face; the severity of the facial defects corresponds to the severity of the brain defect. Life expectancy varies, depending on the symptoms and the severity. Many infants either die in utero or shortly after birth.

Medical advances have led to increased survival of children with severe complex medical conditions, said David Hall, M.D., professor of Clinical Pediatrics at Vanderbilt. Some children may require intensive medical management for years, and their care is often confusing and frustrating for both families and providers.

"These are children who can fall through the cracks in our health care system," Hall said. "The parent, the expert on their child, can end up directing the care because nobody else is doing it. Although parents are certainly the experts on their child, they don't have the medical training to assume this role effectively. Although many primary care providers do the best they can to oversee care, in many cases they do not have the time or resources to serve in this role for the sickest patients."

During hospital admissions, the attending or responsible physician often changes weekly, and physicians-in-training (residents) change by the hour at times due to resident training rules. Medications and procedures to correct one problem can cause adverse effects in another.

Care for medically complex children has become more tailored and less frustrating thanks to the program, part of the Division of Hospital Medicine. Hall, the program's director, led a similar program at Cincinnati Children's Hospital before coming to Vanderbilt.

To be eligible for the Vanderbilt program, children must be followed by at least three subspecialty groups, and be admitted at least twice to the hospital or once to the intensive care unit in the year prior to enrollment. There's also an "I-know-it-when-I-see-it-category," and the rules can be somewhat flexible depending on the need, Hall said. The Complex Care team seeks to partner with the child's primary care provider to supplement their care and help families navigate what can be a complicated medical system.

Steven Webber, MBChB, MRCP, the James C. Overall Professor and chair of Vanderbilt University's Department of Pediatrics, said the Complex Care program fills a crucial need for many of Children's Hospital's patients.

"As the region's tertiary referral center for children with complex and coexisting medical issues, we want to be able to offer these children and their families more coordinated care that spans the inpatient and outpatient divide," Webber said. "Providing our medically complex patients this service should improve the quality of care they receive through improved coordination of services, reduction in return trips to our hospital and clinics and shorter lengths of stay."

Thanks to philanthropic gifts and the support of Children's Hospital, the program has been able to grow and now includes another physician (Katie Freundlich, M.D.), two nurses, a shared nutritionist, pharmacist, social worker, and a program coordinator who helps with scheduling multiple appointments on the same day to minimize trips to the hospital.

It's estimated that although children with medically complex needs account for a small minority of patients, they have a disproportionate impact on the nation's health care system. For example, they now account for almost half of inpatient bed days in children's hospitals around the country, and the inpatient population is growing thanks to medical advances that have allowed them to survive. However, with longer survival comes chronic medical problems that require ongoing management and coordination of care.

"We have a responsibility to take care of these children," Hall said. "Our medical system doesn't support taking care of them because they take more time than is economically viable for primary care physicians. You can't meet the needs of

medically complex children in the time allowed for typical primary care visits.”

Nurse Practitioner Sarah Wilkerson, who works with the complex care patients during outpatient visits and in between, said families are appreciative just to have someone check in with them between visits, critical to keeping children out of the hospital and the emergency room. This type of care is not reimbursed by insurance companies, but is a vital part of the Complex Care program’s mission.

“It is incredibly rewarding to work with these families,” she said. “The one thing we have that other providers, particularly primary care providers, don’t have, is the luxury of more time.”

Wilkerson said she spent several hours recently with a family in the clinic. Their child, who suffers from a rare progressive genetic disorder, had progressed from a normally functioning child to a near vegetative state. The parents were grieving the loss of what their son had been, and needed to work through it and decide on next steps.

“This is not something that could have been worked through in a 15-minute appointment,” Wilkerson said. “I was able to really delve into the heart of what each (parent) felt was important and come up with a plan to ultimately move this child into a strictly palliative mode. The mom sent me an email expressing how much it meant to her to have that block of time to express her concerns, fears and goals for her son.”

Hall said the Vanderbilt program rests on three pillars. “One is continuity of care. Children who are admitted, no matter what service they are admitted to, are seen and followed by a member of our complex care team. We are a familiar face for the family and work to make sure their needs are met during the admission. Secondly, we provide care between visits. We follow up with patients after discharge and manage as many problems as we can over the phone. Finally, we believe strongly in shared decision making with families. This leads to discussions about goals of care. It’s surprising how often the parents’ goals for the care of their child differ from the provider’s.”

ANOTHER VOICE

Before Pearl was enrolled in the Complex Care program, her parents, Ruth and Eric, were frustrated because they had to see different physicians each time Pearl was admitted. This is routine at an academic medical center, but when a patient has a complicated medical history, like Pearl’s, seeing different physicians and having to repeat her history each time is taxing.

“You can’t just choose the doctor you see most frequently,” Ruth said. “You see who’s on service. Sometimes you know them and sometimes you don’t.”

“We would have to start from scratch each time trying to come up with a new treatment plan with someone who hadn’t dealt with her before. Her medical record is a hundred pages



DANIEL DUBOIS

David Hall, M.D., director of the Program for Children with Medically Complex Needs

long. A new doctor trying to sift his or her way through that each time was overwhelming and frustrating.”

Then, during a hospital admission over Thanksgiving 2014, Ruth read an article in a Vanderbilt University Medical Center publication about the new Complex Care program at Children’s Hospital and asked her primary care physician to put her in touch with Hall.

“He’s another voice for kids who don’t always follow the rules when they are sick,” Ruth said, adding that not all children with holoprosencephaly follow the same path. “I met him in the hospital while Pearl was an inpatient, and now see him at least four times a year in his clinic, and every time Pearl is admitted either he or Wilkerson will come to the room, every day, talk with the team in charge of her care and coordinate if there are complications. He’ll say, ‘we’ve dealt with this before,’

and ‘this isn’t the normal treatment plan, but I think this is what we need to do.’ It makes her care so much easier and I believe it’s shortened her length of (hospital) stay several times.”

In fact, data collected by Hall compares hospital stays for those in the Complex Care program six months before enrollment to six months after. Days in the hospital decreased 50 percent, admissions decreased 33 percent and readmissions within seven days decreased 50 percent.

Hall has helped pull all of Pearl’s doctors together, Ruth said. Before her tracheostomy, he coordinated a meeting with several different specialists to discuss the surgery, recovery and care at home afterward.

Ruth says although most of Pearl’s care providers say she has a somewhat limited lifespan, “they don’t give me a current prognosis in terms of months or years.”

Hall and his team also have helped Pearl avoid unnecessary trips to the hospital and have helped coordinate home nurses who come to the Browns’ home to help care for Pearl.

Facts about the Program for Children with Medically Complex Needs

- The team includes two physicians, a nurse practitioner, two nurses, a program coordinator, and a shared social worker, nutritionist and pharmacist.
- If the child needs to see another subspecialist, in many cases, program coordinators are able to schedule it on the same day to reduce the number of hospital visits for families.
- Patients enrolled in the program have markedly reduced admissions and readmissions after discharge and fewer emergency department visits and days in the hospital compared to before enrollment.
- The program offers care between visits. Patients are called after the child returns home from a hospital stay, and problems are handled over the phone when possible. The team works with home nursing and other agencies to maximize care at home.
- Complex Care team members participated in shared decision making with families. Parents are considered the expert on their child, and the providers provide the medical knowledge and experience of working with many other children with medically complex problems. Together, they seek to determine treatment options and goals of care.

“He is seeking to bridge the gaps that often exist between the different subspecialties of complex kids’ care,” Ruth said. “Think of him as the conductor of an orchestra capable of playing each individual instrument, but instead is making sure that everyone is listening to each other, staying in tune, on the same page, and working together to play one, unified piece.”

The Browns have two other children—Brennan, 9, and Abbey, 7. Abbey was diagnosed with juvenile diabetes last year and also requires frequent medical care. In fact, Abbey and Pearl were both in the hospital at the same time last year—Pearl in the Intensive Care Unit (ICU) with respiratory issues and Abbey, who had just been diagnosed with diabetes, in the Emergency Room.

Ruth homeschools Brennan and Abbey. “It cuts down on the stress of not being able to drop them off and pick them up at school and guilt of things like not being part of the PTO (Parent-Teacher Organization). We’re at home a lot.”

Last year, Ruth and Eric decided to take their family on a short vacation, a Make-a-Wish trip for Pearl to Disney World and Universal Studios in Orlando. “Dr. Hall and his team were super helpful in making sure we thought of everything before traveling with Pearl. They helped us make sure all the bases were covered.”

Hall said the program is already near capacity. The goal was to add 75 patients a year. But about two years after the program began, 270 children are enrolled.

NOT ALONE

Medically speaking, 18-year-old Julia Risko is “as complex as you can get,” says her mom, Angell Chance.

A patient at VUMC all of her life, she has severe cerebral palsy and suffers from scoliosis, epilepsy, microcephaly and visual impairment. She uses a wheelchair full time. Angell was told Julia might not live past the age of 3.

Angell met Hall and his team, whom she calls “that group of angels,” in 2015. Julia was a patient in the Intensive Care Unit, and so sick “I thought it was all over,” Angell remembers. “Meeting Dr. Hall was our saving grace,” she said. “When I thought all hope was gone, and we had nowhere else to turn, in walks Dr. Hall. He has the most amazing bedside manner.”

When Julia is seen in the Complex Care clinic she’s “at home, very comfortable,” Angell said. “Nobody leaves you in the dark when you have a thousand questions. I don’t even think there are words to say how this program has impacted our life. Cerebral palsy will always be a battle, but that team is our team and we aren’t alone.”

Angell said after Julia began seeing Carly Noe, the team’s dietitian, her feedings were administered by a pump. Her caloric intake is more regulated and her weight has increased from 50 pounds to 75. “Each member of that team is just



Julia Risko, 18, who graduated from high school in May, receives coordinated care from the Complex Care program.

amazing, and I feel like I know my child a little better because of them,” Angell said.

Julia also has better muscle control and is happier, Angell said. “I have a bright-eyed cheerful little girl. She went through such a rough patch about two years ago,” Angell said. “She had a spinal fusion and her tonsils and gallbladder removed. We’re always going to have an uphill battle, but as long as I have the (Complex Care) team the fear isn’t as overwhelming. They understand me as well as my little girl.”

Despite all she has been through, Julia graduated from Gallatin High School in May.

Hall said there is growing interest in Tennessee and around the country about developing a program like Vanderbilt’s. “Other children’s hospitals have called about developing their own. There are more of these children to take care of than any one place can provide. We’re happy to partner with other organizations to help them develop their own,” he said. “This is the most gratifying thing I’ve ever done. I go to work every day feeling like we are really helping these families. It’s definitely an unmet need.”  hope

Help from Friends

A generous \$1 million gift from the Friends of Monroe Carell Jr. Children’s Hospital at Vanderbilt will be shared by the Program for Children with Medically Complex Needs and the hospital’s pediatric cancer care program.

The Complex Care program, just three years old, is growing rapidly and showing dramatic results in reducing the hospital stays of children who are deemed medically complex—those with a severe chronic disease who don’t fit with an already established program within the hospital, like cystic fibrosis, diabetes or sickle cell disease.

To be enrolled in the program, children typically see at least three subspecialists and have been admitted to the hospital at least twice in the past year or once to intensive care.

The Friends organization, which began in the fall of 1972, includes about 3,000 members representing 1,700 households, who give their time and dollars to make a difference in the lives of children in Middle Tennessee and beyond. The organization supports the mission of Children’s Hospital through fundraising, community awareness and services to the patients and their families along with the faculty and staff of Children’s Hospital.

The Complex Care program, the only one in the state, provides ongoing continuous care to children with severe chronic disease. To care for the largest number of patients possible, the program is intended to supplement, rather than replace, the care provided by primary care physicians.

Other essential components of the Complex Care program include care between visits, critical to keeping children out of the hospital and emergency room, but not usually covered by insurance, and shared decision making with families.

The Friends’ gift will allow the program to hire another nurse practitioner and a case manager to assist with the program’s growing caseload.

“We’re here because of the good graces of Children’s Hospital and the generosity of the Friends organization,” said David Hall, M.D., professor of Clinical Pediatrics and director of the program. “We’re extremely grateful that the hospital and the Friends of Children’s Hospital support us. We simply wouldn’t be able to hire another nurse practitioner or case manager for the program if it weren’t for Friends.”

The program will be able to continue to grow without reducing services, Hall said.

“We wanted to make sure that our gift touched patients and their families directly,” said Tricia Ericson, president of Friends. “We saw this as an opportunity to make an impact on generations of patients and their families.”

—by Nancy Humphrey

CHAMPIONS FOR CHILDREN

NASHVILLE'S STARS STEP OUT OF THE SPOTLIGHT
TO PARTNER WITH CHILDREN'S HOSPITAL

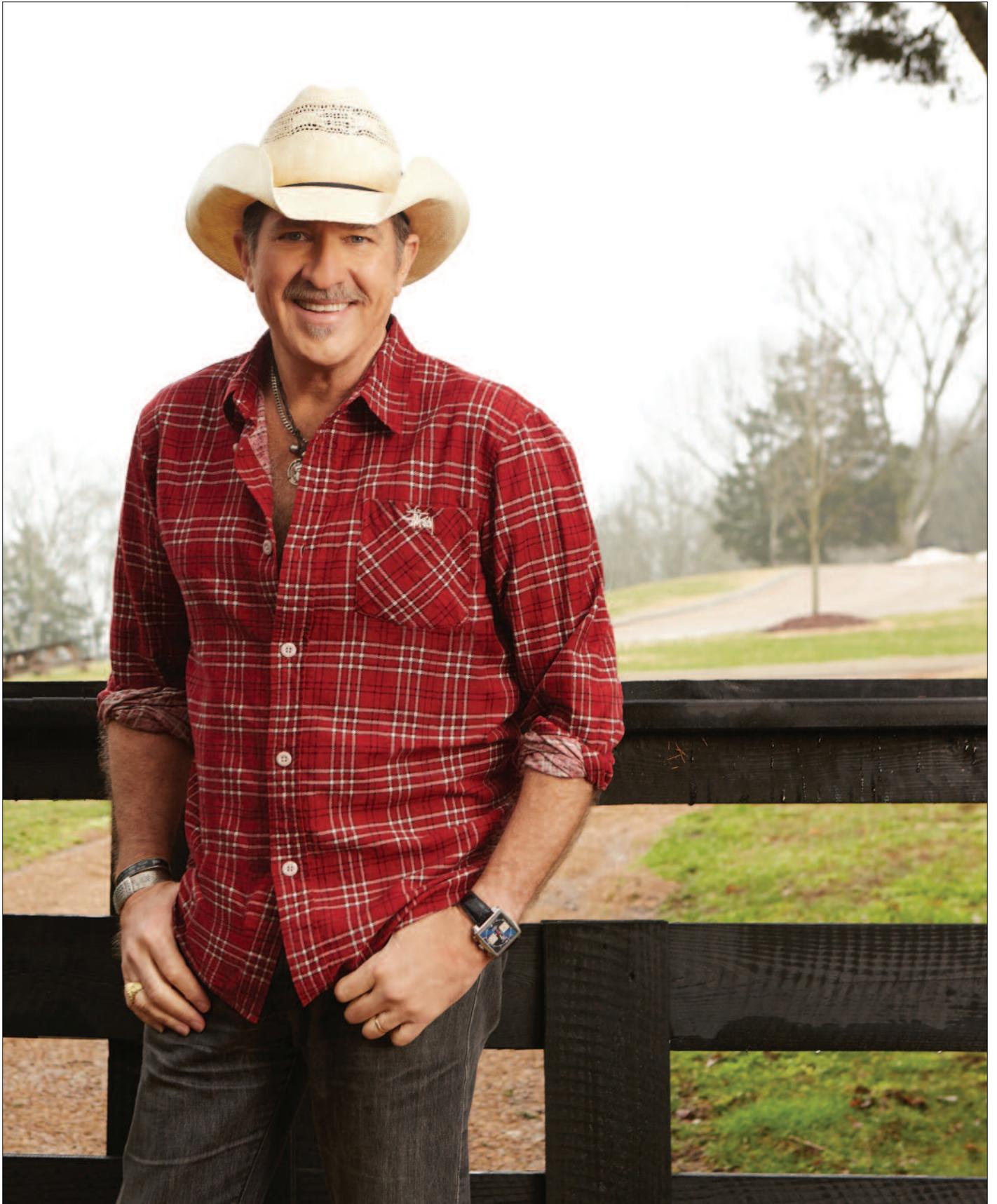
written by Christina Echegaray
photograph by Micah Kandros

Legendary country music artist Kix Brooks, of the duo Brooks and Dunn, was boating on Center Hill Lake near Smithville, Tennessee, for summer vacation a decade ago when his teenage son, Eric, face planted while wakeboarding. Brooks worried when Eric didn't move.

"I went to pick him up (out of the water) and I realized something was terribly wrong. He had lost his ability to speak, and I could tell by the look on his face he was really scared. He didn't know what was happening," Brooks said.

After driving Eric on the boat to where Brooks could call for help, a LifeFlight helicopter descended on the lake area and transported his son to Monroe Carell Jr. Children's Hospital at Vanderbilt. Brooks drove more than an hour with his wife, Barbara, and daughter, Molly, to Nashville. Brooks suspected Eric, who was only weeks away from starting his freshman year at Vanderbilt University, had suffered a stroke. And indeed he had, along with a concussion.

"I didn't even know if I was going to see my son alive again," he recalled. "The whole thing was really frightening. When I got there, he was already receiving the best of care and a diagnosis had been made, tests were being done. Thanks to everyone who is part of this great facility, my son is now 100 percent, and even made straight As by the end of his first semester at Vanderbilt."



Kix Brooks, a supporter of Children's Hospital for more than 20 years, is one of hundreds of artists and athletes who have given their time and financial support.

BROOKS, A LONGTIME VOCAL ADVOCATE FOR CHILDREN'S HOSPITAL AND VANDERBILT UNIVERSITY MEDICAL CENTER, SHARED HIS PERSONAL STORY RECENTLY AS HE SPOKE ABOUT WHAT AN INTEGRAL PART OF HIS LIFE CHILDREN'S HOSPITAL HAS BEEN FOR MORE THAN 20 YEARS.

Brooks represents a steadfast and ever-growing class of champions for pediatric health care from Nashville's music, entertainment and sports industries. In fact, music and health care are two of the city's largest industries. Children's Hospital and Music Row grew up in the same "neighborhood" over the decades with the hallmark country music labels and recording studios and Children's Hospital separated by only blocks.

"Anyone who makes a trip down to Children's Hospital to witness the passion and the good will that happens there becomes committed. The (hospital) sells itself," said Brooks, a member of the Children's Hospital Advisory Board and the committee for the Growing to New Heights Campaign, which supports the hospital's current four-floor expansion.

Hundreds of artists along with record labels and athletes have made transformational gifts—financial and generous amounts of time—to Children's Hospital, both before and after the freestanding hospital opened in 2004. Along the way, the list of artists and athletes to provide financial support to the hospital, visit and/or perform has included, to name a few: Rascal Flatts, Dierks Bentley, Brooks & Dunn, Taylor Swift, Kelly Clarkson, Lady Antebellum, The Band Perry, Amy Grant, Vince Gill, Darius Rucker, Garth Brooks, Luke Bryan, Tim McGraw and Faith Hill, Ryan Seacrest, Wade Hayes, Martina McBride, Kellie



Pickler, Wynonna Judd, Scott Hamilton, Reba McEntire, Billy Ray Cyrus, Miley Cyrus, Brad Paisley, Jeff Gordon, the Nashville Predators and many more.

"Much of the nation has come to know Nashville as the new 'It' city and the heart of country music, which it is. But what people may not know, is that there is a behind-the-scenes altruistic spirit deeply rooted in the artists, entertainers and athletes who call Nashville home. We are very fortunate that Children's Hospital has been a gracious recipient of that support," said John W. Brock III, Senior Vice President of Pediatric Surgical Services, Surgeon-in-chief and Monroe Carell Jr. Professor.

"It's tremendous to have such a caring group of people who go out of their way to give back in very thoughtful ways and who help not only provide resources to expand the hospital and its programs, but also spend time to put a smile on a child's face with a visit or a song. We look forward to the many more opportunities to bring together the power of health and music to heal."

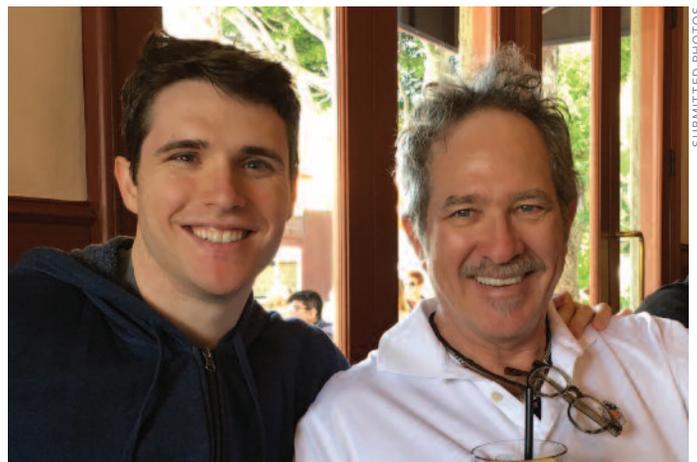
An introduction

Frequently, artists first learn about Children's Hospital and its programs from friends or fellow artists who are already passionate supporters of the facility.

The late Donna Hilley, a top music industry publishing executive and former member of the Children's Hospital Advisory Board, introduced Brooks to Children's Hospital and "suggested" he and Ronnie Dunn donate all the money from their first-ever sell out concert at Starwood Amphitheater in 1993. Brooks knew nothing at the time about the hospital.

"I told her I would go down and check out the hospital, and I did," he said. "I learned at that point, with one visit, firsthand, what she was talking about and why it was so important

Kix Brooks and son, Eric Brooks



SUBMITTED PHOTOS

to her. Children’s Hospital has stepped up to be a premier children’s hospital and not just in Nashville but in a huge area. I think as artists are becoming more educated—and people in the music business and the business community in general are more aware—that this hospital is more important now than ever, that it takes our support and us coming together to continue taking care of children in a much larger region.”

There from the start

Like Kix Brooks, there is a tenured class of champions who very quietly, and often out of the spotlight, advocate for Children’s Hospital.

Grammy award-winning country music group Rascal Flatts, composed of Jay DeMarcus, Gary LeVox and Joe Don Rooney, has been supporting Children’s Hospital for more than a decade.

“We’re very honored and humbled to get to help out Children’s Hospital. It’s so very near and dear to our hearts,” said Rooney. “Of all the sad stories we hear, there are so many positive and uplifting stories. It’s amazing to witness and to be a part of. In many ways, we’re just getting started.”

Rascal Flatts performs for Children’s Hospital patients every year, and has done so for the past 12 years. They also do room-to-room visits to meet patients and families unable to make it downstairs for the performance.

“Going to the hospital is very important to us. We want to visit with every child and young adult we can, and shake the hands of the doctors, nurses and staff. We truly care and want to help the hospital grow.”

The group has helped raise millions of dollars for the hospital. In 2010, The Rascal Flatts Surgery Center, which houses the surgical programs and a state-of-the-art interventional radiology suite, was named in recognition of the trio’s long-

Members of Lady Antebellum, from left, Dave Haywood, Hillary Scott and Charles Kelley, pose with 3-year-old Makenna Bilbrey and her parents, Ronda and Jeff, during a visit to Children’s Hospital.



ANNE RAYNER



JOHN RUSSELL

During one of the many artist visits with patients at Children’s Hospital, Rascal Flatts pose with patient José Gonzalez and his family after performing.

standing involvement. Each year, the Flatts visit Children’s Hospital, host fundraising events and donate concert tour revenues.

Giving back to Children’s Hospital runs in the Flatts’ extended family. Allison DeMarcus, wife of bassist/vocalist Jay DeMarcus, is intimately involved with helping patients and families. She serves on the Children’s Hospital Advisory Board, currently as chair, and is an active supporter of Children’s Miracle Network Hospitals® and Friends of Children’s Hospital through her role as co-executive director of the Miss Tennessee Scholarship Pageant. Both CMN and Friends efforts benefit Children’s Hospital.

Allison has coordinated patient meet-and-greet visits from Miss Tennessee and Miss America.

“There was a little girl who came down the hall in her Elsa nightgown (from Disney’s “Frozen”) and was having chemo but wanted to come down to meet Miss America,” Allison recalls. “She got to put the Miss America crown on her head and get excited and not think about everything else for a while. It was awesome to see her have that moment and that escape from her situation.”

Another country music trio, Lady Antebellum, early in their career, attended a Rascal Flatts concert where they watched an inspiring tribute video to Children’s Hospital. It was their introduction to the pediatric facility, its programs and its families. As Lady Antebellum gained recognition for its music, the group made plans to give back to the community.

The Lady A members—Hillary Scott, Dave Haywood and Charles Kelley—wanted to use their platform for positive influence. They visited several organizations they now support, including Children’s Hospital, and created a nonprofit called LadyAID.

“You walk into these rooms and—even if (the kids) have

no idea who you are— sing a song or a chorus or ask a 5-year-old about their day or what movies they like, and you realize how much that lights up their day,” Haywood recalls.

Haywood, speaking on behalf of Lady A, says it’s important to the group to support the teams caring for the children as well.

“It’s a phenomenal hospital and it needs to continue to have great support from anyone and everyone, entertainment or not. There are all sorts of great people who can make a difference and can help support. We’re happy to be included in that list,” he said.

Industry-wide support

Besides Kix Brooks, several top music industry executives serve on the Children’s Hospital Advisory Board, including Rod Essig of Creative Artists Agency (CAA), Clarence Spalding of Maverick and Sarah Trahern of the Country Music Association (CMA).

Country music duo Maddie (left) and Tae dance with patient Jurnee Scantling during a visit to Children’s Hospital.



JOHN RUSSELL

Also, many music industry supporters of VUMC have held key positions on the CMA, Academy of Country Music Association (ACM) and Country Music Hall of Fame boards. Among them are Scott Borchetta of Big Machine Label Group, Rob Beckham of WME, Frank Bumstead of FBMM, Joe Galante of Galante Entertainment, Randy Goodman of Sony Music, Mike Curb of Curb Records, Troy Vollhoffer of PGP, Colin Reed of Ryman Hospitality and Pete Fisher of the ACMs.

The chief executive officer of the CMA, Sarah Trahern, emphasizes the longstanding relationship between the association and VUMC. Trahern notes that VUMC provides CMA members and their families with health care, including specialized services like the Vanderbilt Voice Center and the Musicians’ Hearing Center, both part of the Vanderbilt Bill Wilkerson Center. CMA gives generously to support VUMC and Children’s Hospital with countless fundraisers, concerts, philanthropic events and direct financial contributions. Many of the artists visit Children’s Hospital to provide the healing power of music.

“We’re very fortunate in our business that the families of people in the music industry have a great facility right down the street to take care of them. The quality care that these kids are getting can’t be replicated,” said Trahern. “Any time the artists have come out and interacted with the patients and the parents, everyone seems grateful for our support.”

The CMA and its members have donated \$3 million to the Children’s Hospital’s current four-floor expansion—an idea that Kix Brooks and Clarence Spalding presented to the CMA Board. Along with Brooks, Spalding also is a member of the Growing to New Heights Campaign committee to support the current expansion at Children’s Hospital.

Ryan Seacrest cut the ribbon at the opening of Seacrest Studios at Children’s Hospital. Helping him are his family, surprise guest Taylor Swift, and patients, from left, Ilana Hanai, Gigi Pasley and Dalton Waggoner.



JOE HOWELL

A new generation of support

Artists like Kix Brooks and Rascal Flatts have also laid the foundation for a new generation of musicians and singers to build upon.

Madison Marlow and Taylor Dye, who make up the duo Maddie & Tae, joke that their first big gig was the butterfly stage at Children’s Hospital. Five years ago when they were 16 and starting out in the music industry, they played some of the songs they were writing for patients and families on the performance stage area of the second floor, the hub of the hospital near the food court.

“We had so much fun. The best part of it was that all the kids had an instrument to play along with us. It was like we were all putting on a concert together. It was a really uplifting experience and we were really glad to start our journey that way with the Children’s Hospital,” said Maddie Marlow.

“We feel very blessed that we get to be in a situation to bring a positive message to these kids and make them smile,” added Tae Dye.

Up-and-comers like Maddie & Tae also have a new avenue for an introduction to Children’s Hospital—Seacrest Studios, a state-of-the-art multimedia broadcast studio that opened in March 2016. The opening ribbon-cutting ceremony took place with help from radio and television host and producer Ryan Seacrest, along with his family and surprise guest Taylor Swift. The studio marked the 10th studio that the Ryan Seacrest Foundation (RSF) has opened inside a pediatric hospital. The Academy of Country Music, a longtime partner of the Vanderbilt Kennedy Center, is also one of Seacrest Studios’ partners.

“Our foundation has always chosen hospitals to partner with that believe a strong quality of care goes hand-in-hand

Members of the Nashville Predators hockey team made holiday cards with patients in December. Children’s Hospital patient Julianna Wooldridge poses with, from left, mascot Gnash, Ryan Johansen, Viktor Arvidsson, Pekka Rinne, Roman Josi and P.K. Subban.



JOHN RUSSELL

with providing programs that improve a patient’s quality of life during treatment. We chose Children’s Hospital as one of our locations because not only do they share these same sentiments, but they truly embrace music therapy and its power to help heal,” said Meredith Seacrest, who is Ryan’s sister and executive director/COO of RSF.

Because of the hospital’s unique location in Music City, a lot of talent has performed and visited over the years. Seacrest Studios, which celebrated its first birthday in March, has ushered in even more talent than before.

“We have been extremely touched by the Nashville community embracing our new studio with such warmth and excitement. We are always working to send artists and special guests to all of our studios, but are moved by the added support we have received from the existing relationships the hospital has within the music industry,” said Seacrest.

Beyond the music

Music businesses and artists aren’t the only well-known group supporting Children’s Hospital. Over the past seven years combined, the Nashville Predators hockey organization has donated more than \$1 million to the hospital and its programs.

The team’s 365 Pediatric Cancer Fund raises awareness for cancer research and allows the hospital’s patients and families to get special “Smashville” hockey game experiences. Two nights a year during the regular season, the Predators also host Hockey Fights Cancer night to raise money for the Fund.

Equally important to the team and its players are the multiple visits throughout the year—even when they’re preparing for a tremendous playoff run—to spend time with patients and families. Players’ room-to-room visits bring smiles and tears of joy. Goalie Pekka Rinne is a fan favorite at the hospital.

“It was a big eye opener for me,” Rinne said of his early visits to Children’s Hospital. He said children and families are always so happy to meet the players and to have the distraction from whatever health battle they are facing. “The impact you can have on kids and their families—that really made me think.”

As part of the 365 Fund, Rinne and the Predators purchased a suite at Bridgestone Arena that accommodates 32 children and families from Children’s Hospital for all Predators home games. A night at the suite includes food and beverages, Xbox games, 365 Fund T-shirts and postgame meet and greets.

“The partnership has grown over the years, and when you have a Hockey Fights Cancer Night, it helps make a big impact,” Rinne said. “For the players, it’s nice to be a part of it and it gives us a different perspective; it makes you think how many people are impacted and how fortunate you are.” 

JR and Kailey Hand with their children (from left), Harper, 4, Beckett, 1, and Jackson, 3.



Helping Hands

How the community worked to grow a hospital

written by Christina Echegaray
photograph by John Russell

Kailey Hand sensed something was wrong with her newborn son, Jackson. At 3 weeks old, he wasn't eating well. His tiny body was stiff and his skin was discolored. He cried more often than not.

Mother's instincts told her he needed help. So Kailey and her husband, JR, took their son to the Emergency Department at Monroe Carell Jr. Children's Hospital at Vanderbilt.

They had been involved with Friends of Children's Hospital and other initiatives to support health and well-being for children—a personal passion for Kailey—but they had never needed the hospital for care.

Jackson, they learned, had a severe staph infection, when staphylococcus bacteria get inside the body. Another day of waiting could have made the difference between life and death. With expert care, Jackson was able to go home a few days later.

"Vanderbilt was the first group of people who really listened to me and moved into action," said Kailey. "The doctors and nurses that night worked miracles, and given the magic of the people that night, I am forever grateful."

While the Hands went through the “what ifs” in their minds, they knew there were many more families facing similar, and in some cases, more dire circumstances. To help those families, they joined the community of families, businesses and entertainers who supported the Growing to New Heights Campaign, a philanthropic initiative to help build a four-floor expansion atop the existing Children’s Hospital structure.

“Everyone’s worst nightmare is to not only see something happen to their child but also maybe not have the means to get care,” Kailey said. “We can’t let that happen for any child or family. We have to champion through for answers and support. We are lucky to have this facility in our backyard. Who wouldn’t want to grow a treasure we have sitting right here?”

As Kailey and JR have grown their family business, Hand Family Companies, they’ve made it a priority to give back through volunteering and fundraising. Kailey also sits on the Children’s Hospital Advisory Board. They have three children: Harper, 4, Jackson, now 3, and Beckett, 1.

“To have healthy children and to have an avenue to get help for your children who are sick, it’s the greatest gift you could give. I don’t think anyone can process the stress that having a sick child puts on a family until they are in it. It’s a no-brainer to help, and we are just very happy to be a part of it,” JR said.

Because of supporters like the Hand family, Children’s Hospital surpassed its fundraising goal of \$40 million in February toward the four-floor building expansion that will advance the size and scope of the hospital’s specialized pediatric health care programs.

The Growing to New Heights Campaign, an ambitious fundraising effort launched in October 2014, garnered generous support from numerous donors and organizations, enabling the hospital to meet its goal under the anticipated time frame.

Construction is currently underway on the project, which will add 160,000 square feet of new space atop the hospital’s existing structure. The additional space will be built over an approximately 30-month period to meet the growing health care needs of children and families from Tennessee, the surrounding region and across the nation.

To launch the campaign, the daughters of the late Ann and Monroe Carell Jr.—Edie Carell Johnson, Julie Carell Stadler, Kathryn Carell Brown—and their families, made a cornerstone gift of \$10 million.

“The success of the campaign really speaks to the energy surrounding the campaign and the hospital. The way the community has embraced this campaign has been phenomenal,” said Kathryn Carell Brown, who chaired the campaign.

Along with Brown, co-chairs for the Growing to New Heights Campaign Cabinet included Kix Brooks, Rick Dreiling, Steven Hostetter, Bob Rolfe and Clarence Spalding.

Families of patients and other individuals with longstanding roots in the community supported the campaign as well, includ-

“To have healthy children and to have an avenue to get help for your children who are sick, it’s the greatest gift you could give. I don’t think anyone can process the stress having a sick child puts on a family until they are in it. It’s a no-brainer to help, and we are just very happy to be a part of it.”

ing some who had contributed to the effort to build Children’s Hospital as a freestanding facility in 2004. Additionally, more than 100 donors made their first-ever gifts to Vanderbilt University Medical Center in support of the campaign.

The campaign also included a \$3 million gift from the Country Music Association, as well as support from numerous partners from the entertainment industry.

Longtime hospital partners who have given generously through the years also left their mark on the expansion campaign, including the Junior League of Nashville, Friends of Children’s Hospital and the 13 Children’s Miracle Network Hospitals® partner businesses and organizations in the region.

“It is thrilling to see so many people come together in support of this great hospital,” said Luke Gregory, Chief Executive Officer of Children’s Hospital. “The success of this campaign underscores the enthusiasm our community feels for Children’s Hospital and the patients we serve. We are grateful to have so many champions of our mission. Together, we offer hope and healing to children and their families in our region and beyond.”  hope

Construction on a four-floor expansion is well underway at Children’s Hospital.



DANIEL DUBOIS

pioneers of 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 providers. 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.

Marlee Crankshaw, R.N., DNP, CNML, has experienced the joys of caring for babies for almost 35 years working in the Neonatal Intensive Care Unit (NICU) at Monroe Carell Jr. Children's Hospital at Vanderbilt.

In 1980, the 30-year-old stay-at-home mom of four faced a big decision that led to a career in nursing.

"My husband's diabetes was worsening and the doctors were discussing dialysis options. I was fearful as he became unable to work," she said. "When I graduated high school, I wanted to get married and have children. I never went to college. I had dreamed of becoming a nurse and taking care of babies. So, I gathered up my courage and started nursing school at age 30, with four children and a sick husband."

That dream was inspired years before by a personal experience. After giving birth to her fourth child, Katie, Crankshaw learned her baby had to spend time in a NICU. Every time her monitor beeped, Crankshaw panicked thinking Katie was in distress and would run to get a nurse.

"I vowed to be a pediatric nurse so moms won't be afraid," Crankshaw said. "I wanted to be that person who keeps them calm, because I knew exactly how it felt to be in such a scary situation."

Attending night classes at Tennessee State University as a non-traditional student, she obtained her associate's degree in nursing in two years, and began working at a small, local pediatric unit.

The sickest patients were sent to what was then called Vanderbilt Children's Hospital, and Crankshaw realized that's exactly where she wanted to be, taking care of the babies who needed continuous care.

On Oct. 31, 1983, Crankshaw began working at Children's Hospital, then housed on the fourth, fifth and sixth floors of the main hospital.

"It was the dream of a lifetime to take care of these families and their babies," Crankshaw said. "I could not get over how amazing this place was. Once I was hired, I never looked back."



SUSAN URMY

Crankshaw, director of Neonatal Services, has now worked in the NICU for over three decades and seen firsthand the growth of Vanderbilt Children's Hospital to Monroe Carell Jr. Children's Hospital at Vanderbilt.

She's also experienced medical advancements in the NICU, caring for babies born as early as 23 weeks gestation. The survival rate of premature babies has increased greatly.

“When a baby dies, it is devastating. We have to step back and look at the bigger picture and know that we have great outcomes, and focus on what we can do for every baby. A larger majority of our babies leave our hospital and have good outcomes,” she said. “Many of these families, I’ve become attached to and I still receive graduation announcements and birthday cards in the mail from them.”

In 2001, she earned her master’s degree in Health Systems Management from Vanderbilt School of Nursing, and went on to earn her Doctor of Nursing in 2010.

“I was very proud to be in the first DNP class for Vanderbilt. There were certainly times in school that I simply thought I could not go on—my husband’s health had continued to deteriorate through the years and I was pushing myself as hard as I knew how. I wanted my children and grandchildren to learn to never give up and your dreams can always come true if you work at them.”

When Crankshaw isn’t at work, she’s spending time with her four children—Stephanie, 44, Chris, 43, Jenny, 42, and Katie, 37. Her husband, Robert, affectionately known as “Shaw,” died in 2010.

She has 13 grandchildren and three great-grandchildren who call her “Mingy.” She enjoys hosting family dinners for them.

– by Tavia Smith



Dai Chung, M.D., chair of the Department of Pediatric Surgery, literally grew up in a hospital—long before he became a surgeon or studied to be one. Nurses helped raise him and his two younger brothers, often taking them to the park while his parents worked.

Born in Seoul, South Korea, his family lived on the upper floors of their family-owned hospital. His mother, an obstetrician-gynecologist, ran her practice on the first floor, while his paternal grandfather, a pediatrician, worked on the second floor of the hospital. Medicine was in his blood.

“I tried to hide that my grandfather was a pediatrician, especially around vaccination time. I didn’t want the kids in the neighborhood to know my grandfather was the one who gave them the shots,” Chung joked. “I remember a lot of sick kids coming in. But really, medicine always seemed natural to me.”

His family immigrated to Dallas, Texas, in the 1970s, when he was a teenager, for his father’s work in international trade relations between South Korean companies, like Samsung, and the United States.

Chung went to University of Texas at Austin where he received his bachelor’s degree in Biology before attending University of Texas Medical Branch (UTMB) in Galveston to earn his medical degree.

A summer research project under his mentor Courtney Townsend Jr., M.D., whom he still communicates with, motivated him to be an adult general surgeon with a focus in surgical oncology.

But simultaneous research on pediatric burns during his residency changed his career focus. His interest in pediatrics was piqued when he spent a fellowship caring for children with burn injuries at Shriners Hospitals for Children in Galveston. That’s also where he would meet his wife, Kimberleye.

“There is something special about helping kids. It was such a rewarding experience. I have fond memories of my time at Shriners. Being able to make a little difference for those innocent kids who happened to suffer devastating burn injuries was truly special,” said Chung, Janie Robinson & John Moore Lee Professor of Pediatric Surgery.

A rotation in pediatric general surgery hooked him further into pursuing a career in pediatric surgery as he loved the broad scope and range of conditions treated by pediatrics surgeons. Chung would do a fellowship in pediatric surgery at the Cincinnati Children’s Hospital Medical Center, then took a position as medical director for the pediatric burn unit at Children’s Hospital of Alabama at Birmingham.

He returned to UTMB to lead a section of pediatric surgery including developing a robust research program, where he remained until taking an opportunity at Monroe Carell Jr. Children’s Hospital at Vanderbilt.

He developed a passion for research in neuroblastoma, a



cancer that originates in the nerve tissue cells and primarily affects infants and young children. He studies the role of gastrin-releasing peptides in neuroblastoma in hopes of developing targeted therapies.

Chung arrived at Vanderbilt in 2009, following the devastation of Hurricane Ike in Galveston, Texas. Coming to Vanderbilt allowed him to continue pursuing his passions.

“I wanted to have a leadership role and to help build a preeminent academic pediatric surgical program where not only as pediatric surgeons we provide the utmost, highest quality care, but where we also train the next generation of outstanding pediatric surgeons to be better than us. I also am passionate about trying to find a cure for neuroblastoma, and to discover how we can deliver better care and make an impact for these kids,” he said.

Chung holds many roles at Children’s Hospital, which include director of the Pediatric Trauma Program and program director of Pediatric Surgery Residency.

When not at work, Chung and Kimberley spend time with their 13-year-old twin girls, Kaley and Camryn. He also golfs, a pastime he used to enjoy with his father.

– by Christina Echegaray



Kathie Krause, MSN, R.N., NNP-BC, NEA-BC, has fond memories as a child in the 1970s watching her aunt prepare for a nursing shift at a local hospital and leave the house donning all-white clothing—a nurse’s cap, dress, shoes and pantyhose.

“She was my inspiration,” said Krause of her aunt who earned a bachelor’s degree in nursing from Boston University. “I decided I wanted to do that too.”

Growing up just outside of Cleveland, Ohio, Krause chose nearby Kent State University to pursue a Bachelor of Science in Nursing. A tour of a neonatal intensive care unit began her love of caring for tiny infants fighting for their lives.

“I loved critical care—I like the excitement, the technology and the type of support you offer to families in a critical care unit. I really enjoyed the babies,” said Krause, Chief Nursing Officer (CNO) of Monroe Carell Jr. Children’s Hospital at Vanderbilt.

After graduation in 1984, she moved to Nashville, where her parents had relocated, and began working as a neonatal intensive care nurse at Vanderbilt University Medical Center, when the pediatric unit consisted of three floors inside the adult hospital.

After a short time at Vanderbilt, Krause became part of a groundbreaking team, one of eight people who would embark on establishing Vanderbilt’s first pediatric extracorporeal membrane oxygenation (ECMO) program. The ECMO machine, which has evolved in the three decades since Vanderbilt began using it for infants, provides temporary heart and lung support for patients experiencing severe pulmonary or cardiac failure.

Children’s Hospital has one of the most well-regarded programs in the world, led by John Pietsch, M.D., surgical director and founder of the ECMO program at Vanderbilt.

“To be in the Vanderbilt Neonatal Intensive Care Unit with Dr. (Mildred) Stahlman, who is such an icon in the field, and learning from her and the faculty and staff, I feel like it’s a story in my career not many people get a chance to tell. We were there on the cutting edge watching babies who literally had no hope and we could turn it around and save their lives,” she said.

“You don’t know that you’re part of something bigger when it’s happening, but you look back on it and say, ‘wow.’”

During her time at Vanderbilt, Krause earned a Master of Science in Nursing from Vanderbilt University School of Nursing in 1992.

Other career opportunities in nursing arose for Krause, pulling her away from Vanderbilt for a time to Alabama and other parts of Tennessee, before she would return back to where she “grew up” in neonatal care to fill the position as CNO of Children’s Hospital in 2015.

In her time away, Krause fell into administrative roles, which she initially never intended to pursue due to a passion for direct care of the babies and families.

“What I enjoy about leadership is not just making a difference for one particular patient but for a patient population

and the staff who care for them. To be able to work with a group of nurses, physicians, respiratory therapists, whomever, to make a better environment for patients and families—that’s really what I enjoy. I take care of people who take care of people,” she said.

When not at work, Krause can be found traveling the world. To name a few places, she’s been to Morocco, Portugal, Italy and Scotland. In December 2016, she took a two-week riverboat cruise along the Rhine River through Europe, visiting Christmas markets. Next year, she is planning a train tour across Canada.

— by Christina Echegaray



William R. Moore, M.D., was doing his residency at Vanderbilt University Medical Center in 1985, working the obstetrics rotation when his heart revealed a passion for pediatrics.

After each birth, Moore found himself gravitating to the newborn’s bassinet.

“I really, really loved the obstetrics program,” Moore said. “I fell in love with following women through their pregnancy. Every time a baby was born I’d be standing at the bassinet with the baby.”

He was pulled to the side by his superior after a birth.

“He said, ‘You just need to be a pediatrician,’” Moore said, with a smile. “And he was right.”

For more than three decades, Moore has learned a lot about life, joy and love from the thousands of children he has cared for as a community physician in Clarksville, Tennessee.

“Children are so fluid. You have such a chance to help them for the good. They are impressionable and I love interacting with them and their parents,” Moore said.

Although Moore has one son, he treats all his patients like his own children.

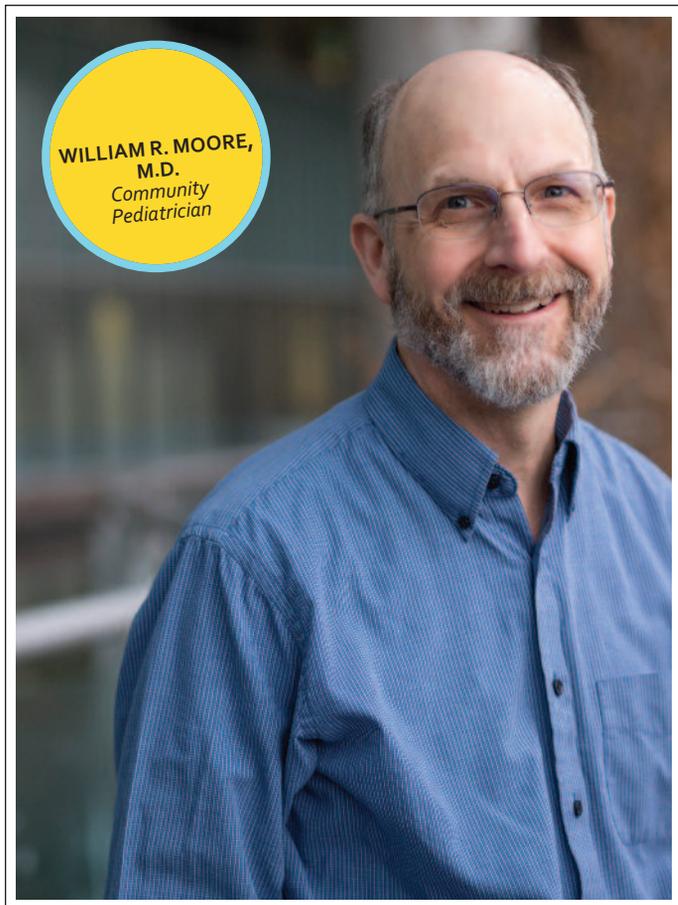
“When people ask me how many children I have, I always answer between 2,000 and 3,000,” Moore said. “Children are fun to talk to and watching them grow up, seeing them change is like watching your own child.”

Moore, a Vanderbilt University School of Medicine (VUSM) alumnus, is a pediatrician at Premier Medical Group, and enjoys a close partnership with Monroe Carell Jr. Children’s Hospital at Vanderbilt.

“I think it’s an excellent relationship I have with Vanderbilt as a community physician. When I need help, I call, and they are always very supportive,” Moore said. “I treat a lot of normal, healthy children, but when we have the few who need specialty treatment, it’s reassuring to know that when I refer them, they will get the best care at Monroe Carell Jr. Children’s Hospital.”

Moore helped form Premier Medical Group 22 years ago. But his path to caring for children was not cut and dried.

“I was doing electrical engineer training at University of Memphis. I was working in biomedical engineering. I did some research and applied to medical school at Vanderbilt University,” he said.



He was shocked and excited when he was admitted into VUSM in 1978.

“It was a God thing,” Moore said. “I was accepted, but not sure how I would afford it. Then I learned I earned a full scholarship. I was so humbled.”

As a medical student, Moore explored patient care, working as a suture tech at John Gaston Hospital’s emergency room in Memphis.

“I’m an empathetic person. It was hard seeing gunshot wounds and seeing people die,” Moore said. “I never dealt well with seeing adults die.”

It was watching the birth of new life that led him to become a pediatrician.

“I love asking children questions and listening to their funny answers. It’s amazing to talk to the parents and help (those parents) make good choices—because the children are our future and we must invest in our future.”

During Moore’s residency at Vanderbilt from 1982-1985, he met his future wife, Mary “Genie,” a Vanderbilt researcher. Ironically they were coordinating the care of a pediatric patient. Married for 33 years, they travel the world, practice photography and hike. They have one child, Evan Moore.

— by Tavia Smith

Hometown Heroes



Predators goalie Pekka Rinne poses for a photo with patient Caleb Daniel and his mom, Ashley.

The Nashville Predators hockey players are heroes on and off the ice—they're devoted supporters of Monroe Carell Jr. Children's Hospital at Vanderbilt.

Over the past seven years, the Predators have raised and donated more than \$1 million to Children's Hospital, with more than \$500,000 going to the Nashville Predators 365 Pediatric Cancer Fund. They also made a gift to the Growing to New Heights Campaign for the hospital expansion that's currently under construction.

On Hockey Fights Cancer nights, pediatric patients from Children's Hospital attend the game and participate in a ceremonial puck drop and ride the Zamboni. All money raised during the games, a night dedicated to the young warriors battling this disease, benefits the 365

Pediatric Cancer Fund.

As part of the Fund, team goalie Pekka Rinne also purchased a suite at Bridgestone Arena that accommodates 32 children and families from Children's Hospital for Preds home games.

In addition to their gifts, the Predators support Children's Hospital in many ways. They make frequent visits to Children's Hospital, which include room-to-room visits with patients unable to leave their room and in-studio appearances at the Seacrest Studios inside Children's Hospital. The organization also was the impetus for starting patient-support programs at the hospital like Flashes of Hope, in which professional photographers donate their time to take portraits of pediatric patients battling cancer; and Beads of Courage, which allows pa-



Max Hermsdorfer, center, served as patient ambassador for Children's Hospital at the Nashville Predators Hockey Fights Cancer Night last fall. Here, Max drops the puck with Predators' captain Mike Fisher, left, and Anaheim Ducks' captain Ryan Getzlaf.

tients to build a necklace with charms documenting their health care journey.

As the Nashville Predators took on the Pittsburgh Penguins in the Stanley Cup

Final (at time of publication), patients returned the support with posters and cards with words of encouragement.

— by *Christina Echegaray*

A SUNDAY WITH FRIENDS

Sunday with Friends, a new benefit event hosted by the Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt, debuted in March at the Belk Cool Springs store. Family activities—inspired by spring break—included a ski station, mini-golf and an opportunity to walk the fashion runway. In addition to Belk, the event sponsors were Lucas Orthodontics, Purity Dairies and Thompson-Burton, LLC.



Brian, Catherine, George and event co-chair Melissa Laskaris enjoy the festivities at Sunday with Friends.

Giving from the heart

LAUREN PEAKE MURPHY says her son, Vaughn Ritzen, rarely slows down. The 8-year-old is the first one in their house to wake up each morning and loves Nerf gun wars, climbing trees and being active.

When Vaughn was born, his pediatrician detected a heart murmur. Lauren and her family are no strangers to cardiac conditions. Lauren herself has a heart murmur, and her father has mitral valve prolapse, a condition in which the two flaps of the mitral valve do not close evenly but instead bulge. Further, Lauren's nephew passed away at 18 months of age from unexplained causes. Through the pain of that family tragedy, combined with what she knew about her family medical history, Lauren said it was important to know everything she could about her children medically.

She sought care for Vaughn's newly detected murmur at Monroe Carell Jr. Children's Hospital at Vanderbilt. At 2 months old, he was diagnosed with pulmonary stenosis, a condition where the pulmonary artery—the artery that carries the blood from the right ventricle to the lungs to become oxygenated—is too narrow, compromising blood flow.

As a patient of Vanderbilt's pediatric cardiology program, Vaughn was seen frequently to monitor his condition.

Today, although Vaughn sometimes gets winded and will never outgrow his condition, pulmonary stenosis hasn't stopped him from living a typical childhood. He will have routine cardiology visits throughout his life.

"We are so thankful for the care Vanderbilt provided our son and are grateful for our positive outcome with Vaughn, but we know that this isn't the case for everyone," Lauren said. "We want other people to be able to benefit from the care Vanderbilt provides."

The Franklin, Tennessee, family has chosen to express their gratitude to the pediatric cardiology program at Children's Hospital by supporting the Thomas P. Graham Jr. Fellowship program, which provides superior training to early-career pediatric cardiologists.

The fellowship is named for emeritus faculty member Thomas P. Graham Jr., M.D., who joined Children's Hospital in 1971 to start its first pediatric cardiology program, served as chief of the division until 2004 and treated patients until his retirement in 2007.

The three-year pediatric cardiology fellowship program challenges trainees through intensive clinical experience and opportunities for investigative work in a number of clinical and basic research fields.



SUBMITTED PHOTO

Thankful for the health care Vaughn Ritzen, 8, received at Monroe Carell Jr. Children's Hospital at Vanderbilt, Lauren Peake Murphy and family are supporting a Pediatric Cardiology fellowship.

The cost of Pediatric Cardiology fellowship training is primarily incurred by the Division of Cardiology, which can present a financial challenge, said Scott Baldwin, M.D., director of the Division of Cardiology and co-director of the Pediatric Heart Institute.

"Funds like those provided by Lauren Murphy go a long way toward ensuring that we can attract the best and brightest individuals and provide the highest level of training and mentorship," said Baldwin, the Katrina Overall McDonald Professor of Pediatrics. "We have become very good at 'repairing' most heart defects early in life, such that many individuals born with congenital heart disease are living well into adulthood. Caring for these patients requires developing expertise in both pediatric and adult cardiology. Thus, now more than ever, we need support for such individuals who are willing to dedicate so much time to developing the skills to deal with a growing population of patients with unique health care needs."

Through the support of this fellowship, Lauren is not only playing a role in cultivating the next generation of cardiologists, but she is cultivating the next generation of philanthropists by instilling altruism in her children. In addition to Vaughn, Lauren has another son, Wesley, age 10, and two stepdaughters, Katie and Michaela, with her husband, Michael.

"Vaughn knows his heart is special, and he knows that the choice to give money to Vanderbilt will hopefully help others," Lauren said. "We want our children to use money in an influential way. By providing for Children's Hospital, if we are able to help the hospital or if someone is able to benefit from what we give, then it makes it all worth it."

— by Jennifer Wetzel

A target to heal tiny lungs

Bronchopulmonary dysplasia (BPD)—a form of chronic lung disease—is a common complication of preterm birth and results from airway injury during a certain stage of lung development.



ISTOCKPHOTO

Jennifer Sucre, M.D., and colleagues hypothesized that a signaling pathway active during lung development—the Wnt/beta-catenin pathway—may play a role in the pathophysiology of BPD. The

researchers found a marker of active Wnt signaling, nuclear phosphorylated beta-catenin, in fetal and preterm BPD lung tissue, but not in lung tissue from full-term infants.

Using a 3D human organoid model they developed, the investigators demonstrated that oxygen conditions that cause BPD-related cellular changes resulted in increased levels of nuclear phosphorylated beta-catenin. They found that inhibitors of the phosphorylation blocked the nuclear localization of beta-catenin and the BPD-related cellular changes.

The findings, reported in the February *American Journal of Physiology – Lung Cellular and Molecular Physiology*, support a role for Wnt/beta-catenin signaling in BPD and suggest that beta-catenin may be a relevant therapeutic target for this disease.

This research was supported by grants from the National Institutes of Health (HD087023, GM114259, GM108087). Jennifer Sucre received a Clinical Fellowship Training Grant from the Eli and Edythe Broad Center of Regenerative Medicine at UCLA, and the California Institute of Regenerative Medicine provided additional support.

— by Leigh MacMillan

Training program teaches alternatives to spanking

Early interventions and discipline training programs for parents may help decrease the use of spanking as a discipline method, according to a Vanderbilt study published in the journal *Clinical Pediatrics*.

Spanking, previous research has shown, has adverse outcomes such as childhood aggression, child abuse, violence and mental health problems. Several leading professional organizations, such as the American Academy of Pediatrics, recommend discipline strategies other than spanking.

Investigators at Monroe Carell Jr. Children's Hospital at Vanderbilt demonstrated several years ago that a brief intervention can shift parents' attitudes about spanking. This new study

explored how the program works to convince parents to stop spanking their children. Ultimately, parents cited education on alternative discipline strategies as the most common reason for changing their attitudes toward spanking.

During a well-child visit, the parent or caregiver was invited to participate in a five-to-10-minute multimedia program called "Play Nicely." The program teaches strategies to respond to childhood aggression. Of the 197 parents/caregivers who participated, 128 (65 percent) planned to change how they discipline, including looking to other discipline options beyond spanking. Additionally, 19 parents (10 percent) said they planned to spank less. A majority of these parents reported that the program works because it offers alternatives to spanking.

Julia Hudnut-Beumler, a fourth-year medical student at Vanderbilt University School of Medicine, was a co-investigator with Seth Scholer, M.D., MPH, professor of Pediatrics and the creator of the Play Nicely program. Play Nicely was designed for parents and teachers to develop a behavior management plan for children with aggression or anger management problems.

— by Christina Echegaray

Saliva test for obesity risk

Saliva is a practical way to assess the risk of preschool children for obesity, and thus may present an opportunity for prevention or early intervention, researchers at Vanderbilt University School of Medicine reported in the journal *BMC Genomics*.

In a first-of-its-kind study, Shari Barkin, M.D., MSHS, and colleagues collected saliva samples from 92 Hispanic preschool children. DNA in the samples was tested for methylation, an epigenetic mechanism that regulates expression of genes, including those affecting accumulation of adipocytes (fat cells) and other obesity risk factors.



Shari Barkin, M.D., MSHS

Methylation at 17 DNA sites was found to be significantly associated with the mother's body mass index (BMI), suggesting that obesity risk may be transmitted from mother to child. Inadequate nutrition or insulin resistance in the mother, for example, may cause epigenetic changes favoring obesity in the child.

If validated by further study, these "epigenetic signatures" could aid discovery of early biomarkers of childhood obesity and metabolic dysfunction, the researchers concluded.

The research was supported in part by National Institutes of Health grants HL103620, HL103622, HL103561, HD068890, HL103629 and DK092986.

— by Bill Snyder



Thank you from the bottom of our hearts.

Our region is growing, and so is the number of children in need of the expert, compassionate care that only Monroe Carell Jr. Children's Hospital at Vanderbilt can provide. That's why Children's Hospital is growing, too.

Hundreds of individuals, businesses and foundations have raised \$40 million to help us add more space for critically ill children — an expansion that will enable us to care for every child who needs us.

To our community of support, our heartfelt thanks.

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The American College of Surgeons (ACS) Committee on Trauma has verified Monroe Carell Jr. Children's Hospital at Vanderbilt as a Level I pediatric trauma center, recognizing the hospital's commitment to provide the highest level of care for injured pediatric patients. As a regional comprehensive pediatric facility, Children's Hospital is the only Level I pediatric trauma center within 150 miles, providing specialty services for children from Alabama to Kentucky and all over Tennessee. There are fewer than 50 ACS verified Level I pediatric trauma centers in the country.