

hope

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WINTER 2018



One second.
One touch.
Lives forever
changed.





cover story

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Lives forever changed.

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THE START OF A NEW YEAR IS A GOOD TIME TO REFLECT UPON WHAT ANCHORS US in life and work. As we continue to “grow to new heights,” we are reminded of our mission at Monroe Carell Jr. Children’s Hospital at Vanderbilt to serve all children, and their families, through the delivery of specialized medical and surgical programs. It is a true privilege to participate in the development and growth of multidisciplinary services that improve the health and well-being of children and adolescents in our immediate community, but also regionally and across the state. Wrapped around and supporting the delivery of excellent clinical care is our commitment to discovery research and teaching the next generation of pediatric providers.

The cornerstone of building specialized programs for children and adolescents is the ability to collaborate, within the greater Vanderbilt medical community but also beyond our campus to meet the needs of families in a more convenient way.

Through the telling of heartwarming stories, you will learn about some of the partnerships that illustrate how we meet the needs of children and their families through our innovative services — some within our hospitals and clinics and some using new technologies that extend far beyond our walls.

One example is our Brachial Plexus Clinic, which brings together specialty-trained pediatric surgeons and occupational therapists to create a personalized approach of care to restore arm movement to children of all ages.

Another example is the combining of expertise of the pediatric intensive care unit in partnership with our regional comprehensive burn center physicians, nurses and therapists to enable not only the physical but equally important emotional healing of children and families impacted by burns.

Children and adolescents with conditions that affect development, like autism, benefit from the efforts of specialty-trained pediatricians in collaboration with researchers at the Vanderbilt Kennedy Center. Through the use of telemedicine, diagnosis and treatment plans can be personalized to care for children of all ages remotely and in partnership with schools and other community-based resources.

We also don’t want to leave out the importance of music as therapy. Our patients love to sing and we provide lots of opportunity for them within the hospital and outside — sometimes with their own caregivers.

The key to great collaborative endeavors is the foundation of relationships between many services but also community partners who generously support our mission of being a place of hope and healing. We begin this new year of further growth and innovation with gratitude for our compassionate staff, our committed faculty, our community and of course our patients and families who come to us with both routine and very complex needs.

Sincerely,

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One second. One touch. Lives forever changed.

Six-year-old Noah Kelly finished Bible study at his Nashville church and asked to play soccer outside with his friends before heading home.

The electricity had been out at the church on that Saturday in July 2016, and the group had hoped that the electric company would arrive to fix the problem before the steamy day ended.

Noah's mom, Rufta Aron, stood by the open door, waiting for Noah to finish playing. As she said goodbye to friends, Noah reached inside a bush to retrieve the soccer ball and touched a live electrical wire. One second. One touch. Lives forever changed.

written by Nancy Humphrey
photograph by John Russell



Noah received life-threatening electrical burns over much of his body. Electricity runs rapidly through the body and not only chars the skin, but also burns muscle and bone, severely damaging tissue beneath the skin.

"Noah's friends all started screaming 'fire, fire,' but when I turned around there was no fire," Aron said. "Noah was lying on a little hill. When I got to him, I lost it. His eyes were open, but he was like stone."

Aron began CPR, during which she pulled melted wire out of his mouth. "I tried to dump water on him. I wasn't thinking right. I wasn't even thinking that I shouldn't touch him (because of the electricity). My reaction was to bring him back. I kept crying, 'He's gone. He's gone,' and my friend said 'No, he's not. Not today.' I appreciated her giving me that hope."

Aron was too distraught to continue CPR, so her friend, Rahwa Bereket, stepped in to perform CPR with help from one of the church members. They finally got a faint pulse. The paramedics arrived quickly and tried to stabilize Noah before transporting him to Monroe Carell Jr. Children's Hospital at Vanderbilt.

"They wouldn't let me ride with him. He was in very bad condition, and they didn't want me in there," Aron said. A friend drove her to the hospital. "I had his shoes and put them in my purse. They had melted. Everything smelled like burned wire."

Every minute counted

Lisa Rae, MD, was on call that afternoon and met Noah at Children's Hospital's Emergency Department.

"Noah had horribly severe injuries," said Rae, director of Burn Center Quality and Performance, Trauma and Surgical Critical Care. "With electrical burns you can't always see the full extent of the injuries right away. Electricity can run through the body and burn muscle and bone under the skin. It can also injure the brain, heart and nerve function throughout the body."

The Pediatric Emergency Department team quickly determined that Noah was burned over 40 percent of his body, particularly his right arm and hand, the back of his head and the entire back of his body. "He had char burns clearly into the muscle and bone and you could see exposed burned bone on his hand. He had muscle that appeared to be 'cooked' in the wound. He was unconscious and we didn't know his mental status and wouldn't know for some time. With this type of injury there's the potential for brain injury," she said. It was the worst electrical burn she had seen.

Rae joined the Vanderbilt faculty in 2013 following general surgery training at Georgetown University in Washington, D.C.,

and burn and trauma critical care fellowships at the University of Washington at Harborview Medical Center's Level 1 adult and pediatric trauma and burn center.

The team's first focus was to stabilize Noah and replace fluid loss resulting from the burn injury in his small body. "We needed to keep him out of multi-organ failure," she said. "He was having a storm of inflammatory responses. Days in, we would still be discovering the extent of his injuries."

Within an hour Noah was transferred to Children's Hospital's Pediatric Intensive Care Unit (PICU) where he would continue to stabilize for about a month.

"Every minute counted," Aron said. "Every minute that went by, there was hope."

A blended unit

Burn patients with large burns — 15-20 percent of the total body surface area or more — often need critical care for at least the first 24 hours or more, said Blair Summitt, MD, assistant professor of Clinical Plastic Surgery and medical director of the Vanderbilt Burn Center, which opened in 1983. Critically burned adult patients are cared for in the Burn Intensive Care Unit, a designated Level 1 burn center. Critically injured burn patients may need resuscitation; they lose large amounts of fluid and need to be taken care of by intensive care specialists.

The Center's stepdown unit, however, treats children and adults. It is the only adult and pediatric blended unit in the Vanderbilt University Adult Hospital.

In 2016, of the Burn Center's 572 admissions, 95 were pediatric patients.

"Pediatric burn patients are first taken to the Children's Emergency Department for assessment, then will be sent to the Children's Hospital's Pediatric Intensive Care Unit for critical care monitoring and/or ventilation," Summitt said. "Having these patients receive critical care in the PICU is invaluable for us. Our (burn) teams go there."

Summitt said the two groups work extremely well together. Surgeries on pediatric burn patients take place at Children's Hospital. When the patients are stabilized and moved to the Burn Center's stepdown unit for continuing care of their wounds and rehabilitation, a pediatric hospitalist often continues to follow their care because children may have other non-burn related issues such as ear infections, etc.

Summitt said that most pediatric burns are from scalding, with about 10 percent being due to abuse or neglect. The first stop, the Pediatric Emergency Department, is critical for assessing whether the burn could be due to abuse or neglect, he said.

“Every minute counted. Every minute that went by, there was hope.”

Electrical burns are seen less frequently at Vanderbilt’s Burn Center (about one a month) and are difficult to assess, Summitt said. “Many times there are no external burns, but the current runs through their body damaging bones, muscle, fat and skin. They need fluid replacement and they can quickly go into kidney failure. Their injuries can be disguised when we first see them,” he said.

One out of four electrical burn patients will require an amputation, he said. They may also have long-term neurologic issues and can suffer migraines and memory loss and long-standing pain in their hands or feet. “Electrical burns are terrible injuries,” Summitt said.

A collaborative, multidisciplinary team

Rae said Noah’s burns were severe enough to require amputation of his right arm while he was in the PICU. This was performed by Wes Thayer, MD, one of Plastic Surgery’s hand specialists. The burns to his head required the removal of dead tissue including his scalp and skull bone. He had several brain scans as they tried to determine whether his brain had been damaged by the current. It had not. “It takes a very collaborative team to get someone through these stages,” she said. It was about a week before Noah was stabilized in the PICU.

“Because all damage cannot be seen on a scan, then the question remained about his mental status,” Rae said. “He started waking up and opening his eyes, and was still on a ventilator to breathe for him, but even at a week out he would really only respond and look at his mother. Since he was hooked to multiple tubes and was on so many medications for pain, it took several weeks for him to respond to others and ‘act like his old self,’” Rae said.

After one month in the PICU, he was transferred to the Burn stepdown unit where he stayed for over three months. His total hospital stay: 145 days — just shy of five months.

Burn injuries require specialized care from burn surgeons, specialty surgeons, pediatric critical care physicians, medical physicians, nurses, Child Life specialists, physical and occupational therapists, nutritionists, social workers, respiratory therapists and mental health professionals. There are both physical and emotional injuries.

“It takes a very collaborative team to get someone through these stages,” Rae said. “Burn units are often touted as the model for multidisciplinary care because the patients are so



Noah with his mom, Rufta Aron

complicated and so many people are required to help the patient get well.”

People with severe burns may require a lifetime of procedures and physical therapy. Their wounds require skin grafts (a surgical procedure that involves removing skin from one area of the body and moving it, or transplanting it, to a different area of the body); they have difficulty maintaining body temperature and fluids, are at high risk of infection and require significant physical and occupational therapy. Noah required about 15 skin grafts.

‘One of the most incredible families’

Keeping an emotional distance from patients isn’t always

possible, Rae said. “There are certain patients and families that you can’t help but become attached to when you’re involved and you care so much,” she said, adding that much of a child’s adjustment depends on his family’s strength. “Noah’s family is one of the most incredible families I’ve ever dealt with. How they coped and stayed positive, how they were there in ways appropriate for Noah, was really remarkable.

“When they saw his amputated arm, they didn’t show their own shock. When Noah had wound care, they said ‘look at how great your skin grafts are. Look how you’re healing.’ They pushed forward and helped him not be afraid. They modeled acceptance. Kids pick that up from their parents.”

The recovery of a burn patient is lengthy and complicated, Rae said. “There’s no adequate education for what patients will

experience with a serious burn, there is no way to truly prepare a patient or their family for how long and difficult recovery is.

“Patients and their families can’t know what’s ahead, but I do. It’s a very long road. It takes a huge amount of adjustment, and Noah is adjusting to his life as a burn survivor.”

Aron said the Burn Center team became like extended family. “They were very caring to the point I was like ‘oh my

During a nearly five-month hospital stay, Noah’s care required a large team of physicians, nurses and staff from the Vanderbilt Burn Center and Monroe Carell Jr. Children’s Hospital at Vanderbilt. Some of those people are pictured here (front row, from left): Noah’s mom, Rufta Aron, Mike Elam, burn care specialist, Zeeshan Rifat, MD, and Noah’s dad, Roy Kelly; (second row) Elizabeth Vorholt, RN, Madison Shinn, RN, Melissa Martin, RN, and Annie Mitchell, RN; (back row) Kensie Harley, DPT, William Andrews, ACNP, and Ellen Schoen, RN.



JOHN RUSSELL



Lisa Rae, MD

God, you're doing more than what your job requires."

The day that Noah left the hospital, there was a celebration; the Burn Center team lined the hallway and cheered, blew bubbles, and gave him high-fives as he walked slowly down the hall.

"Our staff became so close to Noah and his family," said Lindsay Miller, MSN, RN, the Burn Center's Nurse Manager.

"They used their own money to buy ingredients so he and his mom

could bake pizzas," she said. "Our nurses watched him so his parents could go out to dinner. We had staff who requested time off to go to his birthday party at his house after he had been discharged."

Rae, his physician, said she had mixed feelings when Noah was discharged. "I was so happy to see him getting out of the hospital. It was a milestone, but he still has so much work to do and at that point he had skin grafts behind his knee that weren't healing. It wasn't the same sense of accomplishment that he and his family had. I know the hard work that's ahead."

Noah returned to the hospital in February for additional skin grafts behind his knee, an area that was difficult to heal.

"There's only a very small part in the burn textbook about ghosting or wounds that don't heal," Rae said. "I had to talk to colleagues around the country about what to do for Noah," she said. The wounds have now healed.

Noah will require lifelong medical care for his scars since scars don't stretch and grow like the rest of a growing child's body. The scars, which affect not only the outward appearance of the skin but also the muscle and fascia (connective tissues surrounding muscles) below, will limit his movement, so he will require physical therapy to keep his limbs moving appropriately and allowing him to continue to be mobile. He also must wear burn compression garments underneath his clothes that work by applying pressure to the affected area to help flatten and improve the appearance of scars. His prosthetic arm will also need to be adjusted as he grows.

"Noah's grafts are softer than I would expect, they are more like normal skin, so his scarring is not especially bad," Rae said. "He's doing amazingly well. The muscle in the back of his right thigh was blown out down to the bone. There was a big deep hole where the muscle was missing. We didn't know if the sciatic nerve (that runs from the lower back down the back of each leg) would be OK or if he'd have use of his leg. Today, he has no visible tissue defect. His recovery has really

been remarkable — that's part of the blessing of being a kid. They can do amazing things."

Noah's mom said that he is "goofy, quirky and smart," and loves his two dogs, music, superheroes and playing games. He also has eclectic taste in food. He doesn't eat any junk food or any fast food. He loves sushi and Ethiopian food. "He's not your typical 6-year-old," Aron said.

She recalls being fearful about how Noah's classmates and others would perceive him (because of his scarring and prosthetic arm) once he returned to school in April 2017.

"I didn't think we were ready for the outside world. I wanted him to be around people who knew him, who cared for him and who knew what happened — people who wouldn't judge him. But going back to school was harder on me than it was on him. It just doesn't faze him," she said.

"One night, I was putting him to bed and I asked him if it (going back to school) was OK. He said that some of the kids said his arm was weird. I almost got a little teary, and I told him that being weird is good. 'When people say you're weird it means that they don't understand something that has happened. So being weird is actually kind of cool,'" she told him.

"He just said, 'OK. If someone says my arm is weird, I'll just say yeah, that's because I'm cool.' Noah takes care of himself. He doesn't let anybody put him down." 🦋 hope

Understanding Burns: Causes and Types

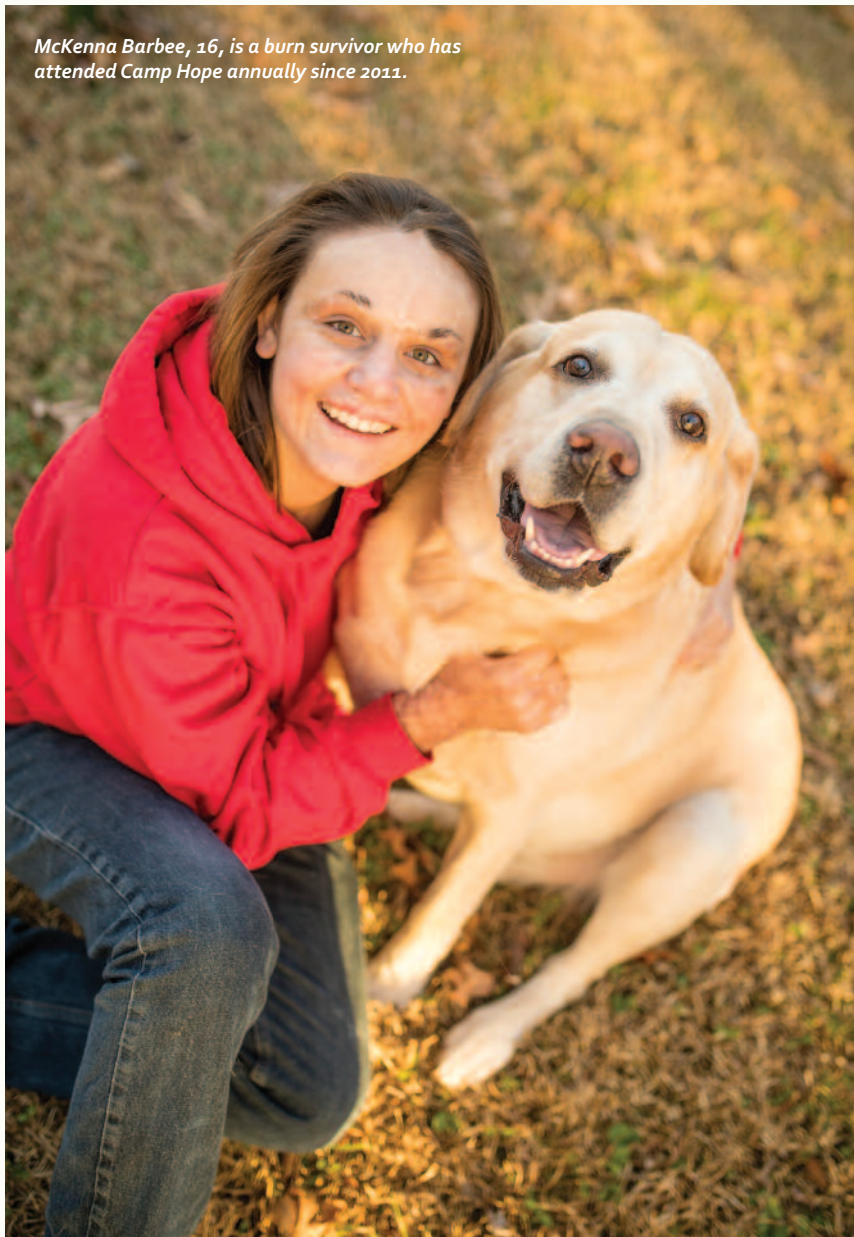
Approximately 80,000 children are treated for various burn injuries in hospital emergency rooms every year. Hot water scald burns can cause more death and hospitalizations than any other hot liquid burns. More than half of the children under the age of 4 who are hospitalized for burn-related injuries suffer from scald burns.

What is a Burn?

A burn is damage to the skin caused by heat, flame, electricity, hot liquids or chemicals. There are three types or degrees of burns.

- Superficial or first-degree burns damage the top layer of skin, usually causing redness and pain like a sunburn.
- Partial thickness or second-degree burns damage the deeper layers of skin, usually causing blisters and pain. The wounds should be pink or red under the blisters.
- Full thickness or third-degree burns damage the entire thickness of skin, including nerves and blood vessels. The skin may be black (charred), brown or white.

McKenna Barbee, 16, is a burn survivor who has attended Camp Hope annually since 2011.



Camp Hope

Physical and emotional healing for children who have suffered burn injuries

written by Christina Echegaray
photograph by John Russell

When McKenna Barbee arrives at Camp Hope each summer, she

knows she doesn't have to explain the scars on her body. The other campers will understand the pain she experiences, the sometimes sleepless nights and the seemingly endless number of procedures and surgeries.

McKenna, a 16-year-old burn injury survivor, has attended the camp every year since 2011.

"The campers have a lot of bonding time and they are able to see they are not the only child who has been burned," said Kim Barbee, McKenna's mother. "They can go there and see that there are other kids who have been burned — some more, some less than others. They do a lot of silly, fun stuff that allows them to forget for a little while all they have to go through."

For 27 years and counting, Camp Hope has been a four-day, three-night camping experience specifically designed for children who have sustained burn injuries. The idea for the camp was born shortly after the Vanderbilt Burn Center opened in November 1983, when nurses realized the need for pediatric burn survivors to have a sense of community.

Camp Hope is funded through private donations from the community and held annually at the William P. Ridley 4-H Center in Columbia, Tennessee. Designed for burn survivors ages 6 to 16, the camp is planned and organized by Vanderbilt Burn Center nurses. This past year, 34 campers, including McKenna, participated in this unique experience where nurses, firefighters and adult burn survivors serve as camp counselors.

Rebekah Lemley, RN, BSN, EMT, burn program coordinator and director of Camp Hope, says the camp provides a safe place for dialogue among peers who have had similar experiences.

"This camp brings so much joy to these children," Lemley said. "In their everyday lives, the kids often try to blend into the background, but at Camp Hope, that's not the case."

The campers have a chance to take part in

a week of fun summer activities while recovering from the devastating physical and psychological injuries associated with burns.

Self-esteem is one of the greatest challenges for a burn survivor, says Lemley.

“The kids just want to be what society deems as normal, and if you have scars on your body, you are seen as different and are often a target for bullying or even become the aggressor,” Lemley said. “Watching these kids progress from the time they get here to the time they leave is unbelievable. They really blossom.”

McKenna suffered burn injuries at age 8, while playing pretend house with her younger cousin in July 2010. Unbeknownst to McKenna’s family, she had found some matches on the street while riding her bike on July Fourth and held onto them. Five days later as part of the pretend play, she and her cousin decided to make a campfire with the matches. Her cousin got scared by the fire and grabbed what she believed was a canister of water from her grandfather’s basement — but it turned out to be gasoline.

McKenna was engulfed in flames and suffered third-degree burns on 76 percent of her body. The only part of her body unburned was the skin covered by a tank top and shorts.

She spent 96 days fighting for her life and healing in the hospital with burn care, time spent between Monroe Carell Jr. Children’s Hospital at Vanderbilt and Vanderbilt University Adult Hospital.

“To watch her go through that was very difficult,” said Kim Barbee. “I couldn’t hug her or touch her — all I could do

“I like being able to be myself. It helps because I don’t feel alone. The first time you go, you’re kind of shy and don’t want to do anything. But the second time — you’ll be begging to go.”

was talk to her. I encouraged her to keep fighting. I kept telling her how much I loved her and how much I needed her. I celebrate her every day. She is my miracle child. She is the most resilient, positive, loving, caring person I know.”

McKenna went to her first camp almost a year after the injury. Nurses were on hand to help her with any care she needed, a comfort to both her and her mother. She has kept going back ever since.

While at the camp, the children and teens get to experience a variety of activities, including swimming, arts and crafts, zip lining, nature hikes and kickball. They also learn about fire safety, complete the Firefighter Challenge course, and engage with emergency workers on Family Safety Day.

“I like being able to be myself,” McKenna said about attending the camp. “It helps because I don’t feel alone. The first time you go, you’re kind of shy and don’t want to do anything. But the second time — you’ll be begging to go.” 🦋 hope

During the final obstacle of the Firefighter Challenge at Camp Hope, camper Ben Myers, 9, gives a high-five to Chattanooga firefighter Chad Williams, who is also a burn survivor.



BRITTNI DAVIS

(From left) Campers Selah Reeves, 6, Brianna Butler, 9, and Riley Medley, 7, bond during the weeklong Camp Hope.



BRITTNI DAVIS



Delanie Neal, 2, has made significant progress since surgery for a brachial plexus injury, which affects the upper group of the arm's main nerves.

Arm *in* Arm

Collaboration key to treating brachial plexus injuries

written by Christina Echegaray
photograph by John Russell

Two-year-old Delanie Neal tightly grips her baby doll

in her dominant right hand, refusing to let go even when coaxed into using her left arm and hand to open a door or to eat. What are seemingly simple tasks to most can be more challenging for the toddler.

Two years ago, she had little, if any, movement in her left arm. It was paralyzed, kept tucked to her side and unused. She has made tremendous progress with occupational therapy and surgical intervention.

Delanie was born with Erb's Palsy, a paralysis of the arm caused by an injury to the upper group of the arm's main nerves, the brachial plexus. One to two babies in every 1,000 births have a brachial plexus injury, often a result of a very difficult birth delivery.

Her parents, Whitley Key and Adam Neal, from Clarkrange, Tennessee, learned 24 hours after delivery that Delanie had the brachial plexus injury. Key had a healthy pregnancy, but after being induced at 39 weeks gestation, she had a difficult labor and pushed for over two hours. Other than the difficult birth process, Delanie was born healthy, weighing 7 pounds, 14.5 ounces and was 19.9 inches long. The news came as a shock.

"I was overwhelmed and didn't know what to think. You think nothing could go wrong and you wake up the next morning and they are telling you this is wrong with your baby," said Key. "She had very limited motion of her arm. She could lift it up just a hair but it always stayed tucked up behind her. She would curve her wrist in, but it was kind of like the arm was dead. She didn't even realize she had an arm."

To help patients like Delanie, Monroe Carell Jr. Children's Hospital at Vanderbilt has a Brachial Plexus Clinic, a collaborative effort among pediatric specialties — neurosurgery, plastic surgery and occupational therapy (OT) — to treat brachial plexus injuries from birth to age 18. In addition to birth-related injury, trauma can also cause injury to the brachial plexus. Treatment can range from intense occupational therapy to the need for microscopic nerve surgery, either by using nerve grafts to bridge across the damaged areas or by borrowing from another working nerve and using a portion of it to reinnervate the nonfunctional muscle.

Lindsey Ham, OTR/L, CHT, lead occupational therapist in the Brachial Plexus Clinic, works closely with families and helps coordinate access to OT services. Occupational therapy is a very important part of the recovery process. Ham evaluates and determines if patients are developing age-appropriate motor skills.

Recovery from brachial plexus injuries depends on the type and severity of the nerve injury. Damage to the affected arm may include loss of sensation, loss of control of the muscles that move the arm and hand, and/or loss of functional use of the arm or hand. Therapy includes caregiver education on range of motion exercises, positioning and functional activities to complete at home. Intense therapy is also needed intermittently to address specific functional goals.

Ham develops a close relationship with the families. She sees them once a month for the first year of life at a minimum. About 80 to 90 percent of pediatric patients with brachial plexus injury recover from their injury with intensive occupational therapy. But the other 10 to 20 percent will need surgery with hopes of regaining significant use of the paralyzed arm, though 100 percent recovery is unlikely.

"I love being able to be a part of this clinic and working with these children and their families. In my eight years working with this population, I have seen patients in all aspects of their childhood from infancy all the way to transitioning into college," Ham said. "My goal is that they are able to accomplish any of their life goals. I have worked with children who were baseball players, football players, cheerleaders, golfers, wrestlers, gymnasts, hunters and involved in many other activities. They may have to perform the activities differently than others, but they can do it."

If needed, surgery is typically performed between 6 months and 9 months of age. After age 1, the chance for recovery with surgery reduces significantly.

Key and Neal researched the brachial plexus in the days following Delanie's birth and looked for care options throughout Tennessee, before deciding Vanderbilt — almost two hours from their home — would provide the best chance for their daughter's recovery.

When Delanie was 2 months old, they met with Jay Wellons, MD, MSPH, chief of Pediatric Neurosurgery at Children's Hospital. Delanie began occupational therapy in order to complete range of motion exercises for the arm to prevent contractures while waiting for the nerves to recover or "wake up."

She did have some movement in her wrist and hand, but virtually no ability to bend the arm and no abduction (the movement of the arm away from the midline of the body).

"Not every child who has brachial plexus injury is going to have surgery, and in reality only about one or two out of 10 will need the surgery," Wellons said. "It's important not to have a surgical bias when making these decisions. That's why it is critical to have Lindsey on our clinic team because she helps us make decisions. She can identify that certain patients are not getting any better (with OT) by the time interval we discussed, and may be a candidate for surgery. She is a critical part of our clinic, our decision-making, and I am proud of the truly collaborative nature of it."

Range of motion activities are critical in maintaining and preventing joint tightness or the development of contractures. Ham ensures that parents are instructed on how to perform range of motion exercises, typically performed at each diaper change. Safety precautions are also taught to avoid further injury to the affected arm such as not pulling on the arm or picking the child up under the arm. Instructions are also given on proper positioning to support the arm.

Ham teaches parents how to dress and play with their babies safely and without the fear of hurting them.

Key and Neal focused on OT sessions and exercises on their own time with hopes they could avoid surgery for Delanie.

"We had therapy two to three times a week, and sometimes four. We were very dedicated parents and tried to do the best we could for her," Key said.

When Delanie was 6 months old, she had made limited progress. She could barely lift her arm. After she received extensive OT for eight months, it was decided that surgery was the best option for recovery with the goal that she would hopefully achieve up to 80 percent functional use of her arm.

"It was heartbreaking that she would need surgery but to know they had confidence she would get some more movement back than she already had, we said we're going to do this," Key said.

Delanie had surgery in April 2016. Wellons worked in collaboration with Reuben Bueno Jr., MD, associate professor of Plastic Surgery, to perform several repairs in one sitting, combining procedures to loosen up the scar tissue around the brachial plexus, as well as using portions of healthy and functional nerves and "rerouting" them to healthy nerves and musculature by sewing the nerves together using suture around the size of a human hair. This technique is called neurotization, and Wellons has published extensively on this procedure in infants and children over the last 15 years.

"Delanie is doing great. She's getting her hand to her mouth and getting her arm out," Wellons said. "I really feel like it's our public health responsibility to provide a place for children with brachial plexus to go for their care. We are well suited to be able to handle this complex care here at Children's Hospital."

Delanie continued with occupational therapy two to three times a week post-surgery.

"Any little thing she would do, we would always be excited if she lifted her arm up even a centimeter more or made a new movement. It was definitely a life-changing experience," said Key.

"She does a lot on her own — way more than we could ever imagine. She's definitely sassy, very independent."

Jaxon Newman, 14 months old, was among the majority of patients with brachial plexus injury who didn't need surgery, but instead follows an intensive occupational therapy routine — both in clinic and at home.

His mom, Jaimie Newman, a chief warrant officer 2 serving in the U.S. Army at Fort Campbell, Kentucky, labored for 61 hours, which included about three hours of pushing, before Jaxon was finally born. The traumatic labor took its toll on the 9-pound, 14-ounce boy. His arm had been stuck on Newman's pelvic bone and the umbilical cord was wrapped around his neck, limiting his oxygen intake.

He was born with the brachial plexus injury, and his kidneys weren't working properly. He was sent to the Neonatal Intensive Care Unit (NICU) at Children's Hospital. He had two stays in the NICU for kidney problems. Jaxon is the first child for Jaimie and her husband, Sgt. 1st Class Marshall Newman, who also serves in the U.S. Army at Fort Campbell in the 52nd EOD Company for the U.S. Army Explosive Ordnance Disposal.

Jaxon's right hand was closed into a fist, he had little to no strength in his arm and he couldn't raise his arm.

"Even if we had a completely healthy baby, we would still be nervous (since we were first-time parents)," said Jaimie, who serves in Charlie Company, 1-101st Combat Aviation Brigade. "For the first month, we didn't even put many clothes on him and turned up the heat. We were afraid we might cause more nerve damage and lessen his chance of healing. It was not anything we knew about."

At about 2 months old, Jaxon went to the Brachial Plexus Clinic at Children's Hospital, and he began working with Ham in occupational therapy. Ham coached Jaimie and Marshall on how to do his exercises at home.

"(Ham) let us know we weren't going to hurt him. We realized it wouldn't cause pain to move his arm," said Jaimie.

When Jaxon was 8 months old, the team thought he might need surgery, but after another month he improved and surgery was not needed. He continues occupational therapy at home, and has seen Ham every other week for six months. In January, a soft cast will be put on Jaxon's good left arm and hand to force him to rely on and strengthen his right arm and hand.

At a recent appointment, Jaxon used his right hand to drop balls in a bucket and turn the pages of a book, occasionally trying to sneak in the use of his healthy left hand. He would also try to eat fresh blueberries his mom brought, frustrated when he couldn't get one in his mouth. At one point, reaching up for his mom to pick him up, Jaxon's right arm went high above his head — a sign of progress and a welcome sight for Jaimie and Ham.

"We've seen dramatic changes over the last few months," Jaimie said. "Luckily, he won't need surgery. Vanderbilt has a great team, and I'm so thankful he has been able to receive such phenomenal care." 🍀 hope

Lindsey Ham, OTR/L, CHT, holds an occupational therapy session with patient Jaxon Newman, 14 months old.



Beyond the Walls

Increasing access for an earlier autism diagnosis

Brittanie and Adrian Doaks and their 2-year-old son, Kingston, sat in front of a computer in their hometown of Jackson, Tennessee, for a videoconference that connected them with a pediatric psychologist and autism specialist two hours away in Nashville. They were hoping for answers.

Kingston, extremely active from 9 months old, was advanced physically, but his verbal abilities lagged. At age 2, he had only three words in his vocabulary — momma, daddy and ball. Initially, he was diagnosed with a speech delay, but there were other concerns as well. He had difficulty sleeping, and engaging with his peers was a challenge for him. While he showed great affection toward his parents, siblings and grandmother, he was often socially withdrawn and would become very agitated around strangers.

“We felt like something else was going on with Kingston, but we didn’t want to think that it was autism,” Brittanie said. “He’s extremely affectionate and we always got good feedback on his behavior from his teachers at day care.”

The Doakses decided to pursue an autism evaluation for their son. Following the screening, Kingston, who has since turned 3, was diagnosed with autism spectrum disorder (ASD).

written by Jennifer Wetzel
photograph by John Russell



Kingston Doaks, 3, is thriving with the help of Vanderbilt Kennedy Center's telemedicine initiative and services for children with autism.

ASD is an umbrella term that encompasses several different neurodevelopmental disorders. According to the U.S. Centers for Disease Control and Prevention (CDC), ASD impacts one in 68 children.

"You're never prepared for the initial shock of receiving news like this," Brittanie said. "As a parent, you want things to be easy for your kids and you want great things for them, so hearing there's something that's going to make his life more challenging just knocked the wind out of me. But then, Dr. (Jeffrey) Hine (who did the evaluation) said something I'll never forget. He said, 'Kingston's diagnosis doesn't change who he is, and he's no different than who he was when he walked in this room. He's just going to learn a bit differently.'"

Currently, in many parts of Tennessee, there are not enough local providers to conduct autism evaluations and diagnoses for young children. As is often the case, the Doaks family was referred to the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders (TRIAD).

For more than two decades, TRIAD professionals have had a close partnership with the Department of Pediatrics and the Division of Developmental Medicine at Monroe Carell Jr. Children's Hospital at Vanderbilt and have been providing evaluations for families when there are early concerns for autism.

Over that same interval, the demand for such evaluations has increased dramatically as community and provider knowledge about autism has expanded. Yet, in many parts of the country, the demand for services is so great that families often wait more than six to 12 months for an evaluation by specialists.

To meet this tremendous need in Tennessee, the Vanderbilt Kennedy Center (VKC) and Children's Hospital have been building their capacity in communities throughout the region and creating outreach services to ensure that children receive evaluations, an autism diagnosis if appropriate and services in a timely manner.

"When early intervention is the key, can you imagine what it must be like to be told to wait months or a year for answers and help?" said Zachary Warren, PhD, associate professor of Pediatrics,

Psychiatry and Behavioral Sciences and Special Education and executive director of TRIAD.

"We may not have all the answers or solutions we'd like to have for parents and children with autism, but there are some places where, if we think beyond the walls, we can truly make a difference for the kids we care for."

Telehealth initiatives, which use telecommunications technologies to support long-distance clinical healthcare and health-related education, are part of that beyond-the-walls strategy. Additionally, TRIAD is providing training for educators in schools and equipping local organizations with the tools to better meet the needs of these children and families.

"With the prevalence of autism on the rise, the need for early identification and treatment of young children with ASD represents a pressing public health and clinical care challenge," Warren said.

"Evidence demonstrates that very young children with ASD receiving early behavioral intervention services demonstrate substantial gains in functioning. Although early diagnosis of ASD is possible in the first years of life, children from traditionally underserved communities are often not identified until much later ages. Using telehealth to diagnose and treat

From his desk at Vanderbilt, Jeffrey Hine, PhD, BBKA, assistant professor of Pediatrics in the Division of Developmental Medicine, is able to perform an evaluation for autism through videoconference with a patient in another city.



JOHN RUSSELL

autism has enabled TRIAD to reach families quickly and in their own backyards, rather than requiring them to travel long distances.”

Diagnosing via telehealth

The Doaks family is one of 70 families who have worked with TRIAD via telehealth since the inception of this program in 2016.

Their journey began around his first birthday, when Kingston had only said “momma,” causing concern for Brittanie and her husband, Adrian, who both work in the education field. The couple expressed concerns about their son’s development to his pediatrician, who initially thought that Kingston’s history of ear infections could have caused some hearing impairment.

Kingston got ear tubes to help with his infections and also started speech therapy. But still his vocabulary remained limited, and he began working with Tennessee’s Early Intervention System (TEIS), a voluntary educational program for families with children through age 2 with disabilities or developmental delays.

Through working with TEIS, the Doakses were told that if autism was suspected, they needed to pursue an evaluation as soon as possible.

Instead of driving two hours from their home for an on-site evaluation in Nashville, the Doakses were able to go to Children’s Hospital’s specialty clinic at Ayers Children’s Medical Center in Jackson, Tennessee. Ayers Children’s is part of the Vanderbilt Health Affiliated Network, a physician-led network of doctors, regional health systems and other health-care providers focused on improving the health of communities in the region.

They met in the Jackson clinic with Mary Fleck, MED, BCBA, a TRIAD educational consultant based in the area, and an autism specialist based at Vanderbilt joined them remotely for Kingston’s evaluation.

Jeffrey Hine, PhD, BCBA, assistant professor of Pediatrics in the Division of Developmental Medicine and one of TRIAD’s licensed psychologists who oversees these telehealth autism evaluations, was on the other end of the camera. He and a local team member from TRIAD led Kingston through a standardized play assessment — the STAT — the Screening Tool for Autism in Toddlers and Young Children — which is an interactive measure developed to screen for autism in children between 24 and 36 months of age.

The assessment involved a series of structured play tests geared explicitly for young children. By playing with things like bubbles and balloons and offering them snacks, clinicians are able to critically evaluate key social communication and play skills that are often areas of concern for young children with autism.

At the end of the screening, the Doaks family received

ABOUT THE VANDERBILT KENNEDY CENTER

The mission of the Vanderbilt Kennedy Center for Research on Human Development is to facilitate discoveries and best practices that make positive differences in the lives of persons with developmental disabilities and their families.

Over the past 52 years, the Vanderbilt Kennedy Center has evolved into an interdisciplinary research, training, diagnosis and treatment institute, embracing faculty and resources available through Vanderbilt University Medical Center, the College of Arts and Science, Peabody College of Education and Human Development, School of Engineering, Divinity School and Blair School of Music. The Center brings together scientists and practitioners in behavior, education, genetics and neuroscience to work together in unique ways to solve the mysteries of development and learning.

The VKC is a Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Center, funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development. This national network advances the diagnosis, prevention, treatment, and amelioration of intellectual and developmental disabilities.

Additionally, VKC is home to the Vanderbilt Consortium Leadership Education in Neurodevelopmental Disabilities, known as LEND, which prepares graduate-level health professionals in 15 disciplines to assume leadership roles to serve children with neurodevelopmental and related disabilities.

The VKC is also a University Center for Excellence in Developmental Disabilities in Education, Research and Service (UCEDD), which provides innovative leadership in education, research and services to people with disabilities, the community and families. The UCEDD works within the community and through public policy initiatives to promote the independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities and provide supports for families. The Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), featured in the article on page 14, also falls within VKC.

answers from a Vanderbilt expert and an action plan for getting Kingston the help he needs.

TRIAD researchers have documented that this rapid action tele-assessment has helped 85 percent of families get definitive information without having to wait or travel to Vanderbilt. This same research has documented a high level of accuracy of this assessment, with over 75 percent of cases of ASD accurately identified via telehealth.

“We are confident that diagnosis through telemedicine is a valid method of assessment, and if there are concerns raised by the families being served or by the psychologists conducting the assessments, we have the option of bringing in the families for in-person visits,” said Alacia Stainbrook, PhD, BCBA, TRIAD Early Intervention program coordinator and

assistant in Pediatrics. “However, satisfaction levels have been high, and we are thrilled to be able to see more families, especially in West Tennessee, where 60 percent of the families we see would not have had the capacity to travel to Nashville for a diagnosis. That means their children likely would have gone unidentified until they entered school.”

In-home training and assistance

Following Kingston’s diagnosis, Fleck conducted in-home training and support for the Doaks family once a week for six weeks. She also connected them with educational resources and autism peer groups in order to help Brittanie and Adrian navigate their son’s new diagnosis.

“Mary has been so sweet and willing to help, and having a person like her, especially so soon after the diagnosis, was very comforting,” Brittanie said.

Acquiring an early diagnosis before age 3 enabled Kingston to start public preschool in August and made him eligible for speech therapy and occupational therapy through state programming.

Brittanie says her son has made great strides in the time since his diagnosis. He went from saying only three words at age 2 to being conversational a year later, and he demonstrates a higher level of comfort in social situations. He also loves running, swimming, playing outside and reading books.

Adrian and Brittanie Doaks with their 3-year-old son, Kingston.



“We’ve accomplished so much since his diagnosis, and if we’d had to wait a long time for an evaluation, who knows where we’d be,” Brittanie said. “A lot of parents are looking for an answer, and in our area there is no one who can give that, so you’re very limited to who you can see or where you can go. [The TRIAD telehealth evaluation] was so easy for us and a seamless process.”

The Doaks family has also participated in TRIAD’s Families First Program, which offers free workshops at the Vanderbilt Kennedy Center and via livestream to caregivers of young children newly diagnosed with autism.

The primary goal of Families First is to equip caregivers with practical tools to support their child, provide resources to more easily apply strategy and planning ideas, and give caregivers an opportunity to meet others with similar questions or concerns.

For caregivers outside the Nashville area, Families First workshops can be attended via videoconference technology in Jackson and Chattanooga, Tennessee, and at sites in Alabama, Georgia, Texas and New Mexico. Following the videoconference sessions, TRIAD consultants are on hand at these sites to provide coaching and feedback to caregivers.

Support for autism in the community

Beyond autism evaluations, diagnosis and treatment, TRIAD is working to ensure continuity of services for children with autism and their families by offering extensive training in school systems throughout Tennessee.

Through a five-year, \$10 million training grant from the Tennessee Department of Education (TDOE), TRIAD and TDOE provide education and training opportunities for school personnel throughout the state.

This TDOE support and 17-year partnership allows TRIAD to provide services to educators serving kindergarten through high school at no direct cost to those educators, their schools or school systems. Further, it allows TRIAD to dramatically increase the number of educational opportunities available to educators.

“This partnership allows us to create innovative programming to support educators across Tennessee as they serve students of varying needs, including those with autism,” said TRIAD Director Pablo Juárez, MEd, BCBA. “Together with the Tennessee Department of Education, we are able to lead the nation in statewide initiatives aimed directly at understanding what ASD means within our own borders, how that compares nationally and how to best approach early intervention and school-based educational and behavioral support for students from Memphis to Mountain City. We’re very proud to be playing this role within Tennessee.”

Through this grant, TRIAD delivers approximately 100 professional development and training opportunities annually

Neul takes helm at Vanderbilt Kennedy Center

Jeffrey Neul, MD, PhD, joined Vanderbilt Aug. 1, 2017, as the new director of the Vanderbilt Kennedy Center.

Neul succeeds Elisabeth Dykens, PhD, professor of Pediatrics, Psychology and Human Development, and the Kennedy Center's director since 2009. Dykens will continue to lead research programs in Prader-Willi, Williams and Down syndromes.

Neul most recently served as division head of Child Neurology and vice chair for Developmental Neurosciences at the University of California, San Diego, and is an internationally recognized expert in genetic neurodevelopmental disorders. Specifically, he studies Rett syndrome, which primarily affects girls and is characterized by loss of hand skills and spoken language. He conducts clinical research and clinical trials on Rett syndrome, genetic research to identify other causes of neurodevelopmental disorders, and translational research using disease models to identify and test novel treatment modalities for these disorders.

For more than 50 years the Kennedy Center has led groundbreaking research into the mysteries of developmental disabilities. In addition to being one of the nation's leading centers of interdisciplinary research seeking breakthroughs in prevention and treatment for developmental diseases, the center offers the region's most comprehensive array of services to people with disabilities, families, educators, healthcare and other service providers.

Steven Webber, MBChB, James C. Overall Professor and chair of the Department of Pediatrics, and Camilla Benbow, EdD, Patricia and

Rhodes Hart Dean of the College of Education and Human Development, co-chaired the committee that conducted the national search that identified Neul.

"We are delighted to welcome Dr. Neul to Vanderbilt. He is an outstanding clinician, teacher and neuroscientist, widely respected for his contributions to our understanding of rare neurologic disorders of childhood. He is equally comfortable in the laboratory and in the clinic, and is passionate about improving the lives of children and adults with intellectual disabilities," said Webber, who is also pediatrician-in-chief of Monroe Carell Jr. Children's Hospital at Vanderbilt.

Neul joins Vanderbilt with a number of actively funded studies that are supported through the National Institutes of Health, the Rett Syndrome Foundation and other sources. He is the author of numerous high-impact, peer-reviewed publications and manuscripts and a frequently invited presenter on the topic of Rett syndrome.

A native of Chicago, Neul earned his undergraduate degree from the University of Illinois at Urbana-Champaign, his medical and doctoral degrees from the Pritzker School of Medicine at the University of Chicago and completed his residency and fellowship in child neurology at Baylor College of Medicine and Texas Children's Hospital. He completed post-doctoral training at Baylor in the laboratory of Huda Zogbi, MD.

"What drew me to the Vanderbilt Kennedy Center was the history and international reputation. These strengths, combined with the Kennedy Center's connections to the broader Vanderbilt community, really give us

an opportunity to develop precision care for developmental disabilities that may span many different types of interventions, from educational therapies to targeted gene therapy," Neul said. "I think we have such a great opportunity to develop new ideas for how we help people with developmental disabilities. My overall goal is to enhance the idea that the Kennedy Center is the leading center for the development of precision care for developmental disabilities. We are going to figure out the best approaches to help people with disabilities through individualized or personalized methods."

Neul says he's excited to be part of a program that houses such distinctive federally funded programs. He hopes to streamline research opportunities for patients that span from registries to intervention trials.

"I want everyone who comes to see us to be presented with opportunities to participate in research," Neul said. "Being in clinical care and being in research should be a seamless transition, so that things we learn in the clinic can guide research, and research can potentially guide how we deliver care."

Neul is joined in Nashville by his wife, Shari, who is a pediatric clinical psychologist, and their children, Collette, 12, and Konrad, 10.

— by Jennifer Wetzel




Jeffrey Neul, MD, PhD

to educators through statewide workshops, trainings and partnerships as well as online education.

In addition to school training, TRIAD works with numerous community organizations in the Nashville area to better equip them to serve children with disabilities and their families.

TRIAD consultants train staff within these cultural destinations to promote full inclusion of all children and adults and help them develop research-based supports to increase accessibility, such as hosting inclusive or modified performances or activities. Participating organizations include the Nashville

Zoo, the Nashville Ballet, the Nashville Opera, Cheekwood, the Frist Center for the Visual Arts and more.

"Partnerships with those invested in our hospital make sure we're improving community integration for children with autism," Warren said. "We feel the Vanderbilt Kennedy Center and Children's Hospital are leading the way in ensuring that children with autism are well-served not just in their clinical care, but in their schools and community, and we want to make sure that our communities are designed to take care of our families far beyond the walls of our clinics."  hope

Ray Cruz, (left) a 17-year-old patient battling cancer, performs at the historic Ryman Auditorium alongside radiation oncologist Mark Stavas, MD.



Strength through Music

written by Jennifer Wetzel
photograph by Daniel Dubois

When 17-year-old Ray Cruz was invited to perform at the Ryman Auditorium, he agreed to do it under one condition — that his doctor would perform alongside him.

Radiation oncologist Mark Stavas, MD, and Cruz, a patient at Monroe Carell Jr. Children's Hospital at Vanderbilt, received a standing ovation after their July 18, 2017, Ryman Auditorium performance at the Music City Harmonies for Hope concert, a cancer benefit presented by the Franklin Brentwood Arts Academy and Allegro Music Dance Academy.

It was Ray's cancer diagnosis that brought the two of them together, but it was their mutual love of music that allowed them to form a bond that transcends the disease they are both working to fight.

In December 2016, Ray was experiencing severe hip pain, which he attributed to his time spent playing basketball on a team he and his dad started with some of his friends.

When the pain intensified, his parents took him to a local emergency department before being transferred to Children's Hospital, where his family was

given the news that the pain in Ray's hip was caused by a metastatic deposit of cancer in his pelvis.

On Jan. 29, 2017 — his father's birthday — Ray was diagnosed with stage 4 Ewing-like Sarcoma.

Ewing-like Sarcoma is an exceedingly rare diagnosis, similar to but lacking the exact characteristics of its more common counterpart, Ewing Sarcoma. The incidence of Ewing-like Sarcoma is thought to affect only a few children in the United States each year. Patients are typically treated with Ewing Sarcoma protocols given their similar morphology.

The Cruz family was told that, without treatment, Ray might only have weeks to live.

The junior at Centennial High School in Franklin, Tennessee, began his spring semester with a one-month stay at Children's Hospital with aggressive chemotherapy, followed by targeted radiation to the lung, where his cancer originated, followed by several more weeks of chemotherapy.

It was through radiation that Ray met Stavas, assistant professor of Radiation Oncology and director of Pediatric and Palliative Radiation Services.

Ray says he immediately felt a connection with Stavas because of his style and candor.

"He was kind of like this hipster, he didn't have on a lab coat. He knew how to talk to me as a kid, and I liked his honesty," Ray said. "After he described my treatment and what he was going to do, I looked him in the eye and asked him what scares him about my treatment. He took a moment and then said, 'I'm truly confident I can target your tumor. However, with this kind of cancer, we often can make it go away for an extended period of time, but the question remains, will it come back?'"

Stavas then asked Ray where he finds his strength, what matters most to him and what his hopes are. The conversation that ensued illustrated Ray's reliance on his faith, his love for his close-knit family and his passion for singing.

A musician himself, Stavas shared with Ray that he also turns to music for strength.

"Music is where I turn when I'm down or when I can't do anything more for a patient. Art is a way of understanding the world when you are out of things to say," said Stavas, who sings and plays guitar and piano. "We jammed on those ideas and he really liked that creative approach. I left doctoring at the door for a while. Of course, I'm going to do everything I can for him medically, scientifically and technologically, but what Ray needed to hear more than anything is that I'm here for him no matter what happens," Stavas said.

From that moment on, music was part of the conversation at all of Ray's appointments.

"There's treating the cancer, and then there's treating Ray," Stavas said. "Music gave us an element to connect and a common work language."

"He brought out a side in me that I'd almost lost. He gives me the strength to do what I do. Someone like Ray is such a gift."

As Ray's cancer treatment progressed, his voice weakened as a side effect, causing him to lose his typical vocal strength. He was drawn to artists like Bruno Mars, but Stavas told him that the tenderness of his voice reminded him of folk artist Joshua Radin and introduced him to Radin's song, "Brand New Day."

The message of the song resonated with Ray, and not only did he discover he liked folk music, but he found his new voice by singing the softer, storytelling genre.

When Ray was asked to perform at the Ryman, he knew that "Brand New Day" was the song he would sing, and he asked Stavas to accompany him.

They began practicing after Ray's daily radiation treatments in a conference room at the Radiation Oncology Clinic and arranged their own version of the song for their performance at the Ryman.

"I could not help but to cry the moment I saw them on stage together," said Ray's mother, Blandina Cruz. "The way they look at each other, you know it's a special bond. As a mom, I worried if the doctors would look at my child like he was their own. All of the doctors and nurses have been wonderful, but Dr. Stavas and Ray have had a one-of-a-kind relationship. No matter how busy he is, he always made time for my son."


Ray's father, Raymond, said, "I love seeing their interaction, and their music and friendship have made the treatment time so much better. We've been blessed in a lot of ways."

Ray finished his treatment in September 2017 and will have ongoing follow-up scans to determine if additional treatment is needed. While he and Stavas hope that no more radiation is needed, they are eager to find more opportunities to play music together.

"He brought out a side in me that I'd almost lost," Stavas said. "He gives me the strength to do what I do. Someone like Ray is such a gift."

Ray hopes to use his music to inspire others who are going through difficult times. His goal is to someday start an organization that supports people with cancer.

"When I got diagnosed, I knew my family was going to be right by my side, but not everyone has the support I have from my family and friends and the community, so I hope I can give back someday and help others battling this disease," Ray said.

"We can't choose what happens in our life, but we can choose how to respond. When I was first diagnosed, I was really depressed, but through this journey, God has given me the desire to help others. God doesn't always give us what we want, but he gives us what we need."  hope

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 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.

Paul Moore, MD, understands firsthand the importance of quality and compassionate healthcare. His 12-year-old daughter, Caroline, the third of his four children, was born with Down syndrome and required open-heart surgery at 10 weeks of age.

"Having your own child go through surgery, you realize how vulnerable our families can be," said Moore, director of the Division of Pediatric Allergy, Immunology and Pulmonary Medicine. "Everyone has the highest hopes for their children, and then to see them be born with a challenge, whether it's short term or long term, you want to do everything you can in the world to provide for them. We are very blessed to live here. She's in middle school now and thrives."

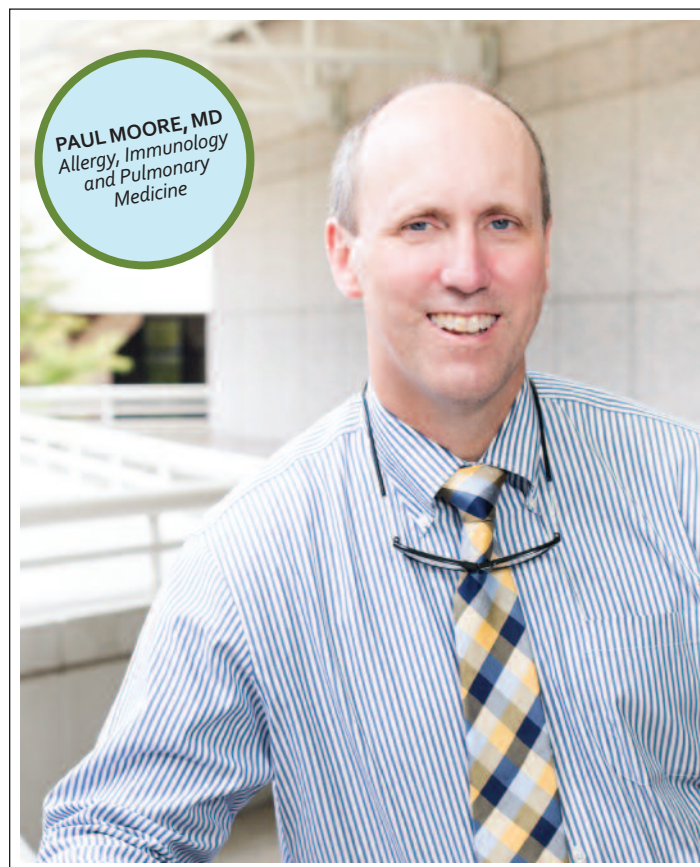
His journey with Caroline's health augmented a passion for his work as a pediatric pulmonary specialist, a career influenced by some of the great icons in the fields of pediatric pulmonology and neonatology.

Moore attended Vanderbilt University as an undergraduate, always interested in medicine. After Vanderbilt, he moved to Boston, where he spent 13 years. He earned a medical degree from Harvard Medical School, followed by a residency and fellowship at Boston Children's Hospital. Boston is also where he met his wife, Catherine, and where he became a die-hard Red Sox baseball fan, a passion his four children now cherish.

While in Boston, he trained with a pioneer of pediatric pulmonary medicine — Mary Ellen Wohl, MD.

"She was a grand dame of pediatric pulmonary medicine and played a huge part in why I became interested in lung disease. She recruited me during residency to become a fellow. I had wonderful experiences in the clinical training as well as becoming involved in research at the Harvard School of Public Health," said Moore, associate professor of Pediatrics and Pharmacology.

"For me, pediatric pulmonary medicine was an interesting career because it allowed me to take care of infants through adolescence; there were aspects of primary care in taking care of patients with cystic fibrosis and other pediatric lung diseases,



SUSAN URMY

and there were opportunities in the hospital to consult on some of the most complex patients."

Moore came back to Vanderbilt in 2001 after Tom Hazinski, MD, recruited him to a growing and flourishing Division of Pediatric Pulmonary Medicine. Hazinski had built the division from scratch under neonatal medicine pioneer Mildred Stahlman, MD.

Moore's research focus seeks to close some gaps in the understanding of lung disease. He recently completed one phase and is continuing another on Prematurity and Respiratory Outcomes Program (PROP), a study that looks at infants born at less than 29 weeks gestation and the development of bronchial pulmonary dysplasia or BPD. These infants are more likely to go home from the hospital on oxygen and are more at risk for asthma and other respiratory complications.

To help further advance care of children, Moore also serves as program committee chair for the American Thoracic Society's Assembly on Pediatrics.

Ultimately, his patients and colleagues at Vanderbilt are what drive him.

"I am blessed to work with such a talented group of physicians, nurse practitioners and an entire team that is dedicated to children with allergic and respiratory disease," said Moore. "Folks in our group are involved in studies in the lab that are translating into care for children with pulmonary diseases."

When Moore isn't devoting his time to patients, he and Catherine are busy with their children: Stewart, 16, Joseph, 14, Caroline, 12, and Mary Elizabeth, 10. He can be found on a soccer field, at a dance recital or on a family cross-country road trip.

— by Christina Echegaray



Amber Greeno, RN, MSN, can't remember a time when Vanderbilt wasn't part of her life. She was 2 years old when her mother, Sandy, began working in the Surgical Intensive Care Unit at Vanderbilt University Medical Center. She has fond memories of going to work with her mom, playing in the former jungle gym on the first floor of the adult hospital and rolling around in wheelchairs in the conference rooms. Becoming a nurse was always in the cards.

"I think just growing up in that hospital environment, having all these nurses whenever I was sick come and check on me...I liked it," she said. "I always thought it was a great job. I always looked up to my mother. She's a strong woman. I think it was just a natural fit that I chose the nursing path."

Greeno is director of Trauma, Injury Prevention, and Project ADAM (Automated Defibrillators in Adam's Memory — an organization committed to preventing sudden cardiac arrest in children and teens like Adam Lemel, 17) at Monroe Carell Jr. Children's Hospital at Vanderbilt. She joined Vanderbilt in 2004 after obtaining her Bachelor of Science in Nursing from Middle Tennessee State University. Her first job was in the trauma unit at Vanderbilt University Adult Hospital, which planted a seed for her future career. "I loved the job, loved the excitement," she said.

After a short stint of travel nursing, she returned to Vanderbilt, specifically Children's Hospital, to become a staff nurse in the Pediatric Emergency Department and later a

nurse educator. Meanwhile, she obtained a master's degree as an Acute Care Nurse Practitioner from Vanderbilt University in 2013.

Greeno's current position involves collaborating with individuals in multiple departments to ensure that quality standards are maintained. Because of that work, the American College of Surgeons verified Children's Hospital as a Level I pediatric trauma center last year, an honor held by fewer than 50 pediatric trauma centers nationwide. She monitors data from trauma patients to explore any possible ways to improve quality of care. She conducts research with a trauma registry that includes more than 300 data fields, all with the goal of improving patient outcomes. "It's a diverse job that I really enjoy," she said.

When she's not working in trauma and injury prevention, Greeno is helping with nurse and physician education as well as Project ADAM, a state program that aims to put automated external defibrillators into schools and train people to use them. The devices send an electronic shock to the heart that can revive patients.

When Greeno is not at Vanderbilt, she can often be found outside, gardening, kayaking or hiking with her 11-year-old Boxer, Zeppelin. When it's baseball season, she roots for the Chicago Cubs, and when hockey season rolls around, she cheers for the Nashville Predators.



AMBER GREENO,
RN, MSN
Trauma/Injury
Prevention

SUSAN URMY

She also loves spending time with family. Her nursing role model and mom, Sandy, is now assistant program director of Portland School of Nursing undergraduate program at Oregon Health & Science University. Her father, Dennis, is a CPA and her brother, Andrew, works in the health insurance industry.

For Amber, Vanderbilt is home.

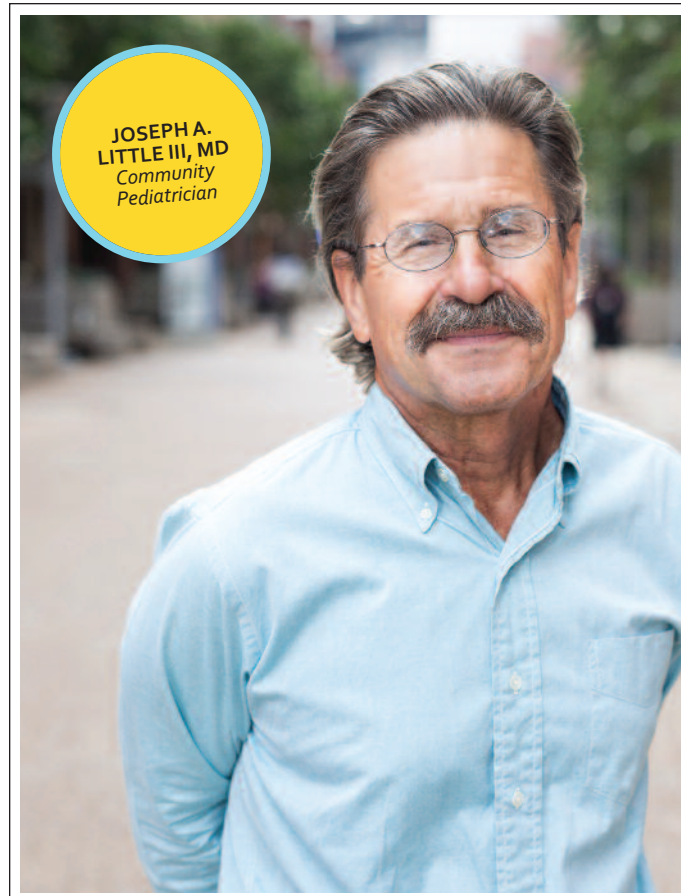
"When it comes down to it, I can't imagine working anywhere else," she said. "I grew up in this environment, and I have worked in other places and they're nowhere near this caliber. The amount of teamwork, cooperation and collaboration among the services, just to make sure that we provide the best care for our patients, is reason enough for me never to want to leave here."

— by Matt Batchelder



Joseph A. Little III, MD, has deep roots at Vanderbilt, deeper than the roots of the Chinese Scholar Tree that his family planted on campus in 1954.

His grandfather, Ernest Goodpasture, MD, a distinguished American pathologist, received his undergraduate degree from Vanderbilt University in 1907, and would later become professor and chair of the Department of Pathology and then dean of the Vanderbilt University School of Medicine (VUSM). He made



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history here by pioneering the method of growing a live virus in fertilized chicken eggs, a technique still used today to manufacture some vaccines.

Little's mother, Sarah Goodpasture, and father, Joseph A. Little Jr., met at Vanderbilt. His father graduated from VUSM and later returned to join the pediatric faculty as an associate professor. The younger Little attended Vanderbilt for his undergraduate and medical degrees and his residency in pediatrics, often walking past the Goodpasture family tree, which still grows near Buttrick Hall on campus.

Little majored in anthropology at Vanderbilt, which informed his future career in medicine.

"Cultural anthropology involves being open to and interested in the differences in the way people approach problems, approach medicine, approach living their lives," he said. "As a clinician, I think it's super important that you're listening, interested and engaged in how people are leading their lives in order to be impactful when you're working with them."

While in medical school, Little became the first student co-director of the Center for Health Services the year after co-directing the university's Student Health Coalition Appalachian Project. After his residency, Little and another physician, both working in the National Health Service Corps, opened a clinic in Monteagle, Tennessee, that continues today to serve the rural population.

Presently, Little is a pediatrician in Murfreesboro, Tennessee, where he has practiced for 35 years and is now serving a second generation of children at Tennessee Pediatrics.

"I believe one of the attractions that draws people to pediatrics is the feeling you can positively influence outcomes in children by helping them and their parents navigate the challenges faced during a child's development," he said. "Children are incredibly rejuvenating. Just being around children and infants helps me feel youthful, healthy and positive."

Little said his family's relationship with Children's Hospital began with his father's training and faculty position at Vanderbilt. It continues to grow with him.

"During my residency at Children's, I developed close working relationships with many of the subspecialists, whose expertise I have relied on to help care for my patients," he said. "Having collaborative partners at Children's Hospital has been indispensable in an effort to provide my patients with the highest quality of care."

Little has four children: Rebecca, a pharmacist; Alex, a defense attorney; Jonathan, a writer; and Beth, a pediatrician working for the Alaskan Indian Health Service. He has four grandchildren — all boys.

He and his wife, Billie, founded the Discovery House, now Discovery Center at Murfree Spring. Currently in its 30th year, the children's museum has grown to 32,000 square feet and is situated adjacent to 20 acres of wetlands. Billie served as its executive director for 25 years.

When Little isn't at the office, he is distance swimming or

working on the extensive gardens and hiking paths at his home and woodland property in Williamson County. The land once belonged to his grandparents and now is enjoyed by a fifth generation.

Vanderbilt and his family history are forever intertwined.

"It's a very personal, intimate relationship," he said. "As I walk around campus, I have memories from when I was quite young. Almost anywhere I go on campus can bring back different times in my life."

— by Matt Batchelder



When John Thomas, MD, sees new patients and their families, he knows they're there for health issues they might be uncomfortable discussing — so he takes his cues on empathy from his earliest role model, his father.

"My dad is my personal hero and has always been the most compassionate and empathetic physician I know," said Thomas, associate professor of Urologic Surgery. "I'm so lucky to have him as my example of what a doctor should be."

Thomas' father, Anthony Thomas, MD, a Cleveland Clinic fertility specialist, was an "old-school urologist who made house calls." Thomas considers himself blessed to have completed his urology residency at Cleveland Clinic, training alongside his dad.

Early in his education, Thomas was fascinated by embryology — the study of embryos and their development during the eight weeks after fertilization — and this influenced his decision to specialize in pediatric urology. Pediatric urologists diagnose and treat illnesses or diseases of the genitals and urinary tract (includes the kidneys, ureters and bladder). An understanding of embryology is critical for this specialty given that the genitals and the urinary system begin to form during that period, and that's also when malformations can develop.

"Much of our surgery is 'one and done,'" he said. "Patients get a problem fixed and go home. But we also keep many patients with congenital problems for most of their lives. You realize quickly what a privilege it is for a parent to trust you with their child and say, 'Please fix them.' I take that responsibility very seriously."

A native of Cleveland, Ohio, Thomas received his medical degree from University of Cincinnati College of Medicine. After his Cleveland Clinic residency, he came to Monroe Carell Jr. Children's Hospital at Vanderbilt for a Pediatric Urology fellowship in 2004. He has been on faculty since.

Another of Thomas' passions is laparoscopic surgery, particularly non-invasive (meaning no major incisions are made) robotic surgery. He received training in advanced laparoscopic procedures from Duke Herrell, MD, professor of Urologic Surgery at Vanderbilt University Medical Center. In 2011, Thomas led the medical team that performed the first robotic surgery at Children's Hospital using the da Vinci Surgical System technology. Thomas now shares robotic cases with his colleague Douglass Clayton, MD.

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"Robotic surgery allows Doug and me to sew more easily, eliminates any potential for hand tremor, and has shortened more complex cases by hours as compared to conventional laparoscopy, which is always better for the children we serve," Thomas said. "Older children and certainly teenagers have less pain and get back to doing regular activities quicker, although kids typically get better faster than adults with open surgery as well."

In 2016, Thomas also helped establish the Complex and Urinary Bowel Issues (CUBI) Clinic, a multidisciplinary clinic at Children's Hospital designed to be a one-stop appointment for children with complex intestinal and urinary issues. The clinic sees patients referred from a multistate region.

Outside work, Thomas and his wife, Colleen, stay busy with their four children, who range in age from 8 to 15 years. In between their baseball and volleyball games, Thomas has recently begun taking guitar lessons.

"I'm not good yet, but I really enjoy it! I just want to be able to pick up a guitar and make sounds that aren't awful."

In the meantime, he and Colleen check out local songwriters' nights, where he loves hearing the stories behind the tunes.

"There's just so much talent here in Nashville," he said. "We absolutely love being here."

— by Jill Clendening

Rascal Flatts' Celebrity Golf Classic

Superstar vocal group Rascal Flatts joined Delta Dental of Tennessee and WME to host a celebrity golf tournament to benefit Monroe Carell Jr. Children's Hospital at Vanderbilt. All proceeds support research and fellowship training in the Division of Pediatric Urologic Surgery at Vanderbilt University Medical Center.

Rascal Flatts' Celebrity Golf Classic was held in October 2017 at the Golf Club of Tennessee. This community golf event matched 24 teams with a celebrity.

Jeff Ruby's Sponsor Celebration and Celebrity Jam kicked off the event the night before, featuring performances by artists including Kix Brooks and Brian White. Rascal Flatts also performed for participants and sponsors following the tournament.

Rascal Flatts members Gary LeVox, Jay DeMarcus and Joe Don Rooney are longtime supporters of Children's Hospital. The multi-platinum recording artists have performed for Children's Hospital patients for 11 years and helped raise millions of dollars for the hospital, which renamed its Pediatric Surgery Center The Rascal Flatts Surgery Center in 2010.

"Monroe Carell Jr. Children's Hospital has always been an organization close to our hearts," said Gary LeVox. "We were so honored to host the Celebrity Golf Classic to help support this important mission."

Delta Dental of Tennessee and WME helped launch the event in 2016 to benefit the Growing to New Heights Campaign, which supports the Children's Hospital four-floor expansion currently underway. WME, which represents Rascal Flatts, has partnered with Children's Hospital over the years, including volunteer visits each spring.

"We were so excited to have Rascal Flatts lead this event and are immensely appreciative of them for their ongoing and



Rascal Flatts members pose with Children's Hospital child ambassadors and Champ, the hospital's mascot. From left: Gary LeVox, Logan Miller, Champ, Lucy Schmitt, Joe Don Rooney and Jay DeMarcus.

steadfast dedication to Children's Hospital," said John W. Brock III, MD, Surgeon-in-Chief for Children's Hospital, Monroe Carell Jr. Professor and Senior Vice President of Pediatric Surgical Services. "I also continue to be amazed at the level of commitment that the entertainment and business communities have shown to Children's Hospital. These partnerships enable us to provide world-class services for children from across Tennessee and around the country." This fall, the golf classic will be held Oct. 8. For more information, contact Jenny Streams, director of community development, at 615-343-5468. — by Jennifer Wetzel

LOREN KAHLE



A HONKY TONK HOLIDAY FOR CHILDREN'S HOSPITAL

In its 64th year, the Nashville Christmas Parade, themed "The Musical Mile!" was a celebration of music with a record number of celebrities, marching bands, floats and large balloons filling the streets of Music City with holiday festivity. Led by Grand Marshal Mike Fisher, former captain of the Nashville Predators hockey team, the nationally syndicated parade was presented by Piedmont Natural Gas and the famous Tootsie's Orchid Lounge and benefited Monroe Carell Jr. Children's Hospital at Vanderbilt.

Children's Hospital Telemedicine in Kentucky Schools

IN A FIRST OF ITS KIND collaboration for both parties, schools in Allen County, Kentucky, have joined with Monroe Carell Jr. Children's Hospital at Vanderbilt so that sick children can receive a more comprehensive array of healthcare services while attending school through virtual visits with Vanderbilt clinicians.

Through a school-based telemedicine program, nurses with the Allen County Health Department who practice in the county's four schools located in Scottsville, Kentucky, work with nurse practitioners and pediatricians in Children's Hospital's Pediatric Primary Care Clinic to offer the county's 3,000-plus students care for certain conditions typically requiring a trip to a pediatrician's office.

The telemedicine initiative is especially beneficial because there are no pediatricians currently practicing in Scottsville or Allen County. Parents often drive more than a half-hour to the nearest pediatrician's office or make the hour-and-a-half drive to Nashville.

A generous gift from Laura Jo and Wayne Dugas, the Cal Turner Family Foundation and the James Stephen Turner Family Foundation made this initiative possible. In addition to serving the healthcare needs of Allen County school children, the gift also supports the hospital's expansion currently under construction — and will establish telemedicine facilities within the new space. The expansion was supported by generous contributions to the Growing to New Heights Campaign from donors throughout the community.

The Dugas and Turner families are from Scottsville, where the family's patriarch, Cal Turner Sr., founded Dollar General Corporation. The family continues to have deep roots in Scottsville and Allen County.

"It's an absolutely wonderful opportunity for the students of the Allen County school system and we're very grateful for the help the Turner Foundation has given us over the years," said Randall Jackson, Superintendent of Allen County Schools. "The potential for the general health and well-being of our students, in connection with Monroe Carell Jr. Children's Hospital, is tremendous."

School-based telemedicine is beneficial when students' health issues fall outside a school nurse's typical scope of practice. The technology includes encrypted, secure, high definition videoconferencing capabilities. Parents are able to link in from anywhere and be part of their child's virtual clinic visit via a phone, tablet or computer. Prescriptions can be sent to the family's preferred pharmacy, and a follow-up communication is sent to the student's primary care clinician.

The initiative is possible because each school is staffed with a full-time registered nurse from the Allen County Health



Pictured here (from left): Julie Carell Stadler, Jeff Balser, MD, PhD, Edie Carell Johnson, Cal Turner Jr., Laura Jo Dugas, Steve Turner and Kathryn Carell Brown.

Department. In addition to common illnesses, the schools' nurses also manage students who have serious chronic health conditions such as asthma, allergies, diabetes and seizures.

"The Allen County Health Department school nursing staff is excited and grateful for the opportunity to collaborate with the Allen County School System and Vanderbilt on the telemedicine initiative. I feel this will become the new standard of nursing care for students not only in Allen County but also for Kentucky. This is a rare and very special opportunity for Allen County to improve health outcomes locally and be a model for our state," said Carolyn Richey, RN, Nursing Supervisor for the Allen County Health Department.

Services offered will include treatment for conditions such as fever, sore throat, ear pain, nausea, abdominal pain, skin irritations and sprains.

"This initiative, which is possible through the generosity of the Dugas and Turner families, will allow us to reduce travel time and stress for these children and their families," said Luke Gregory, Chief Executive Officer of Children's Hospital.

In a joint statement, the Dugas and Turner families said: "In addition to enhancing healthcare for school children in Allen County, our hope is that this collaboration will lead to others with rural communities throughout the region. Making this even more special to us is that our dear friend and Scottsville native Gwen Bond was married to Jim Bond, whom we knew since high school, and who worked for more than 40 years for Monroe Carell at Central Parking."

— by John Howser

Researchers seek best ways to increase HPV vaccination rates

SUSAN URMAY



Cumberland Pediatric Foundation Executive Director Lora Harnack, MSN, left, and Pamela Hull, PhD, a medical sociologist with the Vanderbilt Epidemiology Center, are working together to improve human papillomavirus (HPV) vaccination rates at Tennessee pediatric clinics.

Tennessee has one of the lowest human papillomavirus (HPV) vaccination rates in the nation, and investigators at Vanderbilt University Medical Center (VUMC) hope to change this by improving the way medical providers present these vaccines to patients and by improving patient and patient family education.

"HPV is the most commonly sexually transmitted infection in the United States, with an estimated four out of five adults infected with the virus during their lifetime," said Pamela Hull, PhD, a medical sociologist with the Vanderbilt Epidemiology Center. "Many infections are asymptomatic and resolve without long-term consequences; however, infection with some types of HPV can cause cancer, including cancers of the cervix, vagina, vulva, penis, anus, rectum and of the head and neck."

Last year, Hull received a five-year \$2.7 million grant from the National Cancer Institute aimed at increasing HPV vaccinations at community-based pediatric practices. She is working in partnership with the Cumberland Pediatric Foundation (CPF), a nonprofit organization that supports scientific, charitable and educational efforts to improve children's healthcare services.

An HPV vaccine was first licensed in the United States for females in 2006 and for males beginning in 2009. It's recommended for ages 11 or 12 years, and through age 26 for those who have not been previously vaccinated. Initially, the HPV vaccine was given in a three-dose series, but in 2016, the Centers for Disease Control and Prevention (CDC) recommended a revised two-dose schedule for those under age 15.

The CDC's 2014 National Immunization Survey-Teen showed Tennessee ranked poorly in HPV vaccination rates for both males and females, ages 13–17. Tennessee's rate of adolescents beginning the vaccine series was approximately 30.5 percent in males and 47.8 in females, with only about 14 percent of males and 20 percent of females completing the vaccine series.

Improving the HPV vaccination rate has been a focus of the CPF for several years, said CPF Executive Director Lora Harnack, MSN, RN, and the organization has teamed with VUMC and other organizations in efforts to do so, including community-based educational events and quality improvement initiatives with CPF member practices. CPF currently has 77 community-based pediatric practice locations in its membership.

"Pediatricians want to take the best possible care of their patients," said Harnack. "In having conversations with them, we learned that a lot of physicians perceived that they were doing a lot better than they were, in terms of getting these vaccinations completed."

The grant is helping fund a quality improvement project at 22 CPF-affiliated pediatric practices in Tennessee, in which two methods of coaching are tested for their efficacy in increasing vaccination rates.

One method used is a nurse educator who travels to 11 of the pediatric offices to conduct a needs assessment and train staff on how the HPV vaccine should be presented to patients and their families. The second method provides a web-based version of this service to the remaining 11 participating clinics. The clinics' HPV vaccination rates will be measured at the study's completion.

The clinics also provide patient education materials (get3shots.org) that were developed in a previous study under the Meharry Medical College, Vanderbilt-Ingram Cancer Center and Tennessee State University (TSU) Cancer Partnership led by Hull; Maureen Sanderson, MPH, PhD (Meharry); and Elizabeth Williams, PhD (TSU); in collaboration with a Community Advisory Board.

"The challenge is how to get doctors and primary care clinics to consistently make strong recommendations for HPV vaccinations and that those recommendations occur at the appropriate ages," Hull said.

—by Jill Clendening



Every Birthday is a Gift

At age 2 ½, Grace was diagnosed with leukemia and began a journey through nearly three years of cancer treatment. Thanks to the care of Monroe Carell Jr.

Children's Hospital at Vanderbilt, now, at age 9, she's a third-grader who loves horses and reading. Each year, she celebrates her birthday by finding special ways to help comfort and encourage other patients. Help us care for more children like Grace by supporting Children's Hospital.

Help now: ChildrensHospital.Vanderbilt.org/giving



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Monroe Carell Jr. Children's Hospital at Vanderbilt is once again named among the nation's Best Children's Hospitals in *U.S. News & World Report's* annual rankings. Children's Hospital, a regional comprehensive pediatric care center providing an array of specialty and subspecialty services, achieved national rankings for 10 out of 10 pediatric specialty programs.