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For patients like Charlie Bertotti (on the cover) and Breanna Joyner, who experienced oxygen deprivation at birth, every small achievement is cause for celebration. For two decades, neonatologists at Monroe Carell Jr. Children's Hospital at Vanderbilt have explored treatment options, including body cooling therapy, to help oxygen-deprived newborns. New research is looking at ways to augment that care.

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THOUGHTS ON hope

S WE MOVE INTO SUMMER, we embrace the longer days and find our routine more like that of the children we serve — busy all day long! Since we last connected with you, we have celebrated the reopening of our front doors and the dedication of the Carell Family Balcony. As you read this issue, we eagerly anticipate the moving of our pediatric cardiac patients onto the first floor of our expansion and plan for the internal program transitions that will occur in other vacated spaces. We are excited about how this new space enables our ongoing efforts to advance and create programs to meet the needs of our patients and families.

The foundation of our daily work is built upon excellence in clinical care, discovery, innovation and training. Being part of an academic medical center allows us to bring discovery and innovation to the bedside every day, as well as create novel programs that are possible because of multidisciplinary collaborations that do not occur in other settings. One long-standing partnership that showcases this special collaboration is the relationship between Children's Hospital, Vanderbilt Eye Institute (VEI) and the Tennessee Lions Clubs.

For over 25 years, the VEI Tennessee Lions Pediatric Eye Center has served children from across our state and region in the delivery of comprehensive eye care as well as in the development of novel programs. This team routinely incorporates the latest technologies, such as telemedicine, to bring eye care to communities that do not have access to pediatric ophthalmologists. We are thrilled to highlight a unique partnership between our pediatric oncology, interventional radiology and eye center teams in the development of a vision-saving treatment that delivers chemotherapy directly into pediatric eye tumors.

We also have been a pioneer in neonatology for almost 60 years through the work of our clinicians and trainees as they continually advance treatment strategies for babies through laboratory, clinical and quality improvement discovery. We share this work through the stories of two families impacted by cooling therapy, a treatment for babies who have low oxygen levels at birth, that first started as a research trial then moved to routine care. Our neonatology team is the only clinical trial site in Tennessee participating in research to further improve and refine this treatment.

While we have the ability to do these great things in the discovery space, we also are able to bring together clinical experts when disease or injury is present. As a pediatric trauma center, we see accidents that range from simple to extreme. Our pediatric surgical teams have ready access to experts in certain anatomical areas, such as the hand, to facilitate repairs that return function and enable dreams to be fulfilled.

Monroe Carell Jr. Children's Hospital at Vanderbilt is 'more than a place' — it is people committed to providing healing and hope. We are able to do this work because of Children's Hospital staff like Chelsea Carter and Bonnie Parker, who are March of Dimes nurses of the year, the community partners who enable programs like Friends of Children's Hospital, and the remarkable clinicians, investigators and trainees who turn discovery into treatments.

Sincerely,

Luke Gregory, FACHE Chief Executive Officer

Meg Rush, MD, MMHC Chief of Staff and Executive Medical Director

John W. Brock III, MD

Senior Vice President of Pediatric Surgical Services, Monroe Carell Jr. Professor and Surgeon-in-Chief

Steven Webber, MBChB, MRCP

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



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The Children's Hospital Advisory Board is an advocacy, fundraising and advising group.

Members educate constituents in the community and do outreach to secure resources to support the mission of Children's Hospital. Learn more at ChildrensHospitalVanderbilt.org/advisoryboard.

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BABY'S BREATH

New therapy offers hope for infants who experience oxygen deprivation at birth

> written by Kelsey Herbers photograph by John Russell

A few weeks before the due date of her first child, Katie Bertotti's intuition told her something wasn't right.

She hadn't been experiencing much movement from her unborn son, Charlie, and decided it was worth a phone call to her nurse midwives.

The midwives encouraged her to come to the Emergency Department, where close monitoring showed decelerations in Charlie's heart rate, spurring an emergency C-section delivery.

On Sept. 28, 2017, Charlie was born discolored, silent and not breathing.

he first few minutes of Charlie's life were a blur, as a team of doctors and nurses at Vanderbilt University Medical Center (VUMC) worked to resuscitate him and stabilize his heart rate. He was then transferred to the Neonatal Intensive Care Unit (NICU) at Monroe Carell Jr. Children's Hospital at Vanderbilt.

"I was keeping one eye on Katie's vitals and one ear on the team of doctors and nurses who were trying to get Charlie breathing," said Mike Bertotti, Katie's husband and Charlie's father.

A few hours passed before Katie and Mike had a diagnosis: Charlie had neonatal encephalopathy, a syndrome that occurs when a baby experiences reduced blood flow and oxygen to the brain near the time of birth. The longer a child's brain spends without oxygen, the greater his chances of brain damage — and subsequent risk of death or neurologic disabilities, such as cerebral palsy, cognitive impairment and epilepsy — increase.

"The doctor came in and told us Charlie had a hypoxic ischemic event, and all we heard was 'brain damage,'" said Katie, who at the time was still under the effects of anesthesia. "I wasn't of a clear enough mind to understand what she was telling us or what that would mean. I was thinking, 'Will he live? And, what will his quality of life be if he does?'"

Evolving care

Affecting up to 12,000 births each year in the United States, neonatal encephalopathy isn't common, and not all children who receive the diagnosis suffer brain damage. The condition can have many underlying causes, including uterine rupture prior to birth, the placenta or umbilical cord delivering first, or a stroke suffered by the baby. In many other cases, the cause remains undetermined.

According to William Walsh, MD, professor of Pediatrics in the Mildred Stahlman Division of Neonatology at Children's

William Walsh, MD, professor of Pediatrics, led Vanderbilt's participation in a 1999-2002 trial looking at the initial CoolCap technology for newborn oxygen deprivation.



Hospital, the survival rate for babies with encephalopathy is around 90 percent, but babies who suffer brain damage have a roughly 50 percent chance of developing cerebral palsy.

"The loss of oxygen around birth is a really important and terrible problem. These are beautiful, healthy term babies who experience a catastrophic event," said Walsh, former chief of Nurseries, who began his work in the field in 1976.

"As soon as you know you're pregnant, you have the baby's college education picked out and think about who they're going to marry. You have their whole life imagined, and as you get closer to delivery, it becomes more real. You enter the third trimester and paint their room. And then something like this happens, and it's like being in a car accident — that's the kind of catastrophe this is for these families," Walsh continued.

For the first 20 years of his career, Walsh and his colleagues had no way of treating babies with encephalopathy. The team could only treat resulting seizures and blood pressure conditions, increasing the baby's chance of survival.

One study in animal models in the 1990s, however, showed an interesting observation: although animals with normal functioning brains that endured a hypoxic ischemic event lost brain function within 16 hours of the event, scans taken four hours after the event showed the brain was still functioning normally. This meant damage took time to develop.

"There was this period of time that we called the 'window of opportunity," said Walsh. "Could we do something to keep the brain functioning before it ceased activity a few hours later? The first thing that was shown to have some success was decreasing the brain temperature."

In 1999, Vanderbilt enrolled in one of the first international clinical trials to determine if cooling therapy — or cooling the baby's brain down about five degrees — could prevent brain damage in babies born with oxygen deprivation. The results showed that babies who suffered moderate damage at birth experienced brain damage reductions of almost 60 percent after being cooled for 72 hours, and the child's odds of developing cerebral palsy decreased from two in three to one in two.

While cooling therapy showed progress and was established as a standard of care in the early 2000s, it only helps one in seven babies with encephalopathy. So, when evidence emerged that a drug commonly used to help premature babies repopulate blood cells had neuroprotective and neuroregenerative capabilities, researchers jumped on the chance to test its effect on reducing brain damage.

A new approach

In May 2017 Vanderbilt joined a five-year, Phase III national clinical trial funded by the National Institute of Neurological Disorders and Stroke (NINDS) to determine if the drug — Erythropoietin ("Epo" for short) — improves neurodevelopmental outcomes when combined with cooling therapy.

The first two phases of the study tested the drug's safety



Hendrik Weitkamp, MD, FAAP, director for Patient-Oriented Research in the Division of Neonatology, is Vanderbilt's principal site investigator for a national study hoping to improve outcomes for infants who suffer oxygen deprivation.

and optimal dose for term babies. The current phase, which involves 22 academic medical centers across the country and is sponsored by the National Institutes of Health (NIH), will enroll 500 patients and measure the drug's efficacy based on developmental outcomes at 2 years of age.

The principal investigators of the national study are Yvonne Wu, MD, MPH, at the University of California, San Francisco, and Sandra Juul, MD, PhD, and Patrick Heagerty, PhD, at the University of Washington in Seattle.

"This phase is hopefully the defining study to see if Epo can be used as a standard of care in addition to cooling therapy," said Hendrik Weitkamp, MD, FAAP, director for Patient-Oriented Research in the Division of Neonatology and principal investigator for Vanderbilt's portion of the study. "It's nice to be able to offer something else to these families in addition to cooling, our standard care, that has been studied well. And, since we've been one of the sites involved in those studies, we already have a lot of experience with this group of babies.

"It's comforting to know that participating in this clinical trial may make a difference in how we treat babies with encephalopathy in the future. I feel like it puts us at the forefront of medicine," said Weitkamp.

Vanderbilt, which is the only trial site in Tennessee and one of two in the southeastern United States, has already enrolled 18 patients out of its target of 20.

To effectively measure Epo's role, the trial, known as the HEAL (High-dose Erythropoietin for Asphyxia and Encephalopathy) Trial, is placebo-controlled, meaning only half of the babies enrolled receive the drug. The study is also double-blinded, meaning neither the families nor their doctors know whether the patient received Epo or the placebo.

To be eligible for the study, babies must be at least 36 weeks gestation at birth, suffer from moderate to severe encephalopathy and receive cooling therapy before they are six hours old. Once enrolled, each patient receives five injections of the drug or the placebo over seven days and is cooled for 72 hours following birth.

Although the baby may receive the placebo, the trial offers participating families an additional set of trained providers who work closely with the primary medical team to optimize the patient's care.

"In addition to supporting the clinical care of our patients, we can offer services such as close follow-up and special neurodevelopmental testing through this study that we wouldn't be able to offer outside of this trial," said Weitkamp.

"For a lot of parents, it is comforting to know that even if their child may or may not benefit from participating in the study, they can contribute something to hopefully help the next family who will go through this."

Eliminating unknowns

Four hours after Charlie's birth, the Bertottis were approached by Theresa Rogers, RN, research nurse specialist III in the Division of Neonatology, about enrolling him in the HEAL Trial. Charlie was exhibiting early signs of brain damage and was limp and lethargic.

"The nurse said, 'This has been shown to work in other studies, but it's not 100 percent positive that it will do anything in addition to cooling.' And we basically said, 'Do whatever it

Sub-trials shed additional light

Aside from assessing Erythropoietin's (Epo) efficacy in reducing neonatal brain damage, teams at Vanderbilt are conducting two smaller studies within the HEAL Trial to offer additional insight.

One team is examining near-infrared spectroscopy (NIRS) data to determine Epo's potential mechanisms of action on brain and renal tissues. Researchers will determine how the addition of Epo to cooling may affect brain and kidney NIRS measurements and how these may be associated with improved outcomes.

Another team, led by Erin Havrilla, MSN, RN, nurse manager of Neonatal Services in the NICU at Monroe Carell Jr. Children's Hospital at Vanderbilt, and Uchenna Anani, MD, assistant professor in the Mildred Stahlman Division of Neonatology, is conducting interviews with families who were approached about enrolling to examine their reasoning for participation or refusal. Researchers also ask families about their understanding of the trial to ensure they were properly informed before giving consent.

"We have learned so much about the ability for families to simultaneously cope and communicate when faced with a lifethreatening situation at birth," said Havrilla. "Our hope is to create a more informative decision-making environment that fosters feelings of respect with parents of critically ill neonates while improving consenting rates for neonatal clinical trials."

- by Kelsey Herbers

It helps to have Friends in the fight against prematurity

In 2010, Friends of Monroe Carell Jr. Children's Hospital at Vanderbilt set an ambitious goal: to commit \$1 million to combat prematurity.

The group's gift would benefit the Friends of Monroe Carell Jr. Children's Hospital Prematurity Fund, with the goal of giving the tiniest newborns the best possible start in life. The contribution has already helped the hospital reduce antibiotic use among premature infants, increase the use of breast milk to feed babies with very low birthweights, and reduce unplanned displacement of breathing tubes.

"As a Friends member, I'm constantly amazed to see the long list of support our volunteers have provided Children's Hospital through the organization's 47-year history," said Vera Lee, Friends president. "The emphasis of the Friends organization is to continue making an impact on various departments and patient populations across Children's Hospital. Although past Friends leaders worked to establish the Prematurity Research Endowment Fund, it's heartwarm-

ing to know that the research continues making an impact on the tiniest of patients."

The Friends organization has been a vital partner with Vanderbilt since 1972. Thousands of volunteers have provided countless hours of service, advocacy, public awareness and significant funding in support of patients and their families at Children's Hospital.

Friends established this prematurity fund to further its mission of supporting the needs of patients and their families in the hospital and preventing the need for hospital care.

Tennessee currently has one of the nation's highest rates of premature births. One in nine infants in the state is born too soon, according to the March of Dimes annual report card, which gives Tennessee a 'D' grade. Preterm birth is defined as a live birth before 37 completed weeks' gestation.

The Friends Prematurity Fund has been used to develop and grow a multidisciplinary neonatal quality improvement team at Children's Hospital. It also supported ad-

vanced training for the hospital's lead quality improvement neonatal nurse practitioner Mary Eva Dye.

Through increased educational awareness programs, the quality improvement team has documented several successes. Among them, the Breastfeeding Quality Improvement Team recently reported a 23 percent increase in the number of very low birthweight infants discharged home on breast milk, largely due to a new initiative called NICU Breast Friends, a lactation support group.

"This work is so very important for our patients and their families and goes a long way to fulfilling the mission of Friends," said Susan Guttentag, MD, director of the Mildred Stahlman Division of Neonatology for Children's Hospital and Julia Carell Stadler Professor of Pediatrics. "The Friends' support of our quality improvement team helps us to find new ways to optimize care of our patients and their families."

- by Christina Echegaray

takes. You're the expert. You know best," said Mike.

While in the NICU at Children's Hospital, Charlie was placed on immediate cooling. The first time Katie got to see her son, he was wearing an electroencephalogram (EEG), was intubated, and was hooked up to feeding tubes, a blood pressure monitor and a ventilator.

"At one point, his eyes were taped shut, and he was swollen and bloated. It was devastating because I had no control," said Katie.

"This isn't what you imagine the birth experience being like or how you picture the moment you meet your child for the first time. We weren't able to even hold him until he was six days old."

Despite complications, including seizures and an unidentified infection that required quarantine care, Charlie began breathing on his own after 12 days, sooner than expected. On his 15th day in the NICU, he was released from the hospital and brought home for the first time.

For Katie and Mike, Charlie's homecoming was both a happy and terrifying experience.

"We had gotten so used to beeps and notifications. We un-

derstood how to read his pulse oxygen level and heart rate so we could hear and visually see exactly how he was doing. Not having that for the first night was scary," said Katie.

Before he was discharged, Charlie's NICU nurses helped prepare the Bertottis for life at home by teaching them parenting tips, such as how to give Charlie a bath.

"All of Charlie's nurses were awesome. They were there around the clock tending to him," said Mike. "Being an engineer, I want answers to everything, so I was asking a million questions, and they politely answered them. When we came into the room, they would tell us what movements Charlie made while we were away.

"To me, they almost cared for him as if he was their own. That's the level of care I feel like we got."

Despite a diagnosis of spastic diplegic cerebral palsy — characterized by muscle spasms and tenseness — and delays in his motor and speech skills, Charlie, now 18 months old, is what his parents call "wild, opinionated and extremely happy."

Through occupational and physical therapy, Charlie has learned how to open his hands, take steps on his own and use a pincer grasp to pick up small objects. His receptive language

skills are ahead for a child his age, and he's learning sign language while he develops the fine motor skills needed for speech.

"A lot of the moments we have with him that are so special are amplified because they are things we didn't think would happen," said Katie.

"I've read that other parents call these inchstones, all the steps that get a child to where he needs to be. There are so many. Seeing Charlie reach every inchstone and milestone gives us a clear understanding of the miracle that is growing up and learning new things."

Although it's possible Charlie never received Epo, the Bertottis believe his enrollment in the HEAL Trial contributed to his continued success.

"I think research is incredibly important, and I hope there's more research done to decrease the instance of encephalopathy even happening in the first place," said Katie. "When we were leaving the hospital, there were so many unknowns. It has been miraculous to see some of the changes and experience watching him grow.

"Charlie may end up having some difficulties with his fine and gross motor skills, but he has a great personality. That's what I hope for him most: that he's just a good guy who works hard, is motivated and is surrounded by people who love him for who he is."

Checking off boxes

When Jessica Joyner delivered her first daughter at VUMC in July 2017, the look on her nurse's face gave her cause for concern.

"I remember her saying Breanna hadn't been breathing and hadn't had oxygen," said Jessica, who had just settled into a new life in Nashville after moving from Philadelphia one month prior.

"The words she was saying didn't sound like that big of a deal, but the look on her face was saying that it was a big deal."

Like Charlie, Breanna had suffered a hypoxic ischemic event and was immediately taken to the NICU. Between shock, medication and trying to recover from a C-section, there's not a lot Jessica remembers about the first few hours of Breanna's life.

After Breanna's father, Brian Latimer, MD, left the hospital to care for the couple's 7-year-old son, Kiernan, Jessica was approached about the HEAL Trial and Breanna's opportunity to enroll.

"It was one of those things where it was like, 'Whatever you need to do is 100 percent fine by me," said Jessica. "It wasn't going to hurt Breanna — it could only help, assuming she got the medication — so it wasn't a hard decision to make."

The first time Jessica caught a glimpse of her daughter, she was only able to see her head. The only conscious thought she remembers is being shocked that Breanna had bright blonde hair, as Kiernan was born with black hair.

Jessica and Brian couldn't hold Breanna until almost four days after her birth, when she was taken off cooling therapy. Her NICU stay lasted eight days, and while Breanna experienced weakness in her right side, she didn't have any other complications.

"I'm not a first-time mom, and I spend a lot of time taking care of babies, so it was so frustrating to be in the NICU and to know what she needed and not be able to give it to her," said Jessica, who works in the YMCA's daycare program. "I had to ask permission to pick her up because of all the wires and medication.

What is cooling therapy?

For two decades pediatric neurologists and neonatologists in Vanderbilt's Neonatal Intensive Care Unit (NICU) have researched brain cooling therapy as a treatment option for newborns who have suffered from oxygen deprivation and to understand what brain cooling therapy can achieve.

Vanderbilt began participating in studies on a cool cap in 1999. Use of a cooling cap within six hours became the standard of care when an otherwise healthy, full-term infant experiences a serious lack of oxygen, called anoxic brain injury. The therapy uses cool water to bring the temperature of the brain down about five degrees. Vanderbilt took part in the initial studies of the cooling cap, which was found to reduce serious long-term brain damage and death by about one-third.

In 2012, a switch was made to a cooling blanket instead of a cap. The blanket is as effective in its brain-protecting capacity, but it offers researchers an opportunity to better assess what is happening in the brain as it cools.



Former Pediatric Neurology chief resident Siddharth Jain, MD, uses a doll to demonstrate how a newborn placed on a cooling blanket would be monitored.



Breanna Joyner, 20 months old, participated in a clinical trial at birth that could change the way doctors care for oxygen-deprived babies.

"Taking her home was scary, but we were able to start feeling like we actually did have a baby. Trying to find a new normal was a relief more than anything else."

Breanna, now 20 months old, enjoys being verbal and running on her own. She no longer sees developmental and physical therapists and only makes one yearly return visit to Children's Hospital.

"Every milestone is like waiting for the next box to check," said Brian, a second-year resident in Vanderbilt's Department of Radiology. "We're way more attentive to developmental milestones because of what she has been through."

"I think the hardest part about the diagnosis is you know so little about what the future will hold. It's not like you can say, 'Once X, Y and Z happens, she can come home.' We weren't even able to have that," said Jessica.

"You don't know how your child is going to handle something like this. Statistics are statistics, but your baby is not a statistic. Breanna shocks anyone who hears what happened. She's doing so well."

Walsh, who hopes Epo will prove to be a game changer for babies with encephalopathy, also looks forward to the potential of expanding its use to other babies in the NICU, including those who are born premature. Prematurity is another cause of cerebral palsy.

"The hope is there, but parents need to realize these babies are still at risk. Human birth has become so much safer over the years, but it's still dependent on that little placenta and cord," said Walsh.

"Precious, fragile and not guaranteed: that's just the way life is." hope

Honoring **Extraordinary Nurses**

very year, the March of Dimes honors Middle Tennessee nurses in 17 categories for the Nurse of the Year awards, which honor extraordinary nurses who go above and beyond to deliver compassionate care to help moms and babies.

Two pediatric nurses at Monroe Carell Jr. Children's Hospital at Vanderbilt, Chelsea Carter, RN, and Bonnie Parker, RN, BSN, along with seven Vanderbilt University Medical Center nurses, received Nurse of the Year recognitions for their specialties.

"Both Chelsea and Bonnie exemplify the profession of nursing at its best," said Kathie Krause, MSN, RN, NNP-BC, NEA-BC, chief nursing officer of Children's Hospital. "Their dedication is evident in the care they provide, the compassion with which they provide it and the commitment they make to each and every child and family they touch. The Children's Hospital team knows how these nurses practice with passion and to have the March of Dimes recognize them throughout our community makes them even more special."

For Carter, a pediatric emergency room nurse and quality improvement analyst, the news came as a surprise, particularly since she had nominated a co-worker for the same category - Emergency Room Nurse of the Year.

"When they started reading off the description of the recipient, I was like, 'Wait, that's not who I nominated.' Then I was like, 'Wow, that's me," Carter said, "I knew I was a nominee, but there were so many fabulous nurses. It just never crossed my mind."

She has worked in the Emergency Room at Children's Hospital for five years. It's her first nursing job, and she couldn't be more thrilled with the who, what, where and why of it all, she said.

"I love who I work with, what I do and where I work," she said. "When I am here, I feel valuable and part of the team. I know



Chelsea Carter, RN, was named March of Dimes Middle Tennessee Emergency Room Nurse of the

that I am making a difference in my patients' lives and I can serve as a mentor to help others who are just starting out in their careers."

Nursing was not the first career choice for Carter when she was selecting her major as high school senior. She planned to enter public relations but changed her mind after a conversation with the mother of one of her friends.

"After that talk about how much impact I could have in nursing and all the directions I could go, I called UT (the University of Tennessee at Knoxville) and changed my major to nursing," she said.

Carter has never looked back.

Parker, RN, BSN, nursing case manager in the Neonatal Intensive Care Unit, has been in nursing for nearly 35 years.

As a child she recalls wanting to be a kindergarten teacher, until a car accident changed her life.

"In junior high, my family was in a bad car accident," she recalled. "A drunk driver hit us head on, and I stayed in the hospital for a week and needed multiple facial surgeries after I was discharged.

"It was then that I started thinking about doing something related to hospitals. I started out in medical technology, but



Bonnie Parker, RN, BSN, was awarded March of Dimes Middle Tennessee Pediatric Nurse of the

after a year and a half, I changed to nursing. I knew I wanted to go into pediatrics, but when I accepted my first job, there was only an opening in the NICU. Once I got there I discovered I loved it and stayed. It's where my heart is."

As a case manager, Parker helps to prepare babies for home, ensuring that families have everything necessary to care for their child including appointments, equipment, nursing home care and more.

"I love working with the babies and their families," said Parker. "It feels good being able to help these parents get home and feel like they are going to be OK. We work hard so that they know we are in their corner."

– by Jessica Pasley

"Both Chelsea and Bonnie exemplify the profession of nursing at its best."





KEON JOHNSON WAS A 13-YEAR-OLD SKILLED ATHLETE IN 2015 WHEN HE RECEIVED A DEVASTATING INJURY TO HIS LEFT HAND AND UPPER RIGHT LEG WHILE SETTING OFF EARLY-MORNING FIREWORKS.

written by Nancy Humphrey photograph by John Russell

Two months before he started high school, he dropped an artillery firework, a powerful explosive that is launched high into the sky, into a mortar tube and lit the fuse. But the fuse was too short, and the device exploded too quickly, shooting back at Keon, knocking him backward and unconscious.

Four of his fingers had open fractures (meaning the bone had come through the skin), and the breaks were so traumatic that the fingers were out of their normal positions. The damage to the ring finger was significant. The blood vessels would have to be repaired to avoid amputation. Regaining optimal use of his hand wasn't a guarantee as he was wheeled into surgery at Monroe Carell Jr. Children's Hospital at Vanderbilt. Keon was fortunate to have Doug Weikert, MD, one of the nation's best hand surgeons, on his care team.

This year, Keon, a 17-year-old junior at The Webb School in Bell Buckle, Tennessee, is one of the top college basketball recruits in the nation for 2020, being courted by some of the best programs and universities in the country — Auburn, Mississippi, Tennessee, Vanderbilt, Ohio State, and Virginia. He was named Tennessee's Mr. Basketball for Division II-A by the Tennessee Secondary School Athletic Association for the past two years in a row and is listed as the top-rated

college basketball prospect in Tennessee for the class of 2020, according to 247Sports, an online sports site.

"It was bad"

Keon doesn't remember all of the details about the explosion that could have ended his life or, at the very least, cut his athletic career short. On June 26, 2015, he and his cousin were setting off fireworks at his cousin's house, where Keon had spent the night. He lit the large projectile firework and it went off while he was leaning over it.

He was knocked out, and once he regained consciousness, had to feel his way around. "I couldn't see at first," he said.

He reached for his iPhone in his front right pocket, but the phone had absorbed most of the impact to his leg and groin area and was dented and unusable.

"After I couldn't get my phone to work, I told my cousin to call 911, and then I called my mom on his phone."

He doesn't remember the conversation, but his mom, Conswella Sparrow Johnson, does. She was asleep when her son called and quickly dressed and raced to his side. She got there as he was being evaluated by paramedics inside the ambulance.

"THERE WAS A LOT

of blood on his hand, his leg and his chest," she said. "His chest took some of the after-effects. He had little burns all over his chest. I was worried about his eyes too. The whites of his eyes were blood red, and we didn't know at first if his vision had been damaged, or his testicles. His cell phone definitely saved his groin area."

Conswella rode in the front of the ambulance and could hear the paramedics talking to her son and to each other in the back of the emergency vehicle. "They said they might not be able to save his hand. At that point, my first instinct was to start praying, and that's what I did," she said, pausing to choke back tears while Keon reached out to pat her back.

They hit rush hour as they raced down Interstate 24 to Vanderbilt, more than an hour away. "We ran into all kinds of traffic on the way in. We were on the median, with our flashers on, trying to get him there as fast as we could. I called my husband when we were driving in and told him to get everybody to Vanderbilt, that it was bad."

When the ambulance pulled in to the emergency entrance of Children's Hospital, two hospital staff members were outside, waiting for them. "They checked him from head to toe — his vision and every single part of his body. I was thoroughly impressed with Vanderbilt, and I'm so thankful we came straight there," she said. "Otherwise, he might not have a left hand or might not be able to use it."

Joined at Children's Hospital by her husband, Keith, and Keon's siblings, Kora, who was 6, and Kegan, who was 4, the Johnsons waited with relatives while Weikert repaired Keon's hand.

Weikert, who played basketball for the Vanderbilt Commodores during his undergraduate years, said that he didn't know that Keon was a top-notch basketball player when he first met him and his mom that morning.

But it wouldn't have changed the course of treatment.

"I see a fair amount of horrible injuries to kids," said Weikert, associate professor of Orthopaedic Surgery and Rehabilitation and Plastic Surgery. "You look at it like starting from zero. You have to hope at the end of the day you have components that with healing, therapy and motivation can be turned into a useful and productive hand," he said.

"You don't know what you're going to get at the end of the repair, but you start with the basic principles. Does the patient have a thumb? How many fingers were injured? How many are going to make it? What can I do to help the salvageable parts of the hand?

"I didn't know this 13-year-old, lanky, athletic kid was going to grow up to be a top 20 national basketball player. You can't look at patients like that. You focus on the injury in front of you."

Weikert earned his medical degree from Vanderbilt University School of Medicine and did his internship and orthopaedic residency at Vanderbilt University Medical Center before completing a fellowship in hand surgery at Indiana Hand Center. His work requires skills in both microsurgery and plastic surgery, especially when he's reattaching limbs. He's an adult orthopaedic surgeon but is frequently called by his counterparts at Children's Hospital to handle complicated hand injuries.

Previously, Weikert was involved in one of the youngest arm reattachments in the country — a 14-month-old child who lost his arm in a car wreck. In 2007, he reattached a foot of a 13-year-old girl whose feet were severed by a cable that broke loose on an amusement ride in Kentucky, a story that grabbed national headlines.

A Painful Process

Keon's left hand had open fractures of the middle, ring and little fingers. The ring finger was the most significant injury and did not have blood flow when he arrived.

In the operating room, Weikert had to repair the blood vessels to the ring finger to keep it from being amputated. The bones of the middle and ring fingers were stabilized with pins for several weeks until the hand healed.

After Keon's hand was repaired, he went through eight weeks of intensive physical therapy, three to four days a week. It's essential that therapy begins when the bones are healing, not after, so scar tissue can be neutralized and motion can be restored. It's a painful process, Weikert said.

Keon wore stents to straighten his fingers and had daily exercises he was responsible for doing on his own.

Weikert said that patients with severe hand injuries need to be focused and motivated. Keon was.

"Clearly, injuries like that can go either way. With that kind of injury, the younger you are, the better you do in terms of recovering nerve injuries and skin recovery, and bone healing in a timely manner. All those things in general do better in younger patients than older ones. His potential to recover, based on his age alone, was quite good."

Weikert said that Keon's attitude was key in getting him through the worst of his injury. He was able to remain motivated and able to work through the pain, Weikert said.

"I didn't know this 13-year-old, lanky, athletic kid was going to grow up to be a top 20 national basketball player. You can't look at patients like that. You focus on the injury in front of you."



Keon Johnson, 17, seen here with his coach, Jeff Mitchell, is the top-rated college basketball prospect in Tennessee for the class of 2020.

"He rehabbed it and played through it. He didn't let it get the best of him. He didn't feel sorry for himself. He knew he made a mistake. He owned up to it and took it upon himself to rehab through all the pins sticking out of his fingers and the pain that goes along with that injury and the scar tissue. He recovered. He got over it," Weikert said.

"You never know what you're going to get with a teenager in terms of handling things like that. I've had three of them. Some just don't know what to do. Others are coachable. He was certainly coachable."

The hand is an organ in and of itself, Weikert said. The anatomy is complex and challenging. The structures of the hand include 27 bones. Fourteen bones make up our fingers and thumb, and each finger has three phalanges that connect to each other, forming two joints in each finger. The thumb has only two phalanges and one joint. These bones are held together by a system of ligaments, tendons, muscles, nerves and blood vessels.

"It does so many things for us. We don't realize how important it is functionally until it's in a cast or a dressing or we lose a finger or a thumb. Every digit is so important, and the stakes are high when digits are injured like that, especially for an athlete."

Weikert said hand surgery on athletes is a particularly compelling challenge for him as a surgeon.

"It's a way to keep my hand in the game, doing surgeries that are challenging that make me feel like I could help return athletes and other patients to their previous levels of function. It's some of the most rewarding surgeries we do — when an athlete gets injured, we can measure our outcomes right in front of us. You can tell right away when an athlete excels in

the way they were able to right before the surgery. And when they do excel, it's about as rewarding as it gets for me."

Runs in the family

Keon's mother, Conswella, said her son has played basket-ball since he was about 6. The family is no stranger to athletics, she said. She's a two-time Class AAA Miss Basketball at Shelbyville Central High School, winning the award in 1994 and 1995, and was the Class AAA state tournament MVP in 1994. She went on to become a two-time All-SEC player at Auburn.

She started a fifth and sixth grade girls' basketball program in Shelbyville several years ago, and when Keon was about 6, he'd come to practice with her. From then on, he was rarely seen without a basketball in his hand. He'd line up with the girls, doing the same drills they were doing.

Keon excelled at both basketball and baseball in middle school and played travel baseball until his eighth-grade year. He stopped playing baseball when The Webb School didn't have enough players for a team. But he still loves the game of baseball and considers it his favorite sport.

Keon's basketball coach, Jeff Mitchell, said Keon is a "great kid and a good leader.

"He's tall and quick with a lot of ability. He's skilled on the court, but more than that, he's intelligent," Mitchell said. "What really impresses me is his social intelligence. He's a good reader of people and situations. There are a lot of players who are his size with his quickness and jumping ability, but what sets him apart is how he reads the game. When he's watching, he's studying what happens and thinking about what he'd do. He sees the game differently than most people. Basketball is more of a game of chess to someone like Keon," Mitchell said.

He embodies The Webb School honor code, "do nothing on the sly," his coach said. "You have to buy into that or you don't stay."

Keon often eats lunch with younger students, Mitchell said. "They all look up to him. He's their guy."

Keon said he's in a wait-and-see pattern for his future. He will decide in August about where he will play basketball. In May, he narrowed his choices to three: Virginia, Ohio State and Tennessee.

Mitchell just wants him to be happy.

"We want him to go somewhere where they care about him as a full person and not just a basketball person, where they care about him socially and want him to do well. He's a great young man who's not just interested in basketball."

Keon said his injury changed his perspective on life.

"It changed my life as soon as it happened," he said. "There's no question I put my life in jeopardy. I found out right after my accident there was another kid who had the same accident and passed away. This made me more humble. I don't know where I'd be without basketball, and especially my hand." hope



Vanderbilt's advancements in technology, screening and therapies for ocular conditions are helping children across Tennessee and beyond.

Six-year-old Jude Kee pulled out the book "Little and Big" from his backpack along with a note from his kindergarten teacher instructing him to read aloud to his family as homework. Much to the surprise of his parents, Amy and Lorin Kee, he began reading the book — without any help.

Learning to read words is a typical childhood milestone that often begins in kindergarten, starting with the sounds of letters then the recognition of sight words like "the" and "is."

But the Kees weren't always certain Jude, diagnosed at 18 months old with cancer in both eyes, would be able to read, or if he would have his eyesight.

> written by Jessica Pasley photograph by John Russell

"He prefers for us to read to him, so when he began to read, I called my husband, Lorin, into his room. We both looked at each other, smiling. We were absolutely astounded," Amy Kee said. "After that night, he started reading to us every night. We still sometimes read to him, and sometimes his brother Alex reads him "Harry Potter," but he can even read small chapter books now, like "Magic Tree House." His favorites are the superhero books, though."

For the Kees, the momentous occasion signaled far more than the basics of learning to read. Rather, it was another indication that the decision to embark on a novel therapy to save their son's eyesight was the right choice.

Because of the innovation and cross-discipline expertise offered at the Tennessee Lions Pediatric Eye Center at Monroe Carell Jr. Children's Hospital at Vanderbilt, the Kees see a bright future for their youngest child.

Vanderbilt's pediatric eye care team has the most training within 200 miles of Middle Tennessee and includes six doctors who are fellowship-trained in pediatric ophthalmology, three with specialized training in pediatric optometry, and five subspecialists with specific interest in pediatric eye disorders.

The highly specialized team provides care and surgery to treat children and teenagers who have a variety of vision disorders, including cataracts, crossed eyes or intraocular tumors.

"It is a wonderful opportunity to partner so closely with a major children's hospital and to have all of these subspecialists under one roof," said Sean Donahue, MD, PhD, professor and chief of Pediatric Ophthalmology at Children's Hospital. "It gives parents such a great ability to have all of their care in one place."

Leaders in an emerging therapy

The Vanderbilt Eye Institute has been an innovator in vision care for more than 25 years, and Jude's case is one of the latest examples.

In 2014, Jude's pediatrician referred him to a specialist after his parents suspected a condition called amblyopia, or lazy eye. The day Jude was diagnosed with bilateral retinoblastoma, the most common form of ocular cancer in children, is a day forever imprinted in the Kees' minds. His right eye had four small tumors, they learned, while his left eye was completely consumed with tumors.

Traditional treatment would have involved systemic chemotherapy, external beam radiation and/or surgical removal of the affected eyes. In consultation with the pediatric eye team and pediatric oncology, the Kees opted to try an emerging therapeutic approach called intra-arterial chemotherapy or IAC.

Performed on an outpatient basis (with an overnight stay for observation), the chemotherapy is delivered directly to the tumor via an ophthalmic artery, using an endovascular catheter that is inserted into the groin and threaded to the eye under X-ray guidance. The treatment limits the adverse effects typically associated with systemic chemotherapy.

Vanderbilt is one of just a few centers in the country offering the novel therapy. Jude was the first patient at Children's Hospital to have the IAC procedure under the direction of Anthony Daniels, MD, assistant professor of Ophthalmology and Visual Sciences Cancer Biology, and Radiation Oncology at Vanderbilt Eye Institute. Daniels arrived at Vanderbilt in 2013.

Debra Friedman, MD, director of the Division of Pediatric

In 2014, Jude Kee, shown here with his mother, Amy Kee, and grandmother Ann Westerbeck, underwent therapy at Vanderbilt to treat retinoblastoma.



Anthony Daniels, MD, right, examines Jude Kee's eyes while Joshua Carlson, MD, watches the monitor.



Hematology/Oncology and associate professor of Pediatrics, who holds the E. Bronson Ingram Chair of Pediatric Oncology, works in concert with Daniels to offer IAC and other innovative therapies to treat retinoblastoma at Children's Hospital.

When Friedman joined the faculty at Children's in 2008, she started the retinoblastoma program but was limited on the kinds of treatments the hospital could provide. Prior to her arrival, patients diagnosed with the ocular disease were sometimes sent to other centers for treatment. As time passed, Friedman was able to expand the program, offering more therapy options for patients.

Over the past decade, the program has grown tremendously, said Friedman, who was one of the founding members of the retinoblastoma committee for the Children's Oncology Group (COG).

"In 11 years, we have gone from sending many of our patients to other centers to being able to offer the most advanced care right here," said Friedman. "We are the only program in the state providing the full gamut of therapies for retinoblastoma, including IAC. We have been able to build a

"Every patient here deserves the option for the very best care possible," she said. "In the past five years, we are able to offer every therapy to every child."

The treatment options include enucleation or removal of the eye, intravenous or systemic chemotherapy, IAC, intravitreal chemotherapy (given directly into the eye), laser therapy, thermotherapy or cryotherapy. Radiation therapy is also an option but is avoided whenever possible due to the short- and long-term side effects. Since starting the program at Children's Hospital, Friedman notes that no patients have required treatment with radiation therapy.

A patient might receive one, or a combination, of the available therapies. Treatment depends on if one or both eyes are affected, the tumor size, location and number of tumors.

With the introduction of the most cutting-edge therapies, the retinoblastoma team has been able to save eyes that in the past would have required removal and to radically change the way the disease is treated.

Since Daniels came to Vanderbilt in 2013, there has been a paradigm shift to using IAC and intravitreal chemotherapy as opposed to systemic chemotherapy, whenever possible. Over this time, nearly all eyes treated with IAC or intravitreal chemotherapy at Vanderbilt have been saved.

Upon arriving, Daniels' goal was to introduce the most advanced therapies for retinoblastoma treatment with the overarching goal of saving lives, eyes and eyesight. The hospital was an early adopter of the novel therapy.

"We were the first in the Southeast to offer IAC and intravitreal chemotherapy," said Daniels. "The single, greatest change has been going from telling parents that there is a like"We can now save almost all eyes of children with retinoblastoma. The key is now to save their vision as well. Most patients see well enough to read, to drive when they get older, to lead normal visual lives."

lihood that their child will need to have their eye removed, to telling most parents that we can save their child's eye and also their vision. It's a profound shift."

Daniels explains that with more innovative treatments, the retinoblastoma team is also seeing fewer hospitalizations, episodes of low blood counts and blood transfusions as well as less immune suppression in patients treated with IAC as compared to systemic chemotherapy. The effects on the patient have resulted in statistically significant outcomes. These findings from Vanderbilt have led to an international, multi-institutional, NIH-funded study, led by Friedman and Daniels, to compare outcomes in patients treated with IV chemotherapy versus IAC.

In the past, even when patients could be cured of their retinoblastoma, assessing visual acuity was not always a priority. But more emphasis has been placed on measuring vision in this patient population, the team stressed.

"We can now save almost all eyes of children with retinoblastoma. The key is now to save their vision as well," Daniels said. "Most patients see well enough to read, to drive when they get older, to lead normal visual lives. We emphasize visual rehabilitation after completing cancer treatment, and we see this as an integral part of therapy. That is where the whole team comes in. We have everyone under one roof, which allows us to treat the whole child."

Friedman and Daniels are joined by neuro-interventionalist Michael Froehler, MD, PhD, who inserts a tiny catheter into the patient's groin and threads it to the arterial branch leading to the tumor in the eye. He then injects the chemotherapy blend prescribed by Daniels and Friedman. The technique allows for a high concentration of chemotherapy to kill the tumor while limiting the toxic effects on the rest of the body — a typical consequence of systemic chemotherapy.

IAC prevents new retinoblastoma tumor development elsewhere in the eye by killing early cancer cells before they have a chance to grow. That was not the case with systemic chemotherapy, where new tumors would develop as physicians were battling to get the earlier tumors under control.

The endovascular approach, combining up to three different IAC drugs across one or both eyes of an affected child, allows patient-tailored personalized medicine to optimize the effect of the treatment.



An estimated 3 percent of Tennessee's 1.2 million children have some type of eye problem other than a need for glasses.

The Tennessee Lions Pediatric Eye Center, with the help of Lions Club members across the state of Tennessee, has an outreach program providing free vision screening to identify children with eye problems.

- The Lions Eye Center opened Aug. 23, 1997.
- The pediatric ophthalmology team sees patients as young as premature newborn babies and into young adulthood. Premature infants can have a condition called Retinopathy of Prematurity (ROP).
- Since 2004, the center has recorded 170,550 patient visits, averaging about 12,000 per year.
- The most common vision condition treated at the center is amblyopia, or lazy eye, which affects 3 percent of the pediatric population.
- The center's patients travel from across Tennessee's 95 counties, from 45 states and from countries abroad, including Haiti, Taiwan and European countries.

Today, Jude's vision is 20/20 in the right eye and his vision in the left eye improved from 20/250 before IAC to 20/80, with the help of patching for visual rehabilitation, a practice he has done since he was 2 years old.

"Most people don't even know what Jude has been through. They just know he wears glasses. Jude still doesn't know that he had cancer," said Kee. "We try not to make a big deal out of it.

"We regularly talk about how lucky we have been with the course of treatment we chose. We know things could have turned out totally different."

Changing the standard of pediatric eye care

The innovations that allowed for Vanderbilt to embark on IAC therapy hail back to 1995 when Donahue came to Vanderbilt University Medical Center. He began working on a new technology to detect what causes amblyopia, commonly known as lazy eye, and the leading cause of visual impairment in the United States for the pediatric population.

Amblyopia, which begins during infancy and early child-hood, is a vision development disorder in which an eye fails to achieve normal visual acuity, even with prescription eyeglasses or contact lenses. If left untreated, the brain becomes hard-wired and unable to improve vision. By adulthood, the condition is not treatable.

For Donahue, the Sam and Darthea Coleman Chair of Pediatric Ophthalmology, professor of Pediatrics and Neurology, that was not acceptable. It prompted him to look more closely at the screening practices of young children, which 25 years ago consisted of the traditional method of testing — covering one eye and reading an eye chart.

"The biggest problem with that method is that it took a long time to conduct the testing; most children like to peek, and most children can't read the eye chart until they are at least 4 or 5 years old.

"This disorder needs to be treated earlier than that because by the time a child reaches age 5, the likelihood of a successful treatment starts to drop," said Donahue. "The vision in too many children was being missed."

In the mid-1990s technological advancements produced a mechanism to detect amblyopia which changed the entire landscape, said Donahue.

With a tool in place, Donahue led the way in promoting the need to screen children at a younger age. Using trained members of the Tennessee Lions Eye Clubs, volunteers conducted screenings using hand-held cameras called Photo-Screeners. The black and white photographs were sent back to Vanderbilt for evaluation.

The responses were eye opening.

"We screened about 35,000 children through the Lions Club, which continues to this day. That screening program was used as a model for similar programs being started by Lions Clubs across the nation and worldwide, screening more than 2 million children across the globe," Donahue said.

These screening advances have led to the early detection of amblyopia and its risk factors, which include cataracts and high and asymmetric refractive errors.

"What started as a volunteer effort with the Lions Clubs has become widely accepted as a standard for pediatricians to screen for vision problems, and that is very exciting," said Donahue. hope

Family's personal story spurs passion to give back

achel White and her husband, Aaron, have always been drawn to ministry that empowers people to want to make a change.

In 2016, during a family trip to Haiti, they met a little boy who sparked their most recent quest.

Ferlando Azor White, 4, was living in an orphanage when he stole the hearts of the family.

"Ferlando had been diagnosed with retinoblastoma but he missed treatments because of the lack of resources. His right eye had to be removed," recounted Rachel White. "After spending the next few days with him, we felt like God was telling our family to see what we can do to help him."

Upon their return to Nashville, the

Whites met with Debra Friedman, MD, director of the Division of Pediatric Hematology/Oncology and who holds the E. Bronson Ingram Chair of Pediatric Oncology, to discuss the possibilities for treatment. In a matter of months, the Whites were appointed Ferlando's guardians, obtained a medical visa, began the process of adoption and brought him home.

Although his case was worse than they had imagined – the cancer had spread to his brain - the family did not give up. And neither did his medical team.

Ferlando initially responded to the treatment, but after five rounds of chemotherapy, he relapsed.

"I remember that Dr. Friedman thought she was looking at one of his original scans," said White. "Heartbroken, we moved into hospice care. It is amazing how much life you can pack in when life is limited. We were intentional and focused on the present moments.

"Because of limited resources, many countries have a higher percentage of patients who present with more advanced stages of retinoblastoma, when a cure is very difficult," said Friedman, associate professor of Pediatrics at Monroe Carell Jr. Children's Hospital at Vanderbilt. "We want to

had to act on that."

be a resource for these countries and help educate providers on how to recognize this earlier when it is curable."

Grateful for the care Ferlando received

"Ferlando loved to entertain people

and make them laugh. He had a huge heart,

a great spirit and he loved people really

well," she said. "He was taken by a disease

that could have been treated. We knew we

A few months after Ferlando died.

White met with Friedman. She wanted to

work on extending the physician's knowl-

edge and the hospital's expertise in

retinoblastoma treatment.

and to expand that access, the Whites decided to "make a gift to support the retinoblastoma program and Dr. Friedman's research that will serve children in Nashville and well beyond."

In collaboration with Friedman, the Whites are committed to establishing Children's Hospital as support for physicians seeking to learn best practices in the recognition and treatment of retinoblastoma. As a referral site. Friedman's team will serve as an educational and research

"It's an opportunity for Vanderbilt to extend their knowledge and walk alongside these medical professionals who are in the thick of trying to understand and treat this disease with limited supplies and technology," said Rachel White.

Through the family's support and other philanthropic gifts, Friedman's team will be able to use retinoblastoma research knowledge gained at Children's Hospital to make a difference in the lives of many children like Ferlando.

- by Jessica Pasley

Rachel and Aaron White were inspired by their son, Ferlando Azor White, who died from retinoblastoma, to help children in other countries battle the same disease.



Children's Hospital patient, Jonathan, is excited about the return of the first-floor train display, which was stored during construction.



Full Steam Ahead

Children's Hospital is gearing up to open the first of its new expansion floors.

written by Christina Echegaray photograph by John Russell

hen Monroe Carell Jr. Children's Hospital at Vanderbilt opened 15 years ago, there was a little-known fact about the facility's architectural design that made the current expansion possible.

Children's Hospital opened in 2004 as an eight-floor building, the first freestanding pediatric facility for Middle Tennessee. Almost as quickly as the doors opened, the space was filled, as foreseen by the hospital's namesake and planners. So, when the building was erected, it was designed to ultimately hold an additional four floors atop the existing structure.

In 2014, Children's Hospital set out to build the four expansion floors with support from the Growing to New Heights Campaign, a philanthropic initiative, to advance the size and scope of the hospital's specialized pediatric health programs.

In February, several significant milestones signaled the first phase of the expansion was nearing completion with the first two floors opening this year. Children's Hospital's grand staircase and full lobby reopened after being closed for about 14 months while construction crews added two more elevators to accommodate the increased number of patients and visitors. The two cranes hoisted alongside the building came down as the expansion exterior was complete. And the locomotive train housed on the first floor of the hospital, a favorite of children and adults, made a long-awaited return.

Coinciding with the grand staircase's return, Children's Hospital celebrated the legacy of the entire Carell family, including the memory of Monroe Carell Jr. and his wife, Ann Scott Carell. A balcony atop the staircase was named the Carell Family Balcony, recogniz-

ing the family's enduring commitment to the health and wellbeing of children and families across Tennessee and beyond.

"The newly dedicated Carell Family Balcony and the return of the grand staircase have been exciting signs that we are moving closer to the opening of our first two expansion floors this year," said Luke Gregory, Chief Executive Officer of Children's Hospital. "We look forward to providing comprehensive, quality care to even more children. We are forever grateful to the Carell family and the entire community for making this expansion a reality. We look forward to celebrating the expansion opening in the fall."

Adorning the walls of the Carell Family Balcony are two vibrant oil paintings — the first of the late Monroe Carell Jr. surrounded by a group of children, a picture created in 2003 by Ann Street; and the second newly added painting, of Ann Scott Carell with her dog, Juliette, on her lap, painted in 2018 by Michael Shane Neal.

"Mr. Carell's vision was truly the driving force behind this remarkable children's hospital," said John W. Brock III, MD, Surgeon-in-Chief, Director of the Division of Urology and Monroe Carell Jr. Professor. "The Carell family has been intimately involved with this hospital from the very beginning, starting with Ann and Monroe, and continuing on through their three daughters, Edie Carell Johnson, Julie Carell Stadler, Kathryn Carell Brown and their families. They are tremendously passionate about what their father and mother started. They are not only involved with funding, but they are involved with their hearts.

"I know Ann and Monroe are smiling down on us and this community as we move another step closer to opening the first two new floors of the expansion to provide care for even more children. The Carell Family Balcony is an incredible tribute to an extraordinary legacy of passion and commitment to the health of children," Brock said.

The grand staircase in the lobby of Monroe Carell Jr. Children's Hospital reopened after 14 months when two additional elevators were installed.



"The Carell Family Balcony is an incredible tribute to an extraordinary legacy of passion and commitment to the health of children."

When the first two floors open — the 10th and 11th — Children's Hospital will increase its total beds from 267 to 335. Patients will be moved onto the first expansion floor, dedicated to pediatric cardiac care, around the end of June, with the second floor for neonatal and pediatric intensive care set to open around the end of 2019.

Once completed, all four floors of new construction will add 160,000 square feet of additional space atop the hospital's existing structure, bringing Children's Hospital's total space to more than 1 million square feet.

"Our parents believed deeply that care should extend to the whole family. They were passionate about children, and they were passionate about excellence. My sisters, our families and I are incredibly grateful for the men and women who bring this place to life, translating our parents' passion into exceptional care for so many children and their families," said Julie Carell Stadler, CEO of Skyway Studios and Dance Network.

"The balcony and portraits alongside each other are a very fitting way to celebrate them and their commitment to a welcoming, healing place for children. On behalf of the Carell family, we know our parents would be thrilled to see the hospital's continued growth and the beautiful expansion we will celebrate this year, and we are honored to work alongside everyone at the hospital to carry on our parents' legacy." hope

Children's Hospital honored its namesake and family with a new balcony. (From left) William Johnson, Nicholas Brown, David H. Brown, Kathryn Carell Brown, Julie Carell Stadler, Edie Carell Johnson, David B. Johnson and Monroe Stadler.



hope pioneers 🔠

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.

In 1985, Elizabeth "Betsy" Triggs, MD, applied for a position with Green Hills Pediatrics. If accepted, she would become not only the first female pediatrician in the long-established practice, but also the first female pediatrician in private practice in west Nashville.

She had worked with Joseph Lentz, MD, one of the founding partners of the esteemed practice, during her fellowship and he offered her the job. The other three male partners needed a little convincing.

"The guys took a chance on me. They didn't know if anybody would want to see a woman doctor. I think they thought this is the future; moms are going to want to see some women doctors, and this might just work," Triggs recalls. "They were hesitant; they didn't know if I was going to stay working, because a lot of women (at the time) stopped working when they had children, and I was pregnant with my first child."

Thirty-four years later, Triggs, the senior partner at Green Hills Pediatrics, counts among her patient population the children of patients she saw when she started practicing.

"It's more than just the intellectual part; it's being part of the family, but also part of the community. I love that I know what's happening locally in business and in banking and in the schools. My partners and I end up knowing about all the different local schools. We might know who an outstanding math teacher is and also might know who the impossibly tough one is. We end up knowing a lot about the community, and all of that is important for the kids' health — behavioral, mental and physical."

Triggs earned her undergraduate degree from the University of North Carolina and her MD from the University of Mississippi School of Medicine. She did her pediatric residency and behavioral and developmental fellowship at Vanderbilt University Medical Center. Her ties to Nashville and to Vanderbilt are strong.

"Being in private practice, it is such a luxury to have a world-class children's hospital right down the street. It's just



amazing to know that we've got back-up and it helps me sleep at night. We have all these wonderful specialists, subspecialists and emergency room physicians at our disposal should we need them," Triggs said of Monroe Carell Jr. Children's Hospital at Vanderbilt.

Triggs is past president of the Cumberland Pediatric Foundation, a member of Tennessee Women in Medicine, the Tennessee American Academy of Pediatrics and the national American Academy of Pediatrics.

She and her husband, Austin, have two grown children. Her daughter, Elizabeth Triggs Tipton, and her husband live in

Nashville. Triggs counts spending time with her granddaughter, Louise, among her favorite pastimes.

"It is such a joy to watch my daughter be a great parent," she said.

She enjoys walking the Percy Warner Park trails and participates in a book club with Vanderbilt residents, faculty and private practice attending physicians. Her son, Andrew, is a pitcher for the Oakland Athletics, and she attends as many of his games as possible.

She gets as much enjoyment from her job now as she did when she first began. She has observed increasing stress and anxiety among parents and their children, but her approach to their care remains steadfast.

"I love to talk with kids at their visits, be it about Legos, Harry Potter, YouTube videos or sing Baby Shark with them," Triggs said. "I also love educating parents about the developmental stages all kids go through and let them know that they are universal. No child is a Terrible Two forever."

– by Kathy Whitney

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As a child in Western Pennsylvania, Chris Bonfield, MD, loved playing with Transformers and other toys that could be taken apart and reassembled. He liked tinkering with structures and science.

Foreshadowing his career in his high school yearbook, Bonfield wrote he'd be a neurosurgeon, although he's certain today that his younger self didn't fully understand what that meant.

In fact, neurosurgery isn't as clear cut as it seems. While some neurosurgeons treat brain tumors, epilepsy and hydrocephalus (water on the brain), others, like Bonfield, specialize in areas such as the bones of the skull and the spine.

Bonfield, director of Pediatric NeuroSpine and Neurosurgery Craniofacial Programs, treats about 200 pediatric cases and 80 adult cases a year and tackles craniofacial surgery, pediatric spinal deformity and scoliosis correction as well as complex spine reconstructions in adults.

Early in medical school, he realized he liked the science and surgery of the spine and brain, but the field is so rigorous that students are advised to explore other areas before committing. While on rotation in his fourth year at University of Pittsburgh School of Medicine, he reconfirmed his path.

"The layperson hearing 'neurosurgery' thinks you're slicing into brains all the time, and yes, we do that. When I'm on call I take brain tumors out of babies and do other things inside the brain — it just so happens that a lot of my interests are deformed bones and correcting those to help the brain grow and the spine function normally," said Bonfield.

Bonfield, who came to Vanderbilt in 2015, enjoys rounding on patients at Monroe Carell Jr. Children's Hospital at Vanderbilt because it is anyone's guess as to what the children will say.

There's also a fun element in being able to do follow-ups in clinic that don't involve shots, and where children get to give him high- and low- fives so he can observe their movements.

Pediatric patients also do well with recovery and often have positive outcomes, which may be seen less often in adults with some neurosurgery conditions, he notes.

"We have serious conditions that we can actually fix in children. They heal better so they can come back from brain tumors and bad head injuries, and a lot of them do well — not just OK. That goes missed by people — the chance to get some really incredible wins," he said.

If he's not at work in Children's Hospital, Bonfield is probably on a plane. Since his first trip abroad in college to Greece, he's traveled to more than 80 countries. He and his wife, Stefany, like to take weekend trips to explore new neighborhoods and flavors.

"Often, we don't have anything planned for when we get there. It's just a chance to explore and see something new," Bonfield said.

He also frequently travels to countries such as Tanzania and Peru, where people have little, if any, access to neurosurgery.

In 2013, Tanzania, a country that's twice the size of California and home to more than 50 million people, had four neurosurgeons, all located in the same hospital. The surgeons also lack resources and manpower to execute many basic neurosurgery procedures.



Bonfield has helped train general and orthopaedic surgeons to do routine neurosurgery procedures that can be lifesaving.

He has also established connections for other VUMC neurosurgeons. The chair of his department, Reid Thompson, MD, went with Bonfield on one trip and has gone back to lead a group on his own.

"It's having friendships with the local doctors and having colleagues overseas you're working with to teach and to learn from them. It's helping bring skills to more people, so they can improve the quality of life of their patients. We're trying to take what we're learning here and going global to educate others," said Bonfield.

– by Holly Fletcher

Pediatric infectious diseases specialist Ritu Banerjee, MD, PhD, is an only child of Indian immigrants — postdoctoral researchers who from their home on Long Island commuted to labs in New York City. Her father worked on cholesterol biosynthesis, while her mother focused on reproductive endocrinology.

The family had no relatives in the U.S., so staying in touch entailed some long voyages.

"One of the most impactful experiences I had as a child was going to India when I was 8, and seeing the poverty and the disparity in wealth, and I recall from that time wanting to



do something to aid public health," Banerjee said.

Having discovered interests in science and music early on, she grew up studying violin, and as a teenager worked summers in research labs. Banerjee initially planned to doublemajor, but instead focused on the biology curriculum at Swarthmore College in Pennsylvania, playing in orchestras and chamber groups on the side.

At Washington University in St. Louis, she completed the MD-PhD Medical Scientist Training Program, focusing her dissertation on malaria-causing microparasites and how they survive in the red blood cells of human hosts.

"At the end of my PhD, I went back to do some of my clinical rotations to finish out the MD, and I realized I really like spending time with patients. Having been in the lab for several years working on a single gene, I just said to myself, 'For future research questions I really need to do something more translational, something that bridges discovery in the lab to actual care of patients."

Banerjee's research has since tended toward clinical epidemiology, antimicrobial stewardship and implementation of rapid diagnostics for infectious diseases. After residency and a fellowship at the University of California San Francisco and seven years on the faculty at Mayo Clinic in Rochester, Minnesota, she joined Vanderbilt in 2016, becoming associate professor of Pediatrics, director of the Pediatric Infectious Diseases Fellowship Program and director of the pediatric arm of the Vanderbilt Antimicrobial Stewardship Program (VASP).

The World Health Organization and the Centers for Disease Control and Prevention (CDC) have deemed antibiotic/antimicrobial resistance a major public health threat. Antibiotic resistance is a consequence of the use of antibiotics in health care and agriculture. Rampant misuse is dangerously worsening the problem, with prescribing practices continuing to vary wildly across the world and across the United States. Tennessee's antibiotic prescribing rate is among the nation's highest. The CDC's latest summary estimates show that in 2013 there were 23,000 deaths in the U.S. due to antibiotic and antifungal resistance.

"We're increasingly faced with extremely drug-resistant pathogens, the superbugs that we hear about in the news. You have to treat them with combinations of drugs that are less effective and more toxic than our standard therapy, so outcomes are worse and health care costs are higher," Banerjee said.

"Drug-resistant bacteria are emerging and spreading faster than we're developing new drugs to treat them. We are running out of effective antibiotics to treat some of these strains, so it's really important as clinicians that we use our existing antibiotics judiciously and responsibly," she added.

Under VASP, inpatient use of antimicrobial drugs at Monroe Carell Jr. Children's Hospital at Vanderbilt has decreased 51 percent since 2012. Inpatient orders for certain broad-spectrum antimicrobials require sign-off by an infectious diseases

specialist. Teaming with infectious diseases pharmacist Jessica Gillon, PharmD, Banerjee practices "handshake stewardship," meeting with health care teams across the hospital to discuss individual cases. Assisting the program at Children's Hospital is Infectious Diseases Clinical Fellow Sophie Katz, MD, who will soon join the faculty. Banerjee and Katz are working with the Cumberland Pediatric Association on a program to advance antimicrobial stewardship at pediatric clinics across the region.

Banerjee and her husband met as grad students working in the same lab at Washington University. Andrew Kloek, PhD, works for a health care consulting firm. They have two daughters, Kareena, 11, and Anisa, 13.

– by Paul Govern

Kate Copeland, RN, MSN, hails from a family of teachers, and other than a stint as a candy striper as a teen growing up in East Tennessee, nursing wasn't top-of-mind as a career choice.

When she was offered an academic scholarship to pursue a nursing career at Tennessee Technology University, she took a chance — and fell in love. Nearly four decades later, nursing, for Copeland, has become more a passion than a job, focusing to ensure children have access to compassionate, quality care.

"I found I loved taking care of patients. It didn't matter which clinical rotations I did, I loved it all — adults and children," said Copeland, administrative director of Emergency Services for Monroe Carell Jr. Children's Hospital at Vanderbilt.

She was drawn to the neonatal intensive care unit and believed she would be caring for the youngest, sickest patients. When she graduated with a Bachelor of Science in Nursing, she began working with adult patients, hoping to eventually move toward a job in pediatric nursing.

In 1991, after several nursing jobs working with adults, Copeland decided to relocate to Nashville, where she was born. Upon learning the city had a children's hospital — then located within Vanderbilt University Adult Hospital — she applied for the opening and got the job, first as a staff nurse and then as a charge nurse. At that time, the pediatric units at Vanderbilt, designated to three floors, had a varied case mix, with children needing chemotherapy to those having respiratory illness.

"I knew this was where I needed to be," Copeland recalls about starting out. "I love taking care of all children. There wasn't one area I liked more than another, and I enjoyed the versatility of all the patient cases. We took care of all pediatric illnesses on the floor."

After 10 years of caring for some of the sickest children, Copeland was ready to explore a different area of pediatric health care, joining the pediatric Emergency Department (ED) in 2001— about three years before the freestanding Monroe Carell Jr. Children's Hospital at Vanderbilt opened.

She admits the fast pace and variety of illnesses and in-



juries of the emergency department caught her by surprise at first, and she questioned her abilities.

"There was so much I didn't know. Soon, I became comfortable. I loved the team work and the different sets of dynamics," she said. "You see people in their most stressful time of life as a child and parent and you get to intervene to help them. You get sad cases, but you see patients you get to help, with broken arms or other illness, injuries and they get to go home. There is a quick pace, but you can make a difference."

Copeland worked her way up to a charge nurse position in the ED, and onto an assistant manager, then manager before moving into her current role as administrative director. Her focus is always on the patients and the families.

"Patient experience is something I am very passionate about. Quality and access are very important," she said. "We offer the very best pediatric care here at Monroe Carell Jr. Children's Hospital, without a doubt, and I want to ensure every child has access to that care — not only for emergency services but across all our specialties."

When Copeland is not at work, she enjoys cheering on the Nashville Predators hockey team and visiting her daughter, Jessica Spencer, and son-in-law, Richard, in Austin, Texas. One of her proudest moments was the arrival of her new grandson, CJ, who was born in February.

- by Christina Echegaray

GIVING hope



Kitty Murfree, center, attends the launch event for the Vanderbilt Children's Surgery and Clinics in Murfreesboro with Children's Hospital leadership and patients, Rutherford County Chamber of Commerce officials and community members.

Care closer to home

upport from the community has enabled Monroe Carell Jr. Children's Hospital at Vanderbilt to expand the hospital's pediatric specialty services into Rutherford County with a new 37,500-square-foot facility — Vanderbilt Children's Surgery and Clinics which is slated to open in the coming year.

Featuring 22 multispecialty clinic rooms, after-hours services, operating rooms, imaging capabilities and audiology booths, this addition in Murfreesboro will further Children's Hospital's mission to make expert, compassionate care available to all children.

"Many of the children and families who seek our specialty care and outpatient surgical care at Children's Hospital live in Rutherford and surrounding

counties," said John W. Brock III, MD, senior vice president of Pediatric Surgical Services, surgeon-in-chief, director of the Division of Pediatric Urology and Monroe Carell Jr. Professor. "This new facility will allow families in this fast-growing area to receive the same level of care that has made Children's Hospital the only children's hospital in the state to be ranked in 10 out of 10 pediatric specialties by U.S. News & World Report."

The Christy-Houston Foundation helped make this project possible by providing a \$500,000 grant for construction.

"The opportunity to collaborate with Children's Hospital to locate access close to home in Rutherford County to nationally ranked pediatric specialty care creates a positive addition to the local health care landscape," said Anne

Davis, CFRE, president of The Christy-Houston Foundation. "This addition supports our mission to improve the quality of life for Rutherford County residents, with special emphasis on our youngest residents."

Kitty Murfree, a Murfreesboro civic leader, philanthropist and longtime supporter of Vanderbilt University Medical Center, also pledged a cornerstone gift to help fund the project.

"Monroe Carell Jr. Children's Hospital at Vanderbilt has had a very special place in my heart since I was 26 years old," said Murfree, "I am so excited that the world-class services of Children's Hospital will now be available in our community of Murfreesboro. This new facility will ease the burden for families, reducing the amount of time sick and injured children have to spend in the car on the way to and from appointments."

- by Paige Turner



Making an impact on cancer care

Monroe Carell Jr. Children's Hospital at Vanderbilt launched A Campaign Against Childhood Cancer to support research, training and programs, as well as expand and upgrade space for cancer treatment. With the first two of four new floors of Children's Hospital opening this fall, renovations will be able to begin on the oncology inpatient unit and outpatient clinic.

Community philanthropy has made it possible for Children's Hospital to provide personalized cancer care and improve outcomes for an even greater number of patients. Kevin Fee, co-founder and managing director of Castlerock Asset Management, and his family are among those supporters.

While the Fee family lives in Montauk, New York, Kevin spends a great deal of time in Nashville operating The Westin Nashville and Bobby Hotel. After relocating Castlerock's headquarters to downtown Nashville a few years ago, Kevin wanted to give back to the community that has given so much to him. The Fees committed to a gift in capital support to improve access and patient care for children with cancer and their families.

"I wanted to give back in a way that is meaningful to me and my family," Kevin explained. "Hospitals, children's hospitals in particular, are so important and touch everyone's lives in one way or another. It's not something a lot of people



Kevin Fee (right) with his wife, Kathleen, and their four sons. The Fees, proud supporters of Monroe Carell Jr. Children's Hospital at Vanderbilt, are committed to fighting pediatric cancer and serving the Nashville area.

think about every day until they're in need of excellent care."

Kevin also gives his time, serving on the Children's Hospital advisory board because he was impressed with its innovative, top-notch care and wanted to have a greater impact.

"The work they're doing at Children's Hospital is really impressive, and it touches your heart in ways that other places can't," Kevin said. "That's why we're so proud to be part of this community and the Children's Hospital journey."

- by Erin De May

Walk of Champions

Award-winning vocal group Rascal Flatts, longtime supporters of Monroe Carell Jr. Children's Hospital at Vanderbilt, received a star on the hospital's Walk of Champions, presented by Live Nation, on March 28.

Located on the main floor of the hospital, the Walk of Champions honors lifelong advocates in the entertainment industry. For over a decade, Rascal Flatts have donated their time and resources to Children's Hospital, raising millions of dollars and spending countless hours visiting patients. Center Stage Gala capped off the evening to celebrate the group and raise money for A Campaign Against Childhood Cancer at Children's Hospital.



From left, the trio — Jay DeMarcus, Gary LeVox and Joe Don Rooney – pose alongside their new star with patients Caroline Lantz and Jessica Meyer.

DISCOVERING hope

In utero antibiotics and obesity risk

Identifying risk factors for childhood obesity is necessary for developing prevention strategies. Previous studies of a potential association between antibiotic use during pregnancy and childhood obesity have had conflicting results.

William Heerman, MD, MPH and colleagues in the National Patient Centered Clinical Research Network (PCORnet) conducted a large retrospective cohort analysis to evaluate the possible association between antibiotic use during pregnancy and childhood obesity. PCORnet is a nationwide research network that enables multi-institutional research.

The investigators used electronic health records from seven health care institutions to study 53,320 mother-child pairs. They found that maternal antibiotic use during pregnancy was not associated with childhood obesity at age 5. They evaluated antibiotic exposure by trimester, total exposure and antibiotic type. The large number of mother-child pairs also facilitated study of sub-populations, such as children with complex health conditions.

Reporting in the *International Journal of Obesity*, the authors concluded that the long-term risk of childhood obesity from maternal antibiotic use during pregnancy appears to be negligible.

This research was supported through the Patient-Centered Outcomes Research Institute (PCORI) Program Award.

– by Leigh MacMillan

Cardiac dysfunction in DMD

Duchenne muscular dystrophy (DMD) is a severe muscle disease that causes progressive muscle weakening and degeneration.

Cardiomyopathy is the leading cause of death in DMD, but standard markers of heart failure are poor indicators of disease. Determining factors involved in DMD cardiomyopathy could identify novel biomarkers to follow disease progression and as targets for drug therapy.

DMD cardiomyopathy appears to result from progressive myocardial fibrosis, or scar formation. Jonathan Soslow, MD, MSCI, and colleagues explored a role for proteins called MMPs and TIMPs that regulate the extracellular matrix — the connective tissue between cells.

They found elevated blood levels of three MMPs in patients with DMD compared to controls. One of these, MMP7, was higher in DMD patients with cardiac dysfunction as determined by cardiac MRI.

The findings, reported in the *Journal of Cardiac Failure*, suggest a role for MMP7 in DMD myocardial fibrosis and support

further study of MMP7 as a potential biomarker of cardiovascular disease severity.

This research was supported by the National Institutes of Health (grants HL123938, HL141248, TR002243), the Fighting Duchenne Foundation and the Fight DMD/Jonah and Emory Discovery Grant.

– by Leigh MacMillan

Long-term unemployment linked to increase in babies born with NAS

Babies born after being exposed to opioids before birth are more likely to be delivered in regions of the U.S. with high rates of long-term unemployment and lower levels of mental health services, according to a study from researchers at Vanderbilt University Medical Center and the RAND Corporation.

Studying more than 6.3 million births in a diverse group of eight states, the study found that rural counties plagued by long-term unemployment had significantly higher rates of babies born with neonatal abstinence syndrome as compared to urban counties with lower unemployment rates.

Counties with shortages of mental health providers also had higher levels of neonatal abstinence syndrome as compared to other counties. The association was observed primarily in urban areas.

The study, published in the *Journal of the American Medical Association*, is the first to examine the association between long-term economic conditions, health care provider shortage areas and the incidence of neonatal abstinence syndrome, which can occur when babies are chronically exposed to opioids before birth.

Stephen Patrick, MD, MPH, MS, director of the Vanderbilt Center for Child Health Policy and lead author of the paper, and his colleagues have shown previously that one consequence of the nation's opioid epidemic has been a sharp increase in the number of newborns who show signs of withdrawal from opioids. In 2014, the average was one infant born every 15 minutes in the U.S. with neonatal abstinence syndrome.

Researchers from Vanderbilt and RAND analyzed information about 6.3 million births from 2009 through 2015 in the 580 counties in Florida, Kentucky, Massachusetts, Michigan, North Carolina, New York, Tennessee and Washington. Those cases were compared to the 10-year unemployment rate for each of the counties, as well as factors about health care workforce levels.

Counties with persistently elevated levels of unemployment had higher rates of neonatal abstinence syndrome, with 20.1 cases per 1,000 births, compared to 7.8 cases per 1,000 births in the counties with the lowest unemployment rates.

- by Holly Fletcher





From College Freshman to Cancer Fighter

Right before he was to begin college, Will Mason was diagnosed with Ewing sarcoma. Since treatment, he visits with homemade cookies to thank his care team and has been able to return to college. Help us care for more children, adolescents and young adults with cancer by supporting Monroe Carell Jr. Children's Hospital at Vanderbilt.

Help now: ChildrensHospitalVanderbilt.org/soaringhigher



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







Vanderbilt Children's After-Hours Clinics

Bad cough. Sore throat. Thursday night. When you need a pediatrician and your pediatrician's office is closed, bring your child to one of six Vanderbilt Children's After-Hours Clinic locations, open nights and weekends in Spring Hill, Mt. Juliet, Hendersonville, Murfreesboro, Brentwood and Smyrna. For more information, visit VanderbiltChildrensAfterHours.com.