The Faces *of* Wolfson

HONORING THE JOURNEY

Wolfson Children's Hospital is a sanctuary of hope and healing for children battling various health challenges. These children come to Wolfson Children's for diverse reasons - from premature babies defying the odds, to brave warriors battling cancer, and those wrestling with rare genetic disorders. Yet, despite the differences in their diagnoses and backgrounds, these remarkable children share a common theme that binds them together: joy. A joy that persists amidst the uncertainty and pain, a joy that transcends the hospital walls, touching the lives of those around them, and a joy that is inseparable from the deep sense of gratitude they hold for Wolfson Children's Hospital.

Here we explore their inspirational journeys, highlighting their courage and the unwavering dedication of the hospital staff, making it possible to celebrate the triumphs achieved in the face of adversity at Wolfson Children's. It is a testament to the indomitable spirit of these young patients and the boundless compassion of those who stand beside them, that we can truly celebrate the triumphs achieved in the face of adversity.

Harris Lott

"HARRIS IS A FIRECRACKER."

Thanks to the oncology team at Wolfson Children's Hospital, Harris Lott is a well-adjusted 11 year-old boy who enjoys fifth grade at Riverside Presbyterian Day School. "Harris is a firecracker," said his mother, Dr. Mary Elizabeth Lott, a pediatrician with Jacksonville Pediatrics. "He does well in school, is social, plays tennis. Most people who don't know his history would never guess that he had a problem."

But he did have a physical problem, and it was serious. Harris was only two years old when he was diagnosed with rhabdomyosarcoma, a rare form of cancer in his pelvis that was thought to come from the hip muscle. When it was discovered, the cancer was in an intermediate stage, and little Harris was given only a 60% to 70% survival rate.

However, after 18 months of in-patient chemotherapy at Wolfson Children's and Nemours Children's Health, oral chemotherapy, and 33 proton beam radiation treatments at UF Health Proton Therapy Institute, Harris's tumor eventually disappeared. He rang the bell at the proton institute in November 2015 and finished all chemo treatments by September 2016.

"During his entire third year of life, he was being treated," said his mother, noting that he handled the tough treatments well. After chemo came five years of surveillance MRIs, where Harris was sedated. Over the years these became less frequent. They were all negative, and the little boy was declared "cured" in September 2021.

"A lot of people whose kids get cancer automatically think of going to St. Jude (Children's Research Hospital)," said Mary Elizabeth. "We didn't think we needed to. We thought Wolfson would take proper care of our child, and that is exactly what happened," she said. During his treatment, the Lott family drove from Waycross, Georgia, to Jacksonville two or three times each week.

"Harris got such *great care* at Wolfson, we decided to move to Jacksonville so we could be close to the hospital if there were long-term effects from the treatment."

From the moment Harris was diagnosed until when he had his most recent annual check-up, the Lott family has been impressed with Wolfson. They especially credit pediatric urologist Dr. Mark Barraza, and Harris's pediatric oncology team, Dr. Manisha Bansal, Dr. Allison Bechtel, and Dr. Eric Sandler, and the nurses and staff who made Harris and his beloved stuffed toy Lambie so comfortable.

"They had a plan, and they started helping us right away," Mary Elizabeth continued. "While we were in a state of shock, the whole hospital - all the people who were meant to take care of us - pulled together right away. They were so calm and reassuring that it made me feel at peace even though I was scared to death."

"We felt very confident from the beginning that Wolfson would provide our child with exceptional medical care, and it ended up being the best medical care we could get."

THANK YOU RUSSELL + SHARON HUGHES, BRITTEN HUGHES SHEA + JAY SHEA *and* **JACKSONVILLE PEDIATRICS** *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Marcia Hodgson

Annmarie Ivey

THE FIRST ECMO PATIENT AT WOLFSON CHILDREN'S HOSPITAL

Annmarie Ivey, now 21 and healthy, is alive today because of Wolfson Children's Hospital along with the support and generosity of The Women's Board and other caring benefactors.

In 2007 when she was 4, then Annmarie Zappola, later adopted by the Ivey family, became the first ECMO patient at Wolfson. Through extracorporeal membrane oxygenation (ECMO), blood is pumped outside the body to a machine that removes carbon dioxide and sends oxygen-filled blood back to body tissues, bypassing the heart and lungs and allowing them to rest and heal.

The Women's Board raised funds toward that first machine and is now raising $1.5 million to help purchase two new Kids Kare Mobile ICUs that will have ECMO capabilities.

Denise Talarico, Annmarie's then foster mother, took her to an emergency room near their home in Ormond Beach because she felt her heart pounding when she hugged her. From there, Annmarie was transported by ambulance the approximately 85 miles to Jacksonville.

Annmarie had strep pneumonia and her enlarged lungs were pushing on her heart.

"We had exhausted all conventional therapy and she was essentially about to die until we put her on ECMO," said Dr. Nick Poulos, then ECMO director at Wolfson. "She is a miracle child."

Poulos, now chief of the Pediatric Surgery Division of AdventHealth Tampa, said a main reason he came to Wolfson in 2004 was to start an ECMO program. Back then, Wolfson was transporting more than 10 patients a year to other hospitals for ECMO. The Women's Board also helped finance sending Wolfson specialists to Children's Hospital of Los Angeles for ECMO training. Including studies to prove need, it was a two-year project. First in Jacksonville, Wolfson Children's was the 105th ECMO program in the U.S. altogether, not just at children's hospitals, he said. Now there are more than 600.

"The initial group of ECMO pioneers at Wolfson worked hard and long to develop the intellectual, programmatic and operational capital so essential for a safe and effective program," said Dr. Mark Hudak, neonatologist and chair, Department of Pediatrics, UF College of Medicine-Jacksonville. He said acquiring ECMO was a major factor in Wolfson becoming a true national class children's hospital.

Poulos said that before he left Wolfson in 2021, they transported two patients while they were on ECMO.

"It's huge that they are going to have dedicated ambulances with proper electricity and oxygen for the ECMO machine. It's very complicated. We set it up ourselves to make it portable. We had to run on batteries the whole way; a lot of things were lacking," Poulos said. "Had it not been for The Women's Board stepping up and helping us financially and emotionally, our ECMO program would never have happened."

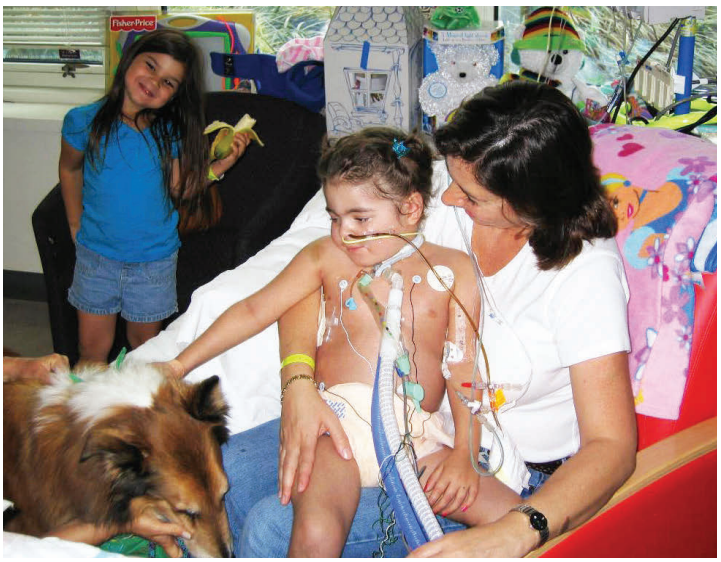
The Women's Board and additional philanthropic contributions funded the original four pumps. "Then 10 years later when we needed to upgrade our pumps, they bought us new ones," Poulos said.

"Without the support of The Women's Board, my team would not be where they are now," said Keith Nordike, manager of Wolfson's Kids Kare Transport Team. "They are a critical resource for us to take care of patients." The ambulances should be available by early 2025.

Mandy York, ECMO co-coordinator, said discussions to raise money for apparatus to secure the ECMO more safely during transport began in fall 2022 following a turbulent air transport. York recalls taking care of Annmarie when she was Wolfson's first ECMO patient. "It was all very up and coming and new to our facility, and she was extremely sick," she said.

Annmarie, however, remembers little of her three-month ordeal except how nice the nurses were to her. "I remember feeling very supported," said the Lake Mary resident who attends Seminole State College. "I spent my fifth birthday in the hospital and the nurses threw a little party for me. They gave me my first pair of pink Crocs. I still have them."

THANK YOU CLARENCE, CORKIE + SARA GOODEN *for* **SPONSORING THIS PATIENT PROFILE**
Written *by* Lorrie DeFrank



Striver Filson

"YOU AMAZE ME EVERY SINGLE DAY."

Sometimes Wolfson Children's Hospital is the place where a baby's congenital heart defect is repaired or where a Kids Kare Mobile ICU rushes with a child transported from a distant ER. For Striver Filson, now almost six, Wolfson Children's is a place where Striver and his family found help and the direction they urgently needed.

The shock and devastation from news that Megan and John, Striver's parents, received in September 2017 about their unborn baby was beyond anything they had ever experienced. Striver would be born with a single ventricle heart defect called a Double-Inlet Left Ventricle with Transposition of the Great Arteries. A healthy heart with two ventricles pumping blood throughout his body was something Striver would never have. But a series of three complex open heart surgeries, if all went well, could give him an "almost-normal life." John and Megan were living in Los Angeles at the time and found an excellent heart surgeon at LA Children's Hospital (CHLA).

At age 3 1/2, Striver had his third surgery at CHLA. The Fontan Procedure helped re-route oxygen-poor blood directly to his lungs. According to Megan, open heart surgery is horrific. But something also happened after the surgery that put Striver in a state of terror. His lung collapsed which required an emergency re-intubation procedure. The trauma of the event became stored in Striver's body memory. He began responding differently to things that used to be routine, such as a his bath or being approached by a dog, which now triggered intense fear and panic attacks. He was gripped by a generalized anxiety that made him seem like a different child.

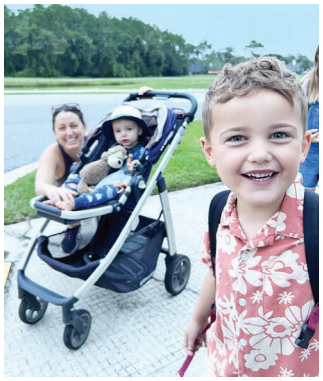
Single ventricle heart defects are known to be correlated with unique neuro-development. Striver was first diagnosed with high-functioning Autism Spectrum Disorder in December 2020.

By November 2021, the Filsons had moved to Jacksonville and Striver's needs were compounding. His family was navigating a new system in Florida and looking for services to help Striver with the challenges he was facing. Dr. Randy Thornton, Striver's pediatrician, referred him to Wolfson Children's/Nemours Health for further evaluation. Team neuropsychological evaluations provided new direction and referrals for therapies in Applied Behavior Analysis (ABA) and trauma-focused Cognitive Behavioral Therapy (CBT) all designed to help Striver learn effective coping mechanisms. Striver attended full-time ABA therapy for a year, and he continues his bi-weekly CBT at Nemours.

The good news? Striver started kindergarten this fall, right on schedule, and he has been *thriving!*

THANK YOU SUN FAMILY *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Karen Read Wolfson



JANUARY 2023, STRIVER'S 5TH BIRTHDAY

Megan, Striver's Mother, Shared These Feelings

Five years ago, we met face to face. You amaze me every single day. You are brilliant, hilarious, empathetic and brave. The journey we have been on thus far has opened me, broken me, and rebuilt me in ways I couldn't have fathomed. I love you so much; it takes my breath away daily.

Ava-Loren and Eliza-Noel Singletary

FROM PATIENT TO PARENT: THE JOURNEY OF WARRIORS

Vanessa Baffour-Singletary is no stranger to Wolfson Children's Hospital. Her family moved to Jacksonville from London specifically to take advantage of the excellent care it provided when she was diagnosed with sickle cell disease.

She has been even more grateful for her adopted hometown since having children, who all needed Wolfson Children's state-of-the art Neonatal Intensive Care Unit (NICU). Daughter Lilah Rae, born September 11, 2021, required only a brief stay.

Then last year, Vanessa and husband Denver Singletary learned they were expecting twins. "When you have sickle cell, that is already considered a high-risk pregnancy. When you add twins, it's very high risk," Vanessa said.

Just 31 weeks into her pregnancy, Vanessa developed preeclampsia, a condition that can be fatal to mother and baby."The only cure is to get the baby out," she said.

Ava-Loren and Eliza-Noel came into the world March 17, 2023, weighing just over 3 pounds each. But Vanessa herself was so critically ill, she needed immediate care, and the babies were whisked away to the NICU.

Denver found himself popping back and forth between the adult and NICU hospital units to check on his wife and the newborns. "I felt like I had failed them," Vanessa recalled. "The nurses just assured me and reassured him that my babies were good in their care."

Both babies had feeding tubes as well as lights to remedy jaundice. Eliza needed a CPAP (continuous positive airway pressure) machine to support her tiny lungs. Then Eliza was diagnosed with Necrotizing Enterocolitis, a potentially fatal inflammation of the intestines. "She was fighting for her life," Vanessa said. It was a fight she won, and she went home at a month old, weighing 4 pounds.

Meanwhile, sister Ava also faced a life-threatening condition: Bradycardia or Bradys, which can halt breathing or drop the heart rate to a critical low. Ava remained hospitalized another 15 days.

While it was a difficult time, Vanessa said they loved the spacious, bright NICU, noting proudly that Denver and his brother work for Miller Electric, the lighting and electrical contractor for the Borowy Family Children's Critical Care Tower, opened in 2022.

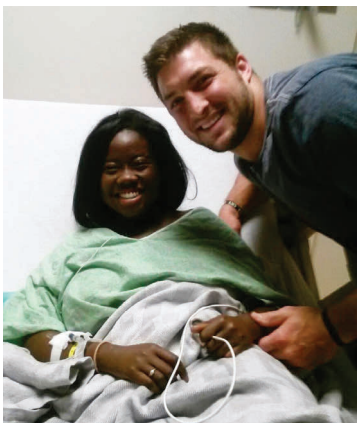
Vanessa also praised Wolfson Children's for the excellent training she and Denver received before taking their girls home.

> **" I'm *grateful* for the time they put into teaching me how to feed my preemies, how to bathe them, and how to swaddle them, which was very important because they were still supposed to be in the womb."**

Vanessa proudly shared that by late August, Eliza weighed 16 pounds and Ava 13 pounds. "They're catching up," she said.

THANK YOU NORTH FLORIDA CORVETTE ASSOCIATION *for* SPONSORING THIS PATIENT PROFILE

Written *by* Julie Howard



Vanessa's connection to Wolfson Children's Hospital runs deep as she herself was once a patient there. She and her family relocated from London to Jacksonville to access the exceptional care the hospital offered when Vanessa was diagnosed with sickle cell disease. Her appreciation for her adopted hometown grew even stronger when not only did her own children need the hospital's state-of-the-art NICU, but Vanessa's own health was in such a critical condition that she required immediate medical attention.


BOBABY

Blair "Bear" Okesson

KIDS KARE HELICOPTER WHISKS BEAR TO WOLFSON CHILDREN'S

Blair, born on November 20, 2020, arrived during the thick of the Covid pandemic. His mother, Christina, had previously faced high-risk pregnancies due to a blood-clotting disorder and gestational diabetes, but despite these challenges Blair was a healthy baby. Due to her history, her doctors advised induction at 37 weeks.

The induction began with no issues, but later the nurse became concerned with the monitor readings and administered terbutaline to slow down labor. The situation worsened and at 5 cm dilation, Christina requested an epidural due to the intense pain. As the nurses attempted to break her water, the baby's condition deteriorated. The doctor ordered an amnioinfusion to relieve pressure, but there was no improvement.

A shift change brought a new nurse, who administered Pitocin. Excruciating pain followed, which led to a dose of epidural anesthesia that only took the edge off. Soon the room was filled with doctors and nurses as the baby's condition became dire.

Christina was rushed to the operating room and placed under anesthesia. Blair was born without a heartbeat and not breathing, requiring 13 minutes of CPR. He was immediately intubated awaiting transport to Wolfson Children's Hospital. Mom and baby had only a moment to meet before Blair was whisked away in Wolfson's Kids Kare helicopter.

In the neonatal intensive care unit, Blair was placed under constant monitoring for seizures and administered cooling therapy. It took 48 days and gastrostomy tube (G-tube) surgery for Blair to finally go home. At five months old, he needed a tracheostomy for a better quality of life, which was an emotionally difficult decision for the family. The surgical team at Wolfson, led by Dr. Angela Black, reassured them it was the best choice and provided exceptional care.

Blair spent 19 days in the pediatric intensive care unit where nurses taught the family how to care for him. Aside from his trach and G-tube, Blair also has HIE, cerebral palsy, and severe developmental delay.

Over time, Blair's health has improved significantly, and he no longer needs oxygen assistance. Currently, he receives physical, occupational, feeding, and speech therapy to aid in his development. Blair, who is affectionately known as "Bear," loves playing in water, cartoons, and spending time with his big sister, Mason. He enjoys playing with his father, Robert, and cuddling with his mother. Blair was recognized as a 2023 Wolfson 55 Warrior, nominated by his NICU nurse, Brittany Leitner, who went above and beyond for their family.

THANK YOU WOLFSON FAMILY FOUNDATION *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Candy Keane

Ali Colteryahn

"AND THEY KNOW THAT GOD IS WITH THEM."

For Ali, hooray. It's February 1, 2023. Early release from school. A few hours visiting with friends. Start up the golf cart to head home through her Nocatee neighborhood. Then—nothing. Blank. Michele Colteryahn, home from her job at Palm Valley Academy, pours a cup of coffee. Her phone rings. It's Ali's number, but on the line is some stranger saying, "Come now." There's screaming in the background.

Michele pulls up to the intersection near the Nocatee pool and park. A knot of people part to let her through. The golf cart is toppled, hit by a car. Her only daughter, 14, lies twelve feet away, unresponsive.

Fire truck and ambulance arrive. Ali is airlifted to Wolfson Children's Hospital, the only hope. At the Porter Family Children's Trauma Center, there's another knot of strangers, but these converge, arms around Michele and her husband, James. "I'm your social worker. This is your Chaplain. We're here for you. This is Dr. Philipp Aldana. He'll take care of Ali."

"Dr. Aldana, just tell me she'll be all right. Please."

"We can't guarantee that. But we will do everything we can for her."

A receptionist places comforting hands on Michele's back and James's shoulder and offers a prayer, and they know that God is with them.

Dr. Aldana, chief of Pediatric Neurosurgery, shows them images of the broken sections of Ali's skull. A brain bleed. Pressure building. Six hours of surgery. "It went well, the way we had hoped."

"But will Ali be all right?"

"We can't tell you that right now. We'll do everything we can for her."

For another 24 hours, Ali lies unresponsive. Then, a movement. Eyes open, but vacant. Finally awake, Ali turns violent, tearing at her ventilator and IV. Five nurses try to restrain her, but her brain's impulse center has been damaged. The yelling, rage, and thrashing lasts for days.

After eight days in Wolfson, Ali is transferred to Brooks Rehabilitation inpatient for another eight days. The Brooks team guides them through cognitive and physical therapy, then a 20 day outpatient program. Brooks coordinator Deb Davis connects them with the Hospital/Homebound School Program.

Incredibly, Ali enters 9th grade at Ponte Vedra High School, right on schedule. She's running with the Cross Country Team and resumes dance classes August 14.

Michele Colteryahn says, "I cannot tell you how much I love these people. Dr. Aldana, Alyssa Tamasi, and the entire staff were amazing. They knew exactly what to do, and when. What to say, and how to say it."

THANK YOU BROOKS REHABILITATION *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Carol Grimes

Jacob Clark

"WE KNOW THEY ARE GUIDED BY GOD."

Jacob Clark is 16 years old, plays drums and guitar in his church band, and loves fishing and target shooting. At 6'7" tall, Jacob is a young man with a loving family, a hefty appetite and a healthy outlook on life. He truly values every moment because he has faced death countless times during the past year.

Jacob was born with Marfan syndrome, a rare genetic condition that affects the connective tissue which holds the body together and supports vital organs. It most commonly affects the heart, eyes, blood vessels, and skeleton. People with Marfan syndrome are usually tall and thin, with unusually long arms, legs, fingers and toes. The most famous person identified with Marfan syndrome was Abraham Lincoln. Damage caused by Marfan can be mild or severe, and in Jacob's case, it has been severe.

"Jacob's chest dips in severely," said his father, David Clark. "It's called pectus excavatum and it usually doesn't require surgery unless it starts putting pressure on your organs, which is what happened in Jacob's case."

Dr. Robert Letton, chief of surgery at Wolfson Children's Hospital, diagnosed Jacob's pectus excavatum as one of the most severe cases he had ever seen. Jacob's heart was significantly misplaced to one side due to the pressure. On April 29, 2022, Dr. Letton performed a NUSS procedure on Jacob, placing pectus rods horizontally across his chest to elevate his sternum. Due to his Marfan's and associated issues, the procedure was followed by four months of major complications, causing Jacob to be readmitted to the hospital four times and to spend almost four months in Wolfson. "He got down to 124 pounds," said his dad, "And there were several close calls where we were afraid we'd lose him."

David Clark, at 6'7" tall, inherited Marfan syndrome from his father, who died at age 27 because he was undiagnosed and working in a job that required heavy lifting. David and his wife, Karmel, homeschool all three of their sons, Jacob, Nicholas, and Landon, since the two older boys inherited Marfan from David.

Today, Jacob has gained weight and is doing well, but still has periodic issues with heart rhythm. Because of his rapid growth, the rods in his chest have become loose and Dr. Letton is now considering whether to replace or remove them.

Dr. Letton commented, "Jacob always has a smile on his face and has one of the most positive attitudes even when things aren't going as planned."

In the meantime, the Clark family has a special place in their hearts for Wolfson Children's. "Jacob calls Wolfson 'home,' and considers the nursing staff on the 6th floor to be family," said David Clark.

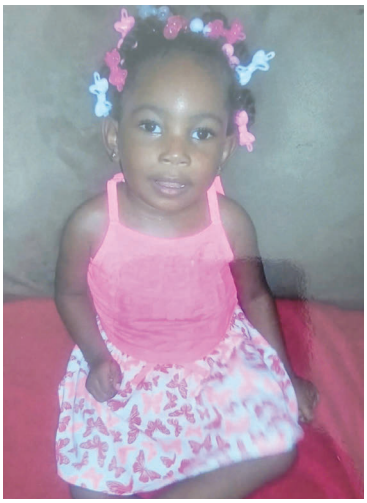
"They gave him the royal treatment while he was there. The staff truly cares about each patient, and we know that they are guided by God."

THANK YOU DR. VANNI R. STRENTA *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Susan Brandenburg

Keira Hardeman

A LOVE STORY OF A SPECIAL LITTLE GIRL + HER DEVOTED MAMA



Keira was born at Jacksonville Shands on June 19, 2012. Her mom, Maurisa, experienced a healthy, full-term pregnancy, an uneventful delivery, and she embraced the joy of motherhood, thrilled to have a precious baby girl.

Shortly after birth, Keira was transferred to the Neonatal Intensive Care Unit at Shands. After only two days, the baby's breathing stabilized, and Keira went home and became Maurisa's world.

Around two months, Keira wasn't responding to stimulus as Maurisa thought she should. While nursing one evening, Keira suffered a major seizure; an ambulance rushed the baby to Shands and then to Wolfson Children's Hospital. Following extensive testing, Keira was diagnosed with epilepsy. A second MRI a year later revealed Cerebral Palsy and a rare, chromosomal disorder. Although devastated and frightened, Maurisa was totally committed to Keira. Without pause, Maurisa recalled expressing, "My baby is my joy. I will do whatever I have to do. I am her Mama Bear, through and through!"

Boundless love infused an unstoppable strength into their daily routine. Keira blossomed into a fearless, beautiful toddler with a wheelchair. She attended Mount Herman Exceptional Student Center and even rode the school bus! She loved her teachers and her "Pink Cadillac" stroller. Maurisa dressed Keira in fun, girlie outfits everyday with matching hair ribbons.

Unexpected challenges ensued. When four, Keira struggled with swallowing, and a permanent gastrostomy tube provided safe nutrition. Once again, Maurisa's "I'll do whatever I have to do" devotion never wavered. Keira seemed to adjust well, even loving a favorite vocalist...Beyonce!

Although Maurisa had long feared the risk of surgery, she cautiously consented. In September 2020, Keira's orthopedic surgeons meticulously attached rods to her spine to alleviate pressure.

Two days after surgery, Mama Bear's fears became reality. Keira developed an ileus and other complications. A tracheotomy was performed after an extended ICU stay and a ventilator became a crucial facet of her care. Another new normal in their journey had now begun.

Love *never* fails.

THANK YOU LEE + DARLENE NUTTER *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Rosemary Naughton

Kyrie Nettles

"WHEN IT'S YOUR BABY, YOU LEARN FAST."

Bobbi Barnes is incredibly articulate when she talks about her vivacious 6-year-old son, Kyrie Nettles, and the challenges he has faced already in his short life. Her deep knowledge of his disease, sickle cell anemia, is evident.

"I didn't know anything about sickle cell when he was diagnosed," Bobbi acknowledges. "No one in my family had had it. But when it's your baby, you learn fast, and Wolfson has helped educate me so I can better manage his care and advocate for him."

Kyrie was brand new when Bobbi was alerted by the Wolfson team that his newborn screening had clear markers for sickle cell anemia. "That's how we were introduced to Wolfson," notes Bobbi.

From that time, Bobbi and her husband have been navigating the many factors involved with Kyrie's diagnosis. He has suffered pain crises that have required hospitalizations. He had a spinal tap at age 3. One time Bobbi recalls waking up in the middle of the night to Kyrie's cries and finding that his whole right arm was dangling. "That was the first really difficult encounter," she recalls, and describes how he went from normal one day to on morphine the next at the age of two.

He underwent a major dental surgery that required full anesthesia and also has undergone multiple blood transfusions, which he still faces every two to three weeks. "We thought he could stop them in the fall of 2021, so they took out his port, but a Trans Cranial Doplar and an MRI this summer led to the port being put back in, and he is back on the transfusions. He is also a candidate for a bone marrow transplant, and the Wolfson team is evaluating matches for stem cells." Kyrie's team is led by Dr. Cynthia Gauger, Dr. Manisha Makker Bansal, both pediatric hematologists/oncologists, and Cynthia Kiddey, APRN.

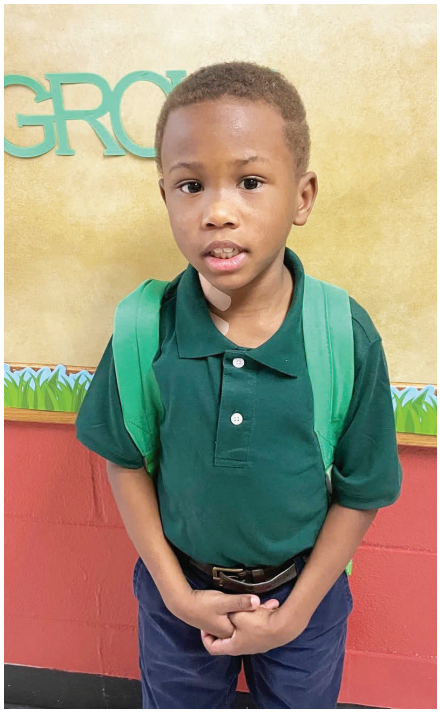
Kyrie has also been evaluated by Nemours' neuropsychiatry team led by Dr. Marcus Dipinto, and diagnosed with ADHD and some other learning disabilities. "This has helped us tremendously in knowing how to navigate Kyrie's education and advocate for him at school."

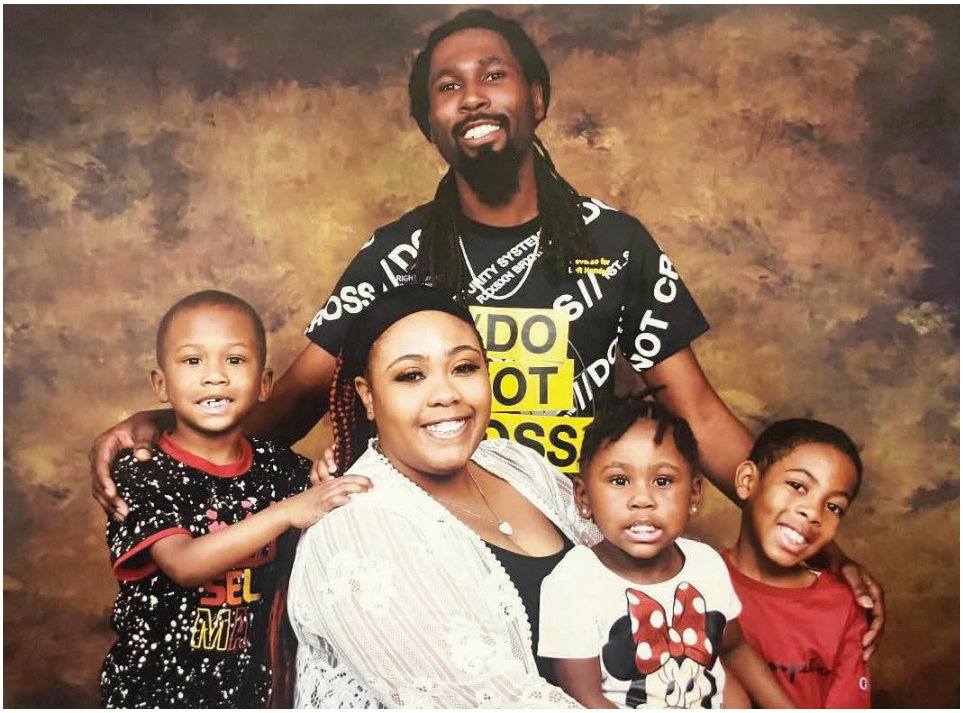
Kyrie is now in first grade, and Bobbi states that every milestone is big for him. He is an avid music lover, even music from the '70s and '80s. "He loves to dance and produces beats with his dad," reports Bobbi. He loves Spiderman, his older brother Malachi and younger sister India, and food, most especially mac and cheese, fried chicken and snowcones.

"Our closest family is five hours away," says Bobbi. "Wolfson has provided support in many ways, giving me people to talk to and making sure I understand everything going on with my son and how to help him. The nurses and doctors are excellent. I don't know where Kyrie or we would be without them. It has been quite a journey."

THANK YOU SARA GOODEN *and* **ANNE + BILL GOWER** *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Grace Martin Wooten






SMOKEY

Dreaven Beimourtrusting

"EVERY MINUTE SEEMED LIKE HOURS."

It was the perfect plan. Brittany and Greg Beimourtrusting had taken the twelve-week Bradley childbirth class. They hired an experienced midwife and a doula for natural birth at home. They had chosen names, Tybalt for a son, Dreaven for a daughter.

But Brittany was two weeks overdue, and when her labor did start, it lasted 17 hours, with four hours of pushing. Finally, on May 15, their baby arrived. Greg said, "It's a girl! It's Dreaven!" They were ecstatic.

Within minutes, their joy turned to panic. Dreaven did not make a sound. The midwife and doula scrambled for an oxygen tank. Brittany's heart nearly broke when she heard, "Call 911."

The midwife discovered a "true knot" in the umbilical cord. Long labor and intense pushing had pulled that knot tighter and tighter, cutting off Dreaven's life-giving fluids and oxygen.

A private ambulance arrived. The bewildered EMTs had no equipment for a newborn, so they took Dreaven to St. Vincent's Emergency on Belfort Road. From there, Wolfson Children's Kids Kare Mobile ICU raced her to the Wolfson Neonatal Intensive Care Unit (NICU), where neurologist Dr. Raj Sheth applied a Cool Cap to mitigate the damage to her brain. She had to be heavily medicated because she was having seizures. Later, an MRI showed Hypoxic Ischemic Encephalopathy (HIE). Brittany kept family and friends updated on Facebook throughout the long ordeal. The nonprofit organization Hope for HIE was a lifeline on social media to support them.

For six days, Brittany and Greg could not hold their firstborn child, because the stimulation would cause more damage. They could only touch her hand through the ports of the incubator. "It was completely counterintuitive," Brittany says. Every minute seemed like hours. Finally, on May 21, they took Dreaven in their arms for the first time. They were overcome with joy.

After 33 days in the NICU, Dreaven was transitioned to pediatrician Dr. Kelly Komatz and ARNP Ellen McAndrews Guth at Wolfson's Bower Lyman Center for Medically Complex Children. She could finally come home.

Brittany and Greg still have a plan. They want their daughter to feel respected and fulfill her potential in every way possible. Now eight years old, Dreaven loves to snuggle with her family and caregivers. She is a student at Neptune Beach Elementary, performs in the Adaptive Dance Superstars program in St. Augustine, and communicates through the Tobii eye tracking system. And because Hope for HIE was so helpful to them, Brittany now volunteers to support other parents.

Brittany says the staff at Wolfson's NICU was incredibly compassionate, especially their nurse, Kerrie. Thanks to Wolfson's Kids Kare transport and expert professionals, Dreaven is here and very much alive.

THANK YOU LANDSTAR SYSTEM, INC. *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Carol Grimes

Kengy Setzler

"A BROKEN HALLELUJAH."

When Kengy Setzler III smiles, you see a big gap where he lost both front teeth. When you hear Kengy's story, you see a young man who's brave beyond his years.

The happy 7-year-old loves dinosaurs, the Minecraft video game, and his second-grade teacher at Highlands Elementary School in Jacksonville. But mostly, he loves his mom, Sheena Horace, who doubles as his protector and sometimes as his personal jungle gym, as he climbs all over her.

Sheena's heart led her and her fiancé to take in Kengy when she got a text message from a relative asking Sheena for help. The couple wasn't sure they wanted children, but they didn't hesitate to bring him into their home. Their family grew when her 5-year-old niece joined them.

"They are two peas in a pod," Sheena said of the children, who are being raised as brother and sister. She said life changed dramatically for the family when Kengy was injured in a car accident in April 2021, while with his father. The young boy sustained a traumatic brain injury and a spinal injury.

Sheena describes her son's injury as a "broken hallelujah," a humbling experience that shook – but didn't break – her faith. She's grateful for the people who have helped hold the family up during this time, including the medical professionals at Wolfson Children's Hospital they've met.

She said her son's pediatric neurosurgeon, Dr. Philipp Aldana, Chief of Pediatric Neurosurgery and Co-Director of the Stys Neuroscience Institute at Wolfson Children's and his staff have been blessings in the family's life. Sheena said Dr. Aldana placed Kengy's halo, which helped stabilize his head and neck, and did a spinal infusion, as well as a revision. She appreciates the compassion Dr. Aldana continues to show her son.

"If I call and say something isn't right, he immediately fits me in the schedule," Sheena said.

Watching how Dr. Aldana and his team interact with her son proves to her it's a safe space.

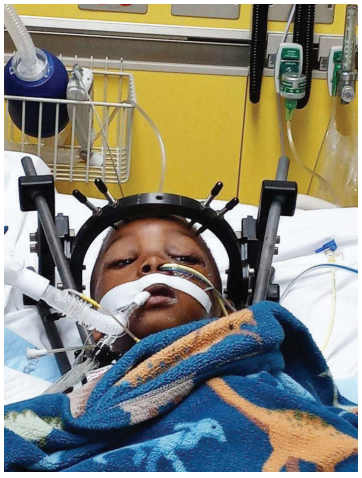
> "When you get a doctor who *really cares* and listens to you, you really appreciate that,"

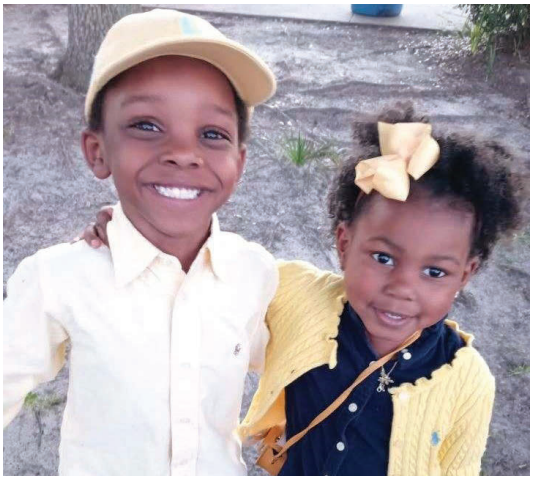
she said. Kengy likes Dr. Aldana, who he says is "really nice." He's also a big fan of the dominos and treasure box in the doctor's office.

One day, when Kengy gets older, he will understand the doctor's office was more than a place to play dominos and check out the treasure box. It was the place that gave him the chance to live his best life. And the place that gave his mother the hope and comfort she needed when she was fearing the worst for him.

THANK YOU LEE AND DARLENE NUTTER *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Marilyn Young





Camilla Pope

"I THINK OF DANCING WHEN I THINK OF HER."

In 2019, after experiencing flu-like symptoms for a few weeks, four-year-old Camilla Pope woke up with severe leg pain and was unable to walk. Her mother, Denise, rushed Camilla to the emergency room where blood work showed that her white count was extremely elevated. Camilla was transported by Kids Kare Mobile ICU to Wolfson Children's Hospital and diagnosed with acute myeloid leukemia, a rare form of blood cancer.

"Once we got to Wolfson Children's, things started taking off quickly and she got the care she needed," Denise said. Camilla began an aggressive inpatient chemotherapy treatment plan. After nearly five months in the hospital, she was able to go home with her cancer in remission. In 2021 Camilla's cancer returned, and she now needed a bone marrow transplant.

Shortly after the transplant, Camilla was diagnosed with graft-versus-host disease, a condition that occurs when donor bone marrow or stem cells attack the recipient. Later she developed a bacterial infection in her brain and lungs, which led to multiple surgeries.

Camilla went home on oxygen support and IV medication and required a wheelchair and began to slowly regain her strength. This past July she was able to have her port removed. Camilla is now cancer-free and like a lot of other kids, she had a busy and exciting summer swimming, visiting family and traveling.

"Camilla has been very brave and did everything we asked her during treatment. She's really a very energetic little girl and I think of dancing when I think of her," said Dr. Michael Joyce, a pediatric hematologist/oncologist with Nemours Children's Health and medical director of the Blood and Marrow Transplantation Center at Wolfson Children's. "She's doing very well. I would say she's one of the most energetic patients I follow."

While Camilla doesn't remember a lot about the early days of her treatment, she does remember the impact of the nurses, staff and Child Life specialists who made her stay a little easier.

"I remember a few things like going out in the hallway to play and dance with the nurses, going to the playroom and doing art projects," eight-year-old Camilla said.

Denise said the days in the hospital were made easier by Camilla's brother Carter, her grandmother and her care team. When Denise recalls Camilla's time at Wolfson Children's, the word family comes to mind.

THANK YOU FORT FAMILY INVESTMENTS *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Katie Nussbaum

Amelia Tharp

"A SLEEPLESS NIGHT FILLED WITH TEARS + PRAYERS."

The Tharp family was enjoying a carefree start to their summer during 2021. From long days spent swimming at the beach club by their house to evenings running around barefoot with family and friends on the bank of the St. Johns River, Dan and Nicole's two daughters were having a great time. Little did they know their joy would take a drastic nosedive.

Early the morning of June 20th, after their younger daughter Amelia awakened and Nicole was changing her diaper, Nicole noticed a lump on her daughter's abdomen. Even though Amelia was not complaining or in any apparent pain, Nicole called a friend who is a former physician's assistant. Since it was Sunday around 10 a.m. and the pediatrician's office was closed, Dan and Nicole were advised to take Amelia to the Wolfson Children's Emergency Room Town Center. Following her evaluation, the ER physician suggested Amelia be taken to Wolfson Children's main campus for further testing and a definitive diagnosis. By evening, Dan and Nicole were checking their precious two-year-old into Wolfson Children's Hospital.

After a sleepless night filled with tears and prayers, the Tharps were greeted the next morning by a team of doctors in hazmat suits due to the unknown nature of Amelia's worsening infection. An infectious disease specialist was brought in to consult and work with her existing medical team. It was quickly determined that Amelia had picked up gram-positive staphylococcus from a small cut on her foot at some point in the recent past. The large mass on her abdomen was an abscess caused by the infection that had entered her bloodstream.

Draining the abscess required more than two and a half hours for little Amelia in the operating room. In addition, her surgical team put in a pigtail catheter so that fluid would continue to drain. Amelia remained in the hospital after the surgery to be monitored for fever and further infection.

It was during these six days that Dan and Nicole saw first-hand the excellent, holistic care at Wolfson Children's Hospital. The nurses and doctors who checked on Amelia would take the time to joke around and play with her, keeping the bubbly toddler in her usual good spirits. The nursing staff spent extra time ensuring that Dan and Nicole were comfortable with the at-home care needed for her pigtail drain, which remained in place for two weeks following discharge from the hospital. "The nurses and doctor rallied around Amelia. Dan and I felt like everything was being done to keep her safe and get her healthy. Thank God for Wolfson Children's Hospital," expressed Nicole.

THANK YOU JESS + BREWSTER J. DURKEE FOUNDATION *and* **MR. + MRS. GREGORY B. ANDERSON** *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Katie Wendell

Mariah Walker

"THEY REALLY TOOK CARE OF MY BABY."

Mariah Walker was born April 9, 2022, at UF Health Jacksonville and for three short days all seemed well, until doctors found a hole in Mariah's heart. This came as a shock to her mother, Jamia Carter, as this was something not detected during her pregnancy. Jamia was scared of what this would mean for her newborn daughter.

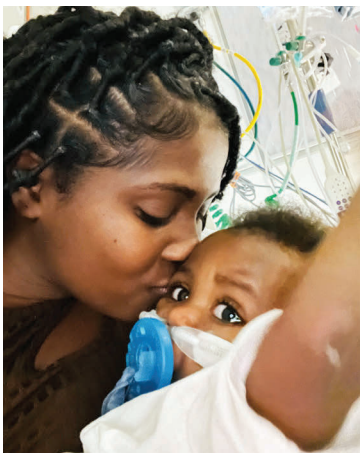
Shortly after this discovery, Mariah was transferred to Wolfson Children's Hospital under the care of Dr. Rajesh Shenoy, Medical Director of Wolfson Children's Terry Heart Institute. On oxygen and prescribed multiple medications to help prevent her critical condition from worsening, Mariah remained resilient. According to Dr. Shenoy, it was a miracle that she made it to four months before needing her first surgical procedure.

Little Mariah was diagnosed with Tetralogy of Fallot, a rare heart condition a baby is born with that results in the circulation of poorly oxygenated blood throughout the body. Four major heart defects pulmonary stenosis (a narrowing of the passageway leading from the heart to the lungs), ventricular septal defect (VSD) (a hole in the wall between the pumping chambers), overriding aorta (the aorta incorrectly positioned over both ventricles) , and right ventricular hypertrophy (a thickening of the heart muscle wall) required surgical intervention by Dr. Michael Shillingford, Medical Director of Pediatric Congenital Cardiac Surgery, and Professor of Pediatric Cardiothoracic Surgery at Wolfson Children's Terry Heart Institute.

In August 2022, Dr. Shillingford completed the first surgery on Mariah's heart, which included closing the VSD, performing a pulmonary valve-sparing repair and relieving her right ventricular outflow obstruction. Mariah recovered quickly in the Cardiovascular Intensive Care Unit (CVICU) at Wolfson Children's where she was closely monitored.

During a routine checkup at the end of May 2023, Dr. Shenoy discovered that Mariah's right-sided heart obstruction had gradually worsened. The preserved valve had become more abnormal over time and her obstruction had returned. Mariah would need another open heart operation, which Dr. Shillingford successfully performed in June. Jamia recalls this being a very frightening experience, but that Drs. Shenoy and Shillingford eased her stress and worry.

Now, at one and a half years old, Mariah is doing great and is off all medications other than aspirin. As for her future, she will not need another surgery until much later in life. Best of all, she will be followed carefully by the Terry Heart Institute at Wolfson Children's.



"Mariah is a fighter and if you look at her, you wouldn't be able to tell she's been through so much," says Jamia. She also expresses her immense gratitude and praise to all of those at Wolfson." I can definitely say they're amazing," she says. "They really took care of my baby." Despite a tumultuous beginning, Mariah, with her smiley, independent ways, gets a second chance at living a normal life.

THANK YOU SKIP + PEGGY ALLCORN, CLAIR BERRY, BERRY & CO., REAL ESTATE, CATERINA + HUGH CARON, TONI + ANDY CRAWFORD, *and* **LINDA + DAVID STEIN** *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Caroline Lamm

Pearl Laubacker

"LOOK AT THIS CHILD WHO WAS NOT SUPPOSED TO LIVE A DAY."

Before Pearl Laubacker was born, there was little hope that the baby would live.

Pearl was diagnosed in the womb with hydrocephalus, a condition characterized by an accumulation of cerebrospinal fluid in and around the brain and spinal cord that causes increased pressure on brain tissue. Her parents, Megan and Paul Laubacker, were unsure if their baby would even survive the pregnancy.

The team at Baptist Health and Wolfson Children's hospital supported Pearl's parents throughout the pregnancy, and once little Pearl was born, she proved to be a fighter. Born with VACTERL-H, a rare genetic condition that affected her vertebrae, anus, heart, trachea, esophagus, kidneys and more, Pearl amazed everyone – particularly her doctors – with her overwhelming strength, tenacity, and grace.

"As her mom, I'm just incredibly proud. Look at this child who was not supposed to live a day, who was not supposed to survive," said Pearl's mother, Megan. "Now she is walking independently. She can go 10 or 15 steps without using her walker. It makes me lose my breath every time she does it because she is becoming so very confident. She is talking – fully communicating – which we were told she would never do, as well. It's just mind-blowing."

But it has not been easy. As a newborn, Pearl had all the associations of VACTERL-H minus limb deformities. She was born with a shorter esophagus. She had abnormalities in her heart, dislocated hips, tracheomalacia. Just a laundry list of overwhelming maladies, many of which were fixable through multiple surgeries. In all, she has had a total of 14 surgeries – 12 at Wolfson Children's Hospital and two in Colorado – over the past six years. Initially she spent 105 days in the Wolfson Neonatal intensive care unit (NICU). "Pearl carries a lot of battle wounds and has a lot of scars," Megan said noting that after Pearl graduated from the NICU, she became a "frequent flyer" in Wolfson's Pediatric Intensive Care Unit and the emergency room.

Known to everyone by her smile, the gem behind Pearl's success is that she has always "just been a kid," said her mother. Another contributing factor to her growth and progress is that she was lucky enough to be born at Wolfson Children's Hospital, she said.

"She has always been resilient, Megan said, adding...

"We have *been fortunate* to have had the right people placed in our lives within the walls of Wolfson, and those people have celebrated the fact that she is just a kid. They have put no limits or boundaries on her. The secret, obviously, is being in the right place at the right time with the right people."

THANK YOU LEE + DARLENE NUTTER *for* **SPONSORING THIS PATIENT PROFILE**

Written *by* Marcia Hodgson