HEARTSTRINGS
Connecting CHD supporters

JANUARY 2024

Dear KHT Family,

Happy New Year! I want to express my heartfelt appreciation for your unwavering support throughout 2023. Because of your generosity, love, and commitment, The Krueger Hat Trick Foundation achieved remarkable milestones. Together, we have made a significant impact in the lives of countless Heart Families, providing them with the support, resources, and hope they need to navigate the challenges that come with a congenital heart defect diagnosis.

Our collective efforts have allowed us to fund critical medical treatments and post-surgery care necessities, provide hospital comfort kits around the US, offer emotional support to families in need, and advocate for awareness and research in the field of CHD. Your contributions have truly made a difference. From our Heart Family, and Heart Families everywhere – we

are immensely grateful for your dedication to our cause.

As we reflect on the successes of the past year, I am thrilled to share our excitement for what lies ahead in 2024. KHT has planned some amazing fundraisers and events, including our **4th Annual Charity Golf Tournament**, as well as our **4th Annual Bull & Oyster Roast**! Stay tuned for announcements about our upcoming events. We are confident that with your continued support, we can reach new heights and make an even greater impact in the lives of Heart Warriors battling CHD, as well as those that care for them.

I want to express my deepest gratitude for being part of our KHT HeartStrings Community. Your compassion, generosity, and commitment to making a difference inspire us every day. Together, we will continue to be a beacon of hope for Heart Warriors and their families. No one walks the Heart Journey alone.

Wishing you a wonderful start to the year and looking forward to achieving more together in 2024!

With heartfelt thanks,
Katelin Krueger

February Is National Heart Month

February is National Heart Month! We're thrilled to announce our February fundraiser, with the aim of providing 10 comfort kits for heart warriors, new Beads of Courage beads for heart warriors, and 60 Heart Hero lunches to

Cardiac PICU staff. Your generosity and support make all of this possible, and we extend our heartfelt thanks to each and every one of you.

Donate

Upcoming Events - Mark Your Calendar!

✦ **Happy Hour for Hope:**
Sunday, June 9, 2024 from 1:00 - 6:00 PM
Twain's Tavern in Pasadena, MD

✦ **4th Annual Golf Tournament:**
Monday, June 10, 2024
Compass Pointe Golf Courses in Pasadena, MD

✦ **4th Annual Bull & Oyster Roast:**
Saturday, September 14, 2024 from 6:00 - 10:00 PM
Jimmy's Seafood in Baltimore, MD

✦ Stay tuned as other events develop!

Heart Warrior Of The Month

Meet Tommy!

Thomas “Tommy” was born on July 14, 2022 in Montgomery, Alabama. His parents were completely unaware of any heart defect until he started turning blue a couple of minutes after birth. He was immediately taken to the NICU and spent 6 hours there before being flown to Children’s of Alabama the evening of his birth.

Tommy was diagnosed with Double Outlet Right Ventricle with Mitral Atresia (more info here) and needed an emergency cardiac catheterization where a stent was placed at only 12 hours old. Three days later, he had his first of three open-heart surgeries. He spent a total of 3 weeks in the hospital before finally being able to come home on a feeding tube.

Tommy had his feeding tube removed on October 3rd. Since his initial hospital stay when he was born, he has had 2 cardiac catheterizations and his second open-heart surgery.

Tommy is growing and thriving today! His favorite things are snuggles and playtime with Mommy and Daddy, his mini stuffed animals, and being read to. He’s also a little Star Wars fan just like his Daddy!

Share Your Heart Warrior Story

CHD News & Articles

3 siblings. 3 heart transplants. Each before turning 3.

Reprinted from American Heart Association News Stories

Nine weeks after giving birth to twin sons, life was a blur of diaper changes, feedings, laundry and sleepless nights for Sara and Jason Siqueiros.

In the midst of the blissful chaos at their Peoria, Arizona, home, Sara noticed that their 2-year-old daughter, Isabel, wasn't feeling well. Based on the initial symptoms, the pediatrician said Isabel only had a respiratory virus and prescribed an oral steroid. Instead of recovering, Isabel became more ill. Her face swelled and she stopped urinating. Sara

strapped Isabel into her car seat and took her to a hospital in Phoenix. Further testing showed that Isabel had a rare form of heart failure called restrictive cardiomyopathy.

The condition meant that chambers of her heart were becoming stiff, making it more difficult for the heart to function properly. It's the rarest form of cardiomyopathy. Isabel's case was so severe that it had caused her liver to retain fluid, enlarging it to five times its normal size.

She needed a new heart. Already exhausted and overwhelmed, Sara and Jason felt as if time stopped when they heard the words "heart transplant." "We thought we had a normal, happy life with our three wonderful kids," Sara said. "Then all of a sudden, something that happens on TV or to other families was happening to us."

Because restrictive cardiomyopathy can have a genetic link, the Siqueiros had the twins – Jason and Jaxon – checked for symptoms at 3 months and 6 months of age. Both boys were symptom-free on both exams.

In May 2018, five months after Isabel was diagnosed, she received her new heart. Sara called it a "perfect transplant." Isabel was back home less than two weeks after the surgery and, soon after, "she was rocking post-transplant life," Sara said.

Six months after her heart transplant, Isabel started experiencing gastrointestinal issues. It was a side effect of her multiple transplant medications. Sara called her mom to watch the twins while she and her husband took Isabel to Phoenix Children's Hospital. She was admitted.

In the middle of the night, Sara's mom called: Baby Jason woke up pale and vomiting. He was being rushed to a hospital close to their home. Sara and her husband Jason grabbed their things and rushed from one hospital to another. It can't be that big a deal, Sara thought. They already checked for restrictive cardiomyopathy and there was no problem.

Minutes later – and just weeks after his first birthday – Jason had his first cardiac arrest. Sara was holding Jason when he had his second.

Jason was airlifted to the same hospital as Isabel; she was on the fifth floor and he was on the sixth. Sara was racing back and forth checking on her children. She was with Isabel

when Jason had another cardiac arrest. To keep Jason alive, doctors connected him to a machine that performed the work of his heart and lungs. Additional tests showed that Jason had signs of restrictive cardiomyopathy. Cardiologists did an emergency procedure to implant a pacemaker to get his heart back into a healthy rhythm.

Once things calmed, Jaxon was tested. He, too, needed a pacemaker. In November 2018, all three siblings were in the hospital. Sara felt hopeless as she raced between hospital rooms, always fearing she was in the wrong place. She often ducked into the bathroom to cry. "Be positive," she told herself. "Everything is going to be OK." She kept repeating those phrases, no matter whether she believed it.

Weeks later, everyone was back home. All remained well for everyone – until June 2020. Baby Jason's heart stopped again. Sara performed CPR in the kitchen until an ambulance arrived. He was stabilized at the nearby hospital, then airlifted to the hospital in Phoenix. Doctors told Sara and Jason to prepare themselves for the worst. She imagined having to pick out a funeral outfit.

Three days later, baby Jason was well enough to be added to the transplant list. Three weeks later, a match was found. Hours before the surgery, his heart stopped again. The transplant team still managed to get the boy his new heart.

Three months later, Jaxon received a new heart. Sara half-jokingly said that of the three, "Jaxon was our only, 'routine transplant.'"

Dr. Bethany Wisotzkey is a pediatric cardiologist who specializes in heart failure. She was part of the transplant team that treated the children. It's a unique story, of course, because there are three siblings, all from the same family, who needed transplants at such a young age. Another aspect is how quickly each was matched to a donor heart. "Some families are, unfortunately, in the hospital waiting for months and months to get heart transplants," she said.

Three years later, all three children are thriving. Isabel is in second grade, learning to write in cursive and making music playlists on YouTube; she loves rainbows and unicorns and Sara describes her as a "fearless and powerful" 8-year-old. Jason is a fan of WWE wrestling and Jaxon loves video games; both boys love listening to music and dancing. The twins will soon turn 6.

Sara has shared her family's story on social media, and in television and newspaper interviews. She's received countless messages from followers who registered as organ donors after learning about how heart transplants saved Isabel, Jason and Jaxon.
Sara makes sure her kids understand as much as they can about their condition, the need for healthy lifestyles and a daily medication regimen. "Luckily, they all get to go through it together," she said. "They are all very aware that they have special hearts."

'It's so much more than a scar': Model now flaunts remnant of her heart surgery

Reprinted from American Heart Association News Stories

For as long as she can remember, Andrianna Acosta went out of her way to hide the 8-inch scar that stretches from near her collarbone down to her belly button. In most photos of her younger self, she's wearing high-collared shirts, turtleneck tops and hoodies.
"Growing up, I was extremely insecure because of this scar that I had, because no one my age had that," she said. "I didn't even really know what it was."

Born and raised in New York's Long Island, Andrianna was about 7 months old when she had the lifesaving heart surgery that left the scar. She was born with a ventricular septal defect, a condition sometimes referred to as a hole in the heart. The opening in the wall that separates the heart's two lower chambers disrupts normal blood flow to and from the lungs. What causes such a birth defect in babies is unknown.

Andrianna's parents told her about the surgery when she was very young. But she couldn't fully grasp the significance of it. All she thought about was the scar. She was about 10 when intense curiosity among her classmates made her self-conscious about it.
"What is that? Why do you have that?" they would ask, pointing to the tip of the scar on her collarbone.

"It was just hard," Andrianna said. "It's that age when kids start kind of picking on you, and you're trying to find yourself. I used to write in my diary about how much I hated my body and how much I wished I could change my scar." She continued covering the scar into her

early 20s – until the random afternoon when she was going through family photo albums with her mother.

Andrianna picked up a journal she had not noticed before. In it, her mom had kept meticulous entries of Andrianna's health struggles as a newborn. It told a story of survival and determination.

There was a time when Marie and Eli Acosta weren't sure if their second-youngest daughter would survive. There were no complications during childbirth, but soon after bringing her home, Marie noticed that Andrianna behaved differently than her 4-year-old sister, Ashley, had as a newborn. Andrianna would sleep long stretches without feeding, and started losing weight. Doctors initially told Marie that it probably wasn't anything serious. A mother's intuition made her sense otherwise.

Marie kept a watchful eye on her baby, noting her observations in the journal. Marie's lingering memory is of "such a tiny little person having such a hard time breathing."
"I remember racing to the hospital with her because her lips would turn blue, and I was like, 'Oh, my goodness, you can't die on me,'" Marie said.

She constantly shared her notes with doctors. Eventually, a cardiologist diagnosed the defect when Andrianna was 1 month old. She underwent the surgery to close the hole six months later. "The way the doctor explained it to me was that a patch just stays there, and that skin just grows around it," Marie said.

After reading the journal and talking with her mom, Andrianna's perspective changed. What she once saw as a blemish was now infused with meaning. "I realized that it's so much more than a scar, so much more than a surgery," she said. "It's a whole story that my whole family was involved in. And it made me realize how much my family loved me and how much they would do for me."

The timing of this newfound appreciation was interesting. It was 2020, around the time she graduated from college and started a modeling career. Andrianna was stunned by one presentation that edited the scar out of her image. "It's like looking at a picture of yourself without something that is incredibly you," she said. It bothered her on so many levels that she set a new standard. She would collaborate only with photographers who respected her wishes to keep her scar visible in photos.

In 2021, Andrianna proudly displayed her scar as she won the Miss New Jersey International title. She used her pageant platform to spread awareness about the congenital heart defect in appearances at schools and community gatherings. Even after her reign ended, she continues to speak publicly about her scar. "It has just been an incredible journey," she said. "And I'm so excited to continue modeling and continue talking about my scarring – showing it off, really."

Watching her daughter's achievements after a rough start in life couldn't make her mother feel more grateful – or proud. "She's always been very determined," Marie said. "No matter what she sets her mind to, she's going to make sure she accomplishes it." Andrianna has had no further heart problems. Still, she gets an annual checkup to remain on the safe side.

Now 29, Andrianna said she is still in awe of what she went through as a baby. "It was almost like I was given a second chance at life – and I had no idea."

Two Brothers, Two Congenital Heart Defects & the Same Happy Ending

Reprinted from NYU Langone NewsHub

New parents Charlotte Jordan and Eric Hoffman were packing to leave NYU Langone's Tisch Hospital with their newborn son, Theo, when a nurse entered the room. The baby's breathing sounded raspy—would they mind if the medical team did some testing? Instead of heading home as planned, the family waited for news.

Testing led to a serious diagnosis: baby Theo had a heart defect. He would need lifesaving heart surgery to repair a faulty connection that was depriving his body of oxygen-rich blood. His surgery took place steps away at Hassenfeld Children's Hospital—34th Street.

After Theo recovered, the family moved from Brooklyn to Riverhead, Long Island, and in 2021 had another baby on the way. Would this child be born with a similar issue? People who have a child with a heart defect, the most common type of birth defect, have a higher

than 3 percent chance of having another child with a heart defect. As a precaution, Charlotte received extensive prenatal testing through the Pediatric Congenital Heart Program, part of Hassenfeld Children's Hospital at NYU Langone. This included a fetal echocardiogram, an imaging test performed at 18 weeks of pregnancy that can detect heart abnormalities in the womb.

Again, the couple received devastating news. Finley had multiple heart defects, including a very large hole in his heart, one that likely would not close on its own. "It was the most difficult day in my pregnancy journey," Charlotte said. "I knew we faced more surgery, and this time the diagnosis was even more severe." When children in the same family develop congenital heart defects, their conditions are typically similar. Not so with these brothers. Each had his own unique issues. "Theo's condition, while uncommon, presented in a classic way, with signs of respiratory distress and low oxygen levels," said Gillian L. Henry, MD, the boys' pediatric cardiologist. "Finley, by contrast, had the extremes of everything."

Little Hearts, Big Fixes

Charlotte's first pregnancy was uneventful. She had no known risk factors, no red flags to indicate that her baby had a congenital heart defect. Two days after his birth, the medical team pinpointed the cause of his raspy breathing: total anomalous pulmonary venous return, or TAPVR. The condition affects about 1 in 10,000 births.

Fortunately, the care Theo needed was right there at Hassenfeld Children's Hospital, where our Pediatric Congenital Heart Program has the best risk-adjusted survival rate of any hospital in New York State. Our outcomes reflect surgical excellence and patient safety, as well as success in caring for children with severe forms of heart disease. "We were coincidentally at one of the best places, probably anywhere in the world, for a person with this particular condition," Eric observed.

Pediatric cardiologist Achiau Ludomirsky, MD, explained the diagnosis to the new parents, even sketching Theo's heart alongside what a normal heart should look like. Normally, blood moves from the heart's right ventricle to the lungs, where it picks up oxygen. The pulmonary veins then move that oxygen-rich blood from the lungs to the left atrium, which pumps it out to the rest of the body. In Theo's case, his pulmonary veins connected to the

wrong side of the heart. He would need surgery to restore normal blood flow and get that oxygenated blood pumped out to the rest of his body.

On the day of surgery, Theo was placed on a heart–lung machine that kept his blood oxygenated while his heart was stopped. Congenital heart surgeon T.K. Susheel Kumar, MD, began repairing a heart no bigger than a walnut. He used a piece of Theo's pericardium, the covering around the heart, to reroute the pulmonary veins to the left side of the heart. He also repaired a hole in the wall separating the upper chambers of the heart.

New Baby, New Diagnosis

Just 14 months later, Theo's little brother Finley entered the world with his own complicated set of heart issues. Finley had Shone's complex, which means most of the left-sided structures of the heart were smallish, explained Dr. Kumar. A portion of the baby's aorta, which is the artery that carries oxygen-rich blood to the rest of the body, was narrower than it should be. He also had a large hole in his heart, known as a ventricular septal defect, or VSD, among other anomalies.

As soon as Finley was born, the medical team whisked him to the hospital's Congenital Cardiovascular Care Unit for care and monitoring. His first surgery took place about 10 days later. During the procedure, Finley's heart and blood circulation were stopped, allowing Dr. Kumar to open the entire aorta and restore it to its normal size using donated tissue.

Repairing the hole in Finley's heart during the same surgery would have been too risky. "It was a very big defect," said Dr. Kumar. "The infant's heart may not have been able to withstand such a long operation." Instead, he placed a temporary band around the pulmonary artery to reduce the flow of blood to the lungs. During a second surgery in February 2023, when Finley was 21 months old, Dr. Kumar removed the band and closed the hole with a synthetic patch.

A Team Effort

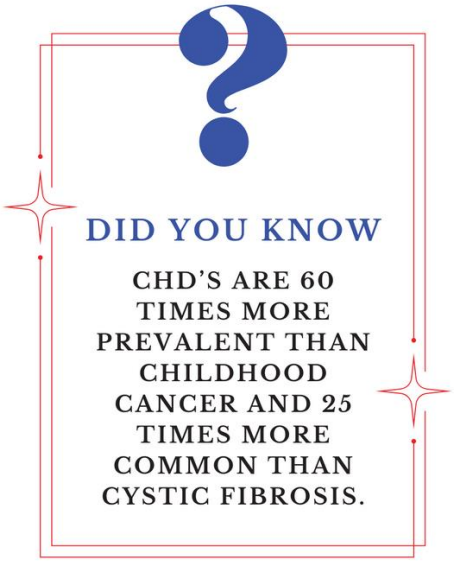
Theo, age 3, and Finley, who will be 2 in September, are now happy and thriving thanks to the care they received from a multidisciplinary team that includes pediatric cardiologists

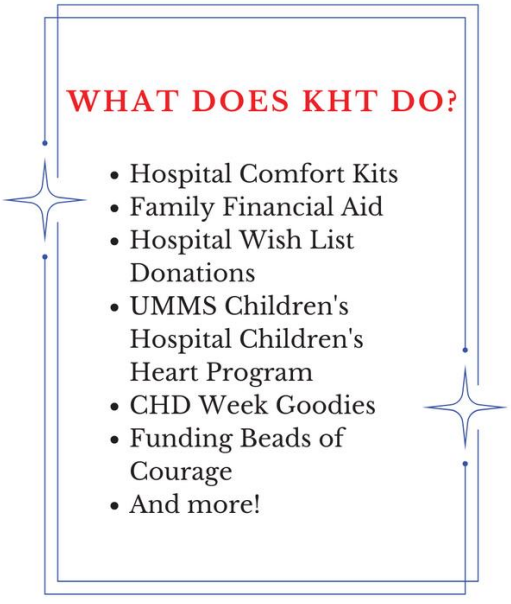
and cardiac surgeons, imaging experts, anesthesiologists, perfusionists, and nurse practitioners.

Because of his complex condition, Finley required additional services, including home monitoring to keep tabs on his weight, oxygen level, and heart rate. At 4 months of age, he had a feeding tube, called a gastrostomy tube, inserted in his abdomen to help him gain weight. He now gets most of his nutrition by mouth, although he still uses the feeding tube overnight for extra calories.

Finley continues to see Dr. Henry every two to three weeks. Despite many obstacles, including hospitalizations for respiratory syncytial virus and COVID-19, the toddler is climbing and racing around everywhere to keep up with his older brother. Theo isn't expected to need any additional surgery.

"In the end, we have two kids with normal, healthy hearts who will lead normal, healthy lives, which is incredible," said Eric, whose sons like to run around in superhero capes. Three major surgeries later, and on the other side of the COVID pandemic, the family can finally relax a little. They're planning their first trip to England this summer so the boys can meet their extended family. "Having the right hospital and medical team partnering with us really made all the difference," Charlotte added. "What they can do is incredible."





Learn More

CHD Resources

General CHD Support

- Kids Health
- My Heart Visit- Peer Support
- Children's Hospital of Philadelphia

Sibling Support

- Sibling Support Project
- Comfort Zone Camp

Family Support

- Medicine Assistance Tool
- Rx Hope
- CDC

View More

Sponsorship Opportunities

Is your organization or company looking for a nonprofit to partner with in 2024?

✦ Come be a part of our fundraising efforts and make a difference in the lives of Heart Families both locally and beyond!

✦ KHT's Corporate Sponsorship Program allows your organization to be recognized as a sponsor at all KHT events, as well as recognized as a partner in our HeartString Newsletter and on social media.

	MIRACLE MAKERS DIAMOND $15,000	HEALING HEARTS PLATINUM $10,000	HEART HEROES GOLD $7,000	LITTLE ANGELS SILVER $4,000	LITTLE WARRIOR SUPPORTERS $1,500
BRAND EXPOSURE					
Name on KHT Heartstrings Newsletter	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Featured social media posts throughout 2024	♥ 12	♥ 12	♥ 6	♥ 4	♥ 3
Name placement on official event website	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Gratitude posts on event-related social media platforms	♥	♥	♥	♥	♥
Opportunity to provide items in welcome gifts and/or auction items	♥	♥			
Opportunity to set up info booth	♥				
EVENT RECOGNITION					
Name featured in promotional materials & event signage	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Name in electronic programs	♥ LOGO	♥ LOGO	♥ LOGO	♥	♥
Verbal recognition during events	♥	♥			
VIP ACCESS & EVENT TICKETS					
Hearts for Hope Family Happy Hour June 9th | Twain's Tavern	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	
Green Hearts Open: Charity Golf Tournament June 10th | Compass Pointe Golf Courses	♥ 2 foursomes	♥ 2 foursomes	♥ 1 foursome	♥ 1 foursome	
Entry into Fairway Fortune: 50/50 Raffle for Tiny Champions Drawing June 10th	♥ x3	♥ x2	♥	♥	♥
Little Hearts, Big Hopes Bull & Oyster Bash Fall 2024 | Jimmy's Famous Seafood	♥ 2 tables	♥ 2 tables	♥ 1 table	♥ 1 table	
Entry into Tiny Beats Jackpot: 50/50 Raffle for Heart Warriors Drawing Fall 2024	♥ x3	♥ x2	♥	♥	♥
Merry Morning for Little Hearts: Breakfast with Santa Charity Event Winter 2024 | More Info to Come	♥ 10 tickets	♥ 8 tickets	♥ 6 tickets	♥ 4 tickets	

Sponsorship Spec Sheet

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