HEARTSTRINGS

Connecting CHD supporters

SEPTEMBER 2024

Dear Friends and Supporters,

As we enter the final stretch of 2024, I want to extend my heartfelt gratitude to each of you who have stood by The Krueger Hat Trick Foundation this year. Your unwavering support has made a tremendous impact, allowing us to continue to provide crucial resources and comfort to Heart Warriors and their families. Together, we've achieved so much, and your generosity fuels our mission.

With the anniversary of our son, Aiden, receiving his angel wings, Tom and I, as well as the boys, are feeling the heaviness of the grief that can be consuming at times. However, we are humbled and honored that each of you in your own way continues to not just remember Aiden but continues to spread the love that he shared with us for two years and five months. Countless Heart Families have received support from KHT, and it couldn't be done without each of you.

We're looking forward to our upcoming Little Hands Big Hearts Bull & Oyster Roast that is just around the corner on September 14th. This event promises an evening of delicious food, fun, and most importantly, an opportunity to make a real difference in the lives of those facing congenital heart defects. I encourage you to join us for this special evening and consider attending. Your participation helps ensure we can continue offering support to those who need it most.

As we approach the end of the year, I am reminded of how vital your contributions are to our success. We simply couldn't do it without you. Thank you for your ongoing dedication, and I look forward to seeing you at our upcoming events as we continue to make a lasting impact together.

Warm regards,

Katelin Krueger

President & Co-Founder

Upcoming Event

LITTLE HANDS
BIG HEARTS
BULL & OYSTER BASH

LITTLE HANDS BIG HEARTS

Bull & Oyster Bash

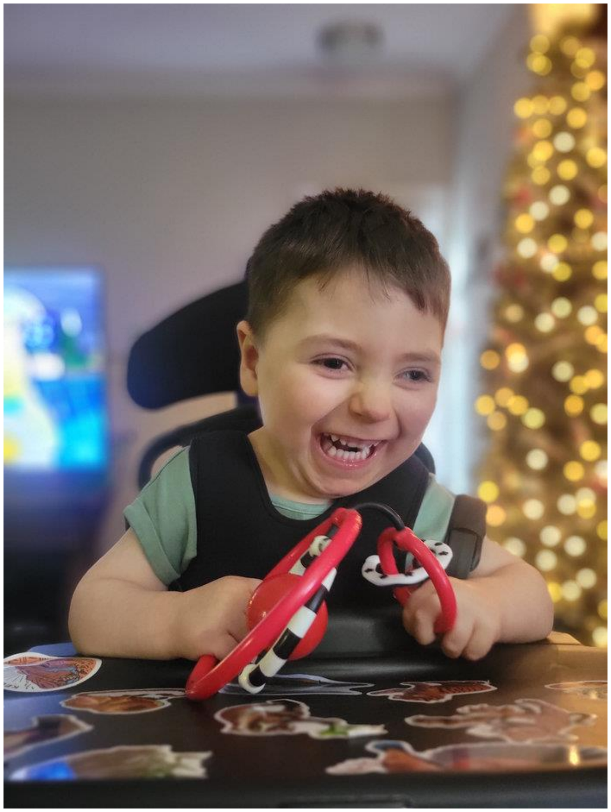
Saturday, September 14, 2024

Jimmy's Famous Seafood | Baltimore MD

6:00 - 10:00 PM

Buy Tickets **View Full Details**

Heart Warrior Of The Month



Meet Elijah

Elijah was born in 2019. He was born a full-term baby with no known complications, but a small heart murmur was noticed a few days after birth.

Elijah’s parents took him to a cardiologist at 12 days old for an echocardiogram. It was then that they discovered he had a congenital heart defect called Hypoplastic Left Heart Syndrome. This condition impacted oxygen getting to his brain and as a result Elijah became blind, non-mobile, and g-tube dependent. This condition is normally discovered during anatomy scans during pregnancy, but unfortunately was missed.

Elijah had his first open-heart surgery at 3 weeks old. Before he was 4 months old, he had 2 heart catheterizations and a second open-heart surgery. Later, he will undergo an additional open-heart surgery.

Despite his struggles and continuous setbacks, Elijah’s parents describe him as a fighter who has the greatest smile. Elijah family and friends around him are enjoying every moment while he continues to fight and defy the odds.

Share Your Heart Warrior Story

CHD News & Articles

All in the Family: 3 Generations Take on the Same Defective Heart Valve

Reprinted From American Heart Association News

Around the time a cardiologist diagnosed Keri Mathew with a heart problem at age 4, her dad once again failed the physical required to increase his life insurance policy.

So Gary Peterson went to see that cardiologist, too.

Mathew, who grew up in southwest Iowa, had been born with a heart murmur that might eventually correct itself. When it was still there at her pre-kindergarten physical, she went to cardiologist Dr. Ward A. Chambers of Omaha, Nebraska, for more tests.

Chambers found that Mathew was born with a bicuspid aortic valve, meaning the aortic valve in her heart had two flaps rather than the normal three; this allowed blood to leak backward into her heart instead of getting fully pumped into the aorta and to the rest of her body. Even back then, in the late 1970s, the problem was considered manageable, although Chambers warned that Mathew might eventually need the valve replaced.

Peterson also had been told he had a heart murmur. He'd learned that in high school. By the time he met Chambers, he was in his early 30s. He'd never had any trouble with his heart, so he hadn't looked into the murmur before his daughter's diagnosis. Chambers found that Peterson also had a bicuspid aortic valve. Also like his daughter, Peterson was told to wait and see about any treatment.

To Peterson, the devastating part of the diagnosis was "that I had passed it on." Six years later, Peterson was hospitalized for a bacterial infection in his heart. Once back home on his farm, he began getting tired more easily as he ran the combine and cared for his livestock. "I just didn't have the stamina," he said. At 39, he had open-heart surgery to replace his defective valve with a mechanical one.

Mathew, who was 10 at the time, worried for her dad and knew it "was what I was going to face one day." By middle school, she began to get winded easily. She avoided athletics, never playing on teams or even running laps in PE class. She wished she could be like other kids, doing everything they could do.

By college, singing in the show choir left Mathew short of breath. At 29, simply vacuuming or walking between her car and office left her gasping for air. Now living in the Kansas City, Missouri, area, her local cardiologist recommended a new aortic valve. "I'd put it off as long as I could," she said. Like her father, Mathew got a mechanical valve. Her surgeon also reinforced a damaged part of her aorta.

By this point, a third generation of the family had been diagnosed with a bicuspid aortic valve: Dakota Mathew, Keri's first child. Keri and her husband, Kip Mathew, knew that could happen. Sure enough, doctors heard a heart murmur in Dakota as a newborn and diagnosed the congenital heart defect at 6 months old.

Given all the knowledge and experience from her own case and her dad's, Keri thought it "was probably something that we could handle." A few years later, Keri gave birth again, to a daughter named Riley. Her heart turned out normal.

Then, when Peterson was 62, he endured more heart problems. He underwent a second open-heart surgery, this time to bypass two clogged arteries and repair an aneurysm in his aorta. A few years later, after he became winded climbing the 18-foot ladder to the top of the grain bins on his farm, he also got a pacemaker.

Along the way, Keri faced new challenges, too. Her heart began beating irregularly, sometimes abnormally slowly. She received a pacemaker to regulate her heartbeat. Three years later, during an especially stressful time, she had a mini-stroke; it left no lasting effects.

Through it all, Dakota hardly thought about his defective valve beyond occasionally wondering when he would need the same open-heart surgery as his mother and grandfather. Although he ran out of breath more quickly than other kids, he was healthy enough to play competitive soccer and sing in a choir.

Dakota grew up in the Kansas City area, then attended the University of Nebraska-Lincoln. Chambers was still seeing patients, including Peterson, at the University of Nebraska Medical Center in Omaha. Chambers began seeing Dakota as well.

"To see a bicuspid valve that leaks – sure, that happens," said Chambers, a professor of medicine and public health. "But to have it in three generations? I've seen a lot of bicuspid valves in my 47-year career, but I'd never seen it in three generations like that."

Dakota was 24 when Chambers said it was time to replace the faulty valve and part of his aorta. Dakota was nervous, of course. However, "it eased my mind a little bit that there were two people that had it and got on with a normal life afterward," he said.

Now, two years later, Dakota is a high school choir teacher in a suburb of Omaha. Like his mother and grandfather, he said he's grateful for Chambers and the care team. He also feels lucky that their heart problem could be fixed.

That's why, he said, he doesn't worry if he and his wife, McKenna, someday have a child with the same defect. "I know with the medical advancements that have been made, my kid will be OK if they have it," Dakota said. "It's been proven three different times now with the three of us that the medical field is amazing."

Bernadette's Heart Story

Reprinted From The Children’s Heart Foundation

"My greatest goal in life is to give back by saving lives." I was born with Hypoplastic Left Heart Syndrome (HLHS) in 2001. My parents found out about my heart defect during a routine ultrasound appointment. After the doctors delivered the news that I would be born with a severe and likely fatal heart defect, my mother’s doctor advised her to go home and begin making funeral arrangements incase I didn't live far past birth. But I proved them wrong and defied the odds. After being born, I stayed in the NICU for just over a month. My family watched me undergo three open heart surgeries before Kindergarten. First, the Norwood at University Hospitals Rainbow Babies and Children's Hospital. Then the Glenn procedure, at Cleveland Clinic. Finally, my third, the Fontan, at Akron Children's hospital.

Since my third surgery in 2004, I have not been in the hospital for any complications related to my HLHS. I am truly blessed to have been able to grow up without any of the frightening and life threatening complications that many children with HLHS have. I still see my pediatric cardiologist annually, take heart medicine daily, and have routine tests and procedures done to assess how my heart is functioning. I was an active child where I danced ballet for 12 years, played recreational soccer, and high school softball. I was an honors student throughout middle and high school and am currently a student at Kent State University studying nursing in their Honors College. It came as no surprise that I choose a career in healthcare - I literally owe my life to the healthcare workers that treated me as a child and continue to treat me today. I hope to become a pediatric cardiac nurse practitioner, treating and healing patients like myself and working with their families.

DID YOU KNOW

1 OUT OF EVERY 120 BABIES IN THE UNITED STATES IS BORN WITH A HEART DISEASE.

WHAT DOES KHT DO?

- Hospital Comfort Kits
- Family Financial Aid
- Hospital Wish List Donations
- UMMS Children's Hospital Children's Heart Program
- CHD Week Goodies
- Funding Beads of Courage
- And more!

Learn More

Following Her Heart: Marissa's Story

Reprinted From Children’s Hospital of Philadelphia

Marissa was born in southern New Jersey, at the same hospital where her mom was a nurse. Just a few hours after birth, her mom noticed that Marissa’s color was off, and she “looked blue.” When her pulse oximetry readings were measured in the low 70s (normal hovers around 100), a specialist was brought in to examine Marissa’s heart.

Tests revealed that Marissa had six complex congenital heart defects, which fell under the category of single ventricle heart defects. Several abnormalities can cause single ventricle defects, but the common outcome is that only one of the two lower chambers in the heart can pump blood.

Thirty years ago, patients with this diagnosis did not survive past infancy. Now, successful treatment involves three open-heart surgeries, a series known as single ventricle palliation, performed in the first years of life.

“My six defects kind of ended up looking like something called hypoplastic left heart syndrome (HLHS), but not exactly,” Marissa says. “Treating them with single ventricle palliation was the most appropriate [surgical] option at that time.”

Three Surgeries to Address Six Defects

Marissa’s single-ventricle palliation surgeries took place at a hospital near her family’s New Jersey home. In the first operation, performed when she was three days old, doctors installed a Blalock-Thomas-Taussig (BTT) shunt. At eight months old, Marissa had the Hemi-Fontan surgery. Marissa had her final major open-heart surgery — the Fontan procedure — at 22 months old.

Together, these three surgeries “send [deoxygenated] blood flow passively into the lungs, as opposed to a healthy heart, where half the heart would be pumping to the lungs and the other half to the body,” Marissa explains.

Navigating the Transition to Adult Care

Marissa continued her pediatric cardiac care until 2017 with the same cardiologist who had treated her since infancy. She then transitioned her care to Emily Sue Ruckdeschel, MD, at the Philadelphia Adult Congenital Heart Center.

“A lot of patients don't want to leave the pediatric side because they've literally grown up with their cardiologist,” Marissa says. “But the adult congenital cardiologist really specializes in how to care for me. Because of this joint program between CHOP and HUP, they understand how to care for the child with congenital heart defects. And that helps them [care] for an adult that has grown up as a single ventricle patient.”

Aging out of pediatric cardiac care and into adult care was a logistical challenge. “Patients like us, we don't just see the cardiologist, we see a bunch of other specialists yearly or every six months,” Marissa says. Whereas before her pediatric cardiologist handled most logistics, once she reached adulthood, responsibility fell on Marissa to coordinate her specialist care. “I know how to advocate for myself,” she says. “But I've always had an interest in bridging that gap between the pediatric and adult population.

Following Her Life’s Passion

Helping others navigate the road she has walked is a recurring passion for Marissa. Inspired by the care she received as a child, Marissa progressed to nursing school after earning her bachelor’s degree. She also volunteers as a peer mentor and a patient family advisory board member with the Adult Congenital Heart Association.

In a poetic coincidence, Marissa worked as a nursing assistant, then later as a nurse, at the hospital where she had her surgeries — and she worked alongside nurses who had once cared for her as a baby.

Marissa’s history as a patient brings insight to her nursing work. “I understand what it means to be a patient …. I get what it's like to lay in that bed, but you want to be home with your friends, and you feel like a burden towards your family for bringing them into the hospital with you.”

Looking Ahead

Marissa recently completed a master’s degree in adult gerontology and now studies in a post-master’s program to be a certified pediatric clinical nurse specialist.

“Because of medical advancements over the past 20 or 30 years, there are now more adults living with CHD than there are children,” Marissa says. “So I think one new opportunity that will be expanding is [the number of] CHD patients that reach their older years.”

Her Advice? Let Kids Follow Their Hearts.

What does Marissa say to families navigating CHD-related challenges? Don’t limit what your kids can accomplish just because they have a heart condition. “Of course, the cardiologist may set limitations in different areas, but as long as you're following that guidance, I always recommend that parents let the kids do what they want to do. It's important that they're not held back just because of their heart."

Following her own advice, Marissa learned how to ski last winter. "It's always been a bucket list item of mine to try, but I was never sure if I'd be allowed to because I do have some restrictions with strenuous sports," she says. "When we realized that it was fine, I just went for it. It was so fun. In winter, I would ski every day if I could." Marissa hopes her work makes a lasting impression on the kids who have crossed her path.

"Maybe 20 years from now, a parent and their adult child will look back at their pictures, or think back to memories of being in the hospital," Marissa says, "and maybe they will remember me as somebody that helped them along in this process, encouraged their child and gave them some hope."

Heart Families

Want your Heart Warrior's courage to be featured by KHT? Email us your story. By sharing, you're raising CHD awareness and giving hope to other Heart Families.

If you've navigated life with a CHD, your advice could be a lifeline to others. Share your helpful tips to support the Heart Family community.

Share Heart Warrior Highlight

Share Helpful Advice

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

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