



**NOVEMBER 2023**



**Dear KHT Family,**

I hope this message finds you well and filled with the warmth of the holiday season. As we reflect on the year gone by and anticipate the year ahead, I am honored to share some significant updates and heartwarming stories from the heart of our mission.

**A Year of Progress:**

The past year has been marked by incredible strides in our collective effort to make a lasting impact on the lives of children battling congenital heart defects. Through the unwavering dedication of our team, the generosity of our supporters, and the resilience of the families we serve, we have had an amazing impact.

**Empowering Families:**

We continue to expand our outreach programs, ensuring that families facing the challenges of congenital heart defects receive the support and resources they need. Our community events, third party fundraisers, and partnerships with other organizations have created a network of strength and

understanding, fostering connections that extend beyond hospital walls.

### **Looking Ahead:**

As we embrace the possibilities of a new year, our commitment to the cause burns brighter than ever. We are excited to expand our initiatives, forge new partnerships, and amplify our impact. With your continued support, we can reach even greater heights and make a profound difference in the lives of countless children and their families.

### **How You Can Help:**

- [Donate](#): Your financial support is the heartbeat of our organization. Consider making a tax-deductible donation to fuel our research, support families, and drive positive change.
- [Volunteer](#): Join us in our mission by contributing your time and skills. Whether it's organizing events, lending a compassionate ear, or assisting with administrative tasks, your involvement makes a tangible difference.
- [Spread Awareness](#): Advocate for the cause. Share our newsletter, engage with our social media, and help raise awareness about pediatric congenital heart defects.

I want to express my deepest gratitude for your unwavering support. Together, we are nurturing hope for little hearts and building a future where every child can thrive. May this season be filled with love, joy, and the promise of brighter tomorrows.

Wishing you and your loved ones a heartwarming holiday season,

Katelin Krueger  
President, The Krueger Hat Trick Foundation



[Make A Donation](#)

## Upcoming Events- Mark Your Calendar!

◆ **Happy Hour for Hope:**

Sunday, June 9, 2024 @ 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:**

Date TBD @ Jimmy's Seafood in Baltimore, MD

◆ Stay tuned as other events develop!

◆ No Christmas fundraiser this year, it will be back next year!

[KHT's 3rd Annual Bull & Oyster Roast Highlight](#)

Thank you to everyone who attended our 3rd Annual Bull & Oyster Roast! We had a blast and we hope you did too. None of this would be possible without your support, generosity, and donations and we are so grateful!



## Heart Warrior Of The Month



### Meet Daisy!

At just eleven days old, her pediatrician heard a small murmur and referred her to a cardiologist. At almost two months old Daisy had her first visit to the cardiologist. During her ECHO (sonogram of the heart), her left pulmonary artery couldn't be found. For an

entire month Daisy underwent tests to finally diagnose her with Left Pulmonary Sling. Left Pulmonary Sling happens when the Left Pulmonary Artery branches from the Right Pulmonary Artery (instead of the main trunk) and it forms a sling around the airway passing between the airway and the esophagus to reach the left lung. This caused compression to Daisy's airway and esophagus. At eight months old Daisy underwent open heart surgery to fix her left pulmonary artery.

She has fully recovered and since has had one cardiac catheterization to make sure the artery is growing appropriately with her. It's unknown if Daisy will need any more catheterizations or surgeries; it all depends on how her artery grows over the years. It is possible that one day she will need stents placed until she is considered full grown, but it still too early to tell. A fun fact about Daisy is that she was born on Veteran's Day with a father who is active duty military and two veteran grandparents! Let's celebrate Daisy and her journey and amazing outcome! And lets salute her father and grandparents for their service. Congrats Daisy!

[Share Your Heart Warrior Story](#)

## CHD News & Articles

### **A lifelong series of heart problems turned her into a staunch advocate**

Reprinted from [American Heart Association News Stories](#)

As a young girl, Chrissy Gaffney endured occasional fevers and body aches that made her struggle to walk. Although the family doctor diagnosed her with arthritis, her parents weren't convinced.

Then, when she was 12, she struggled to breathe while doing the 1-mile run for the presidential physical fitness test. She was sent home for the day. Her parents ended up taking her to a cardiologist. Tests led to the discovery of a congenital heart defect: a hole between the upper chambers of her heart. "Your daughter is going to need heart surgery," the doctor told her parents. "Sooner, rather than later."

The surgery at a Boston hospital went well. She remembers that once she recovered, she felt stronger than before. Indeed, she went on to play volleyball, basketball, track and

soccer into her adult years. (Last year, she was inducted into the athletics hall of fame at her alma mater, Worcester State University.) She went on to have two sons and a daughter.

In her early 40s, juggling the schedules of three children, Gaffney exercised less often. At 45, she resolved to try losing the roughly 25 pounds she'd added. Her new routine included walking on a track at the high school next door to the middle school where her two sons attended in Worcester, Massachusetts.

During a walk one day, Gaffney wasn't even halfway around the track when she started gasping for air. "It literally felt like an elephant was sitting on my chest," she said. She didn't call 911 because she feared her sons would see her taken away by an ambulance. She stumbled to her car and managed to drive home. She talked about it with her husband and they chalked it up to her being out of shape. She decided to wait for an upcoming appointment with her primary care physician.

Over the next few weeks, climbing the stairs at work left her completely winded. By the time she saw that doctor, she knew there was a serious problem. She wound up seeing a cardiologist, who diagnosed her with atrial flutter, a type of irregular heartbeat that causes the heart to pump very rapidly.

A procedure called a cardioversion was supposed to correct it. However, she had another episode a few weeks later. Another doctor performed a similar but different procedure, an ablation. All was well – for three years.

Sitting at the kitchen table, Gaffney's heart started racing again. Her husband, Stephen, a firefighter, rushed home from his overnight shift and took her to the emergency room. Doctors gave Gaffney another cardioversion. She later had another ablation. Three years after that, Gaffney's fingers, face and ankles swelled. These turned out to be signs of heart failure.

Now 57, Gaffney gets winded easily. She has occasional bouts of atrial fibrillation, an irregular and rapid heartbeat that can lead to blood clots. She goes through phases where she struggles and phases when she feels especially healthy and energetic. "This is my new normal," Gaffney said. "Your heart is a muscle. Over time, it takes a toll."

Gaffney continues to walk and tries to follow a heart-healthy diet. She uses her story to help other women understand their risks, such as emphasizing that heart disease is the No. 1 killer of women. She also has encouraged Massachusetts legislators to support

healthier school lunches and funding for stroke awareness and tobacco cessation. And, for many years, she's demonstrated how to perform hands-only CPR.

"Chrissy is a fantastic human being who has used her experience with adult congenital heart disease and serious symptomatic arrhythmias to help others," said her cardiologist, Dr. David D. McManus. "Her resilience, her spirit and her contributions to others through the AHA and other organizations is inspirational to me."

Gaffney's primary message: Listen to your body. "You know your body better than anybody," she said. "If something doesn't feel right, check it out and don't wait, because you just don't know."

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## **A Big Hole, Tiny Vessels & a Pioneering Procedure to Save a Newborn's Heart**

Reprinted from [NYU Langone NewsHub](#)

Max Gettinger is a typical toddler. Chubby cheeks, endlessly curious, always on the go. But his heart is unique. Unique in spirit, yes, but also unique in medical history.

Max was born with a cardiac defect so rare that the condition has no name. Only six cases have been documented worldwide since the first was reported in 1981. Max's mother, Ellen Gettinger, 35, describes her pregnancy in 2019 as uneventful until a routine ultrasound during her third trimester detected an abnormal heart. She was referred to NYU Langone Health's [Fetal Heart Disease Program](#) and [maternal-fetal medicine service](#) for an evaluation.

Tests confirmed the troubling news—a tunnel-shaped hole, or fistula, between the left and right chambers of Max's heart. The breach caused blood to recirculate, enlarging his heart and depriving other organs of oxygen. Without an urgent intervention at birth, the condition would cause heart failure. Ellen and her husband, Jonathan, were devastated by the news.

[Congenital heart conditions](#), the most common type of birth defect, affect about 1 percent of the babies born annually in the United States—some 40,000 infants. Doctors at the [Pediatric Congenital Heart Program](#), part of [Hassenfeld Children's Hospital at NYU Langone](#), treat about 250 patients each year. Hassenfeld Children's Hospital has the highest risk-adjusted survival rate of any hospital in New York State for pediatric patients



who require [congenital heart surgery](#), but Max's case was unusually complex. He was also diagnosed with a cardiac condition known as Wolff-Parkinson-White syndrome, an [arrhythmia](#) which causes a rapid heartbeat. "Max had a lethal combination of defects," explains [Frank Cecchin, MD](#), the Andrall E. Pearson Professor of Pediatric Cardiology at NYU Grossman School of Medicine and director of the [Division of Pediatric Cardiology](#).

The Gettings needed an urgent postnatal medical plan to save Max's life. About 20 members of the Pediatric Congenital Heart Program team convened to strategize ways to close the hole in Max's heart once he was born. Pediatric cardiac surgeons determined that sealing it surgically would be too risky because the defect was located on the back wall of the heart, making it difficult to access if postoperative bleeding occurred.

Interventional cardiologist [Michael Argilla, MD](#), director of the [Pediatric Catheterization Laboratory](#), suggested closing the hole with a vascular plug made of a pliable nickel-titanium alloy delivered through a catheter. The only catch: it was designed for adults. The procedure would be extremely delicate and unpredictable, the team agreed, but without it, Max would die.

Ellen began 30 hours of labor on September 25, 2019, and Max made his debut the following evening. She was able to hold him for just a few minutes before he was whisked away to Hassenfeld Children's Hospital's [Congenital Cardiovascular Care Unit](#), where Max was later placed on a ventilator. With Max in heart failure, the device enabled his heart and lungs to meet his body's need for oxygen and nutrients.

After 12 days, when Max weighed just 6 pounds, Dr. Argilla and his partner, pediatric interventional cardiologist [Sunil Saharan, MD](#), began the process of threading a tiny catheter into his heart through veins and arteries no wider than a strand of spaghetti. Just in case the plug didn't stay in place and emergency surgery became necessary, a pediatric cardiac surgeon was on standby.

For the next seven hours, without a break, Dr. Argilla and Dr. Saharan tried multiple pathways to get to the fistula, using the baby's groin, navel, and femoral artery as entry points and trying different approaches to seal the hole. For visualization, they relied on real-time X-rays with a contrast dye injected to highlight blood vessels. "We needed four hands working with all these catheters," explains Dr. Argilla. "You can't be aggressive and fast inside a heart the size of a plum."

Each step presented daunting challenges. The pathway in Max's heart had sharp turns, making it difficult to negotiate. The first mesh plug, designed for adults, didn't fit. Just as

the doctors were starting to lose hope after hours of painstaking effort, they tried one more time, using a different wire through the umbilical vein to deploy a larger plug. “We got the plug in position in 10 minutes,” recalls Dr. Saharan, “and we could tell that it fit.” The doctors felt a wave of relief as Max’s heart function improved immediately. “I’m a parent as well,” says Dr. Argilla, “so it chokes me up to think of a parent putting their child’s life in someone else’s hands. Ellen and Jonathan are phenomenal people.”

For Ellen, the intervention’s success was “the best news we ever received.” At last, they held their baby, and within days, Max was weaned off the ventilator, and then most medications. Tissue began growing over the device, securing it in place. After learning how to give a daily injection into Max’s thigh to treat his heart’s electrical problem, the Gettingers took him home to their apartment in Astoria, Queens.

Max showed no signs of an irregular heart rate over the following months, as the pandemic descended upon the world. That fall, after celebrating his first birthday, Max returned to Hassenfeld Children’s Hospital, and Dr. Cecchin normalized his heart rate by [ablating cardiac tissue](#) with a heating device to create tiny scars that block abnormal electrical signals. With both critical heart defects resolved, Max buzzed with energy.

Now a high-spirited 2-year-old as stubborn as any other, Max ran nonstop around the hospital courtyard recently as Dr. Argilla and Dr. Saharan looked on with bemused awe. “He’s a unique baby, with a unique heart,” says Dr. Saharan, clinical assistant professor of pediatrics. “He was in the right place at the right time. It doesn’t get any better than that.”

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**She wanted to thank the surgeon who saved her life as a baby. She did – as his colleague.**

Reprinted from [American Heart Association News Stories](#)

Hours after Sarah Hernandez was born in La Verne, California, doctors diagnosed problems with her heart – problems they couldn't fix. So they arranged for her to be flown to nearby Children's Hospital Los Angeles.

The trouble involved two valves in the newborn's heart. One valve was deformed and the other was overly narrow. Both congenital heart defects prevented proper blood flow. She needed open-heart surgery. After 12 hours in the operating room, pediatric cardiac surgeon Dr. Vaughn Starnes told her parents that things went even better than expected.

Sarah grew up hardly thinking about her dramatic start to life. Annual checkups with a cardiologist were about the only reminder. Her parents were somewhat reluctant to allow her to play sports, but once they did, she jumped right in. Alongside soccer and tennis, she added a love of snowboarding and surfing.

Sarah also grew up with a younger brother, Manny Jr., who was born with several issues that required frequent medical attention. He was treated at CHLA, just as Sarah had been. At the hospital, the family always used the same elevator. This meant always passing walls decorated with photographs of important events and people in the history of the hospital. One of the photos was a portrait of Starnes. "This man saved your life," Sarah's mother, Shelley, would say to her, pointing to the image. "One day you will have to thank him."

By middle school, Sarah wanted to become a heart surgeon, just like Starnes. Then she saw how the nurses caring for Manny treated him and her family with so much care and respect. The nurses made everyone feel safe. One of them paid special attention to Sarah. Knowing that Sarah dreamed of working in medicine, the nurse gave Sarah a doll to demonstrate everything she would be doing for Manny.

Manny died at age 11. Sarah, then 15, changed her dream job. She wanted to become a nurse and help families like hers.

Starnes remained a touchstone in her life. For instance, when Sarah's track team set a record, her parents congratulated her, followed by, "You've come so far, thanks to Dr. Starnes." With every achievement, Starnes' role was always acknowledged.

In April 2020, Sarah graduated from college with a bachelor's in nursing and became a registered nurse. She landed a job at her most coveted place – the same hospital where she'd had her surgery. She took the post in January 2021. At the time, all new nursing graduates were doing COVID-19-related work, such as screenings and vaccinations. She was able to switch to the cardiac ICU a few months later.

While Sarah always remembered her vow to thank Starnes, she never had. She'd considered sending a letter, but it felt awkward, and she wasn't sure what to say. In June 2021, she was working in a room that included two patients. As she treated one, a doctor entered to see the other patient. "I'm Dr. Starnes," he said, prompting Sarah to whip her head around.

After both finished with their patients, Sarah followed Starnes into the hall. "Dr. Starnes, do you have a moment?" she asked, her voice trembling. "Yes," he said. "What's up?" "I just wanted to thank you so much," she said. "You were my heart surgeon almost 25 years ago. If it wasn't for you, I wouldn't be where I am today." Starnes has performed about 9,000 surgeries during his 30 years at CHLA. He's met countless patients as teens and adults. Sarah was the first he met as his colleague. This past spring, the hospital arranged for Sarah and Starnes to meet again and have a photograph taken to accompany a hospital article.

Sarah now works in the hospital's cardiovascular acute care unit. There, patients begin their recovery after complex surgeries while their families learn the intricacies of caring for a cardiovascular patient at home. That's exactly what her parents had to do when she was a baby.

"I love being able to take care of and treat people," Sarah said. "But even more, I love being able to teach their families and make them feel safe and comfortable taking their kids home." Sarah shares her own story when it seems appropriate. It gives families hope. For Sarah's family, the emotions run deep.

"I feel like everything came full circle," Shelley said. "First, Sarah was saved by Dr. Starnes. And now she's giving back."

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**DID YOU KNOW**

APPROXIMATELY  
2-3 MILLION  
PEOPLE ARE  
THOUGHT TO BE  
LIVING WITH  
CHDS IN THE U.S.  
ALONE.



**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](#)

## 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](#)

## Advice Column

Are you a Heart Family with helpful advice? Share it with us!

[Email Us](#)

## Sponsorship Opportunities

Exciting news: KHT is offering new Corporate sponsorship packages and opportunities!

✦ **Year-long Sponsorship Packages:**

This package includes representation at all KHT events throughout the year, as well as included registration for all events.

◆ **Individual Event Sponsorships:**

This option allows you to purchase sponsorships for individual KHT events with the option to include registration.

If interested, please email [hello@thekht.org](mailto:hello@thekht.org) for details and more information.

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and support!



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