



JULY 2024



Dear Supporters,

I am filled with so much gratitude for the incredible generosity you have shown so far this year. Your unwavering support has made a profound impact on the lives of Heart Warriors and their families across the country. Our recent events, the Hearts for Hope Family Happy Hour + Cornhole Tournament and the Green Hearts Open Charity Golf Tournament, were tremendous successes that allowed us to raise over \$40,000 all thanks to you.

A heartfelt congratulations to the winners of our Cornhole Tournament, the Fairway Fortune 50/50 Raffle for Tiny Champions, and the foursome winners of the Charity Golf Tournament. Your participation

and enthusiasm were truly inspiring. We can't wait to see you all again next year!

As we look ahead, I invite you to join us for our upcoming [Little Hands Big Hearts Bull & Oyster Bash](#) in September located at Jimmy's Famous Seafood. This event promises to be an unforgettable evening of delicious food, fun, and camaraderie, all while supporting a cause close to our hearts. [Sponsorship opportunities](#) and [tickets](#) are still available, and your participation can make a significant difference.

Thank you for being a vital part of our mission. Your generosity and support ensure that we can continue providing essential resources and comfort to those who need it most. With the rising costs of items, your contributions are more crucial than ever in helping us maintain the same level of support we've always strived to provide.

Together, we continue to bring hope and support to heart warriors and their families. I look forward to seeing you at our upcoming events and being able to share with you all the good we can do because of your support.

With heartfelt thanks,

Katelin Krueger

Event Spotlight: KHT's 4th Annual Golf Tournament





Thank you to everyone who joined us at our 4th Annual Green Hearts Open: Charity Golf Tournament, presented by [WatersEdge](#)! We're thrilled to announce that we raised \$42,000 at the golf tournament and an additional \$6,000 at our Hearts for Hope Happy Hour. Your support and generosity enable us to provide resources, financial aid, programs, and more

for Heart Warriors and their families year-round. We appreciate you more than words can express!

Upcoming Event



LITTLE HANDS BIG HEARTS Bull & Oyster Bash

Saturday, September 14, 2024

Jimmy's Famous Seafood | Baltimore MD

6:00 - 10:00 PM

[Buy Tickets](#)

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Heart Warrior Of The Month



Meet Knox

Knox was born in 2019. During pregnancy, no one found that Knox had a congenital heart condition. Right when he was born and laying on mom's chest, he started to become lethargic and turned blue.

The nurses and doctor took him straight to the NICU where they found that his heart sounded good and his lungs were great, but his oxygen levels were low, which tipped off the doctor that something was wrong with the heart and the oxygen exchange.

Knox was diagnosed with Transposition of the Great Arteries and was transferred to a larger hospital for open-heart surgery. The next morning the doctors performed a septostomy to allow some oxygenated blood to flow through the body.

Two days later, mom and dad were finally able to hold their little boy for the first time, right before they handed him over to the surgeon for his open-heart surgery. The surgery went to plan and Knox did amazing during recovery.

Mom & Dad are so grateful for every some hiccups that happened towards the end of the pregnancy that pushed them to deliver to a larger hospital, and even more grateful for the team and the support they received when they had to transfer hospitals for Knox's surgery. Mom said, "We had guardian angels looking out for us this whole time." They continue to share Knox's story and every year on his birthday try to give back to those that helped them along their Heart Journey.

[Share Your Heart Warrior Story](#)

CHD News & Articles

I Am a Heart Mom

Reprinted From [Mended Hearts Blog](#)

I've really been wrestling with my identity as a heart mom. I don't want it, and I don't want it to define me, but it does. The day we found out about Mae's heart, my life changed. My title changed. I didn't feel ready, but I never will. I felt totally overwhelmed, and I still do. I still fall asleep thinking about my heart child. I still wake up thinking about my heart child. The future is so unknown, but each day is a victory.

It's one thing to be a heart mom at home: scheduling, monitoring vitals, managing medication, juggling kids, keeping everyone healthy. It's another thing to be a heart mom at a doctor's office or hospital: advocating, translating, holding and protecting. It's another thing to be a heart mom out in public: watching closely, avoiding injury and sickness, explaining things ("Yes, those are surgical scars," "No, please don't touch my child," "She might look cold, but she's not," "If she says she's dizzy, she is," "Don't push her."). One

thing that has been really hard about being a heart mom is meeting new people. It has been nearly impossible to meet people and not tell them that I am a heart mom. Because when one mom meets another mom, the first thing we talk about is our kids and when I talk about my kids it inevitably comes up that my son has a metabolic condition and, oh yeah, my daughter has half a heart. At that point things always get awkward, and that is when I get frustrated that this heart life defines us. There is so much more to Mae than her broken heart, and there is so much more to me than having kids with medical needs, but it is a huge part of our lives. I've only been a heart mom for four years, but it feels like a whole lifetime.

I am a heart mom. I've thought about burying my child more times than anyone ever should. I've handed her off to be sawed open, twice. I've seen her scream in overwhelming pain and fear. I've looked into her eyes and not seen her in there. I've seen her stare back at me with no expression but pain in her eyes. I've held her while doctors and nurses did things to her that she did not approve of. I've had to tell her, "It's OK," when really I didn't believe it myself. I've seen her question her safety with me. I've cried for her and with her in ways that have touched my soul in a place that I didn't even know existed. I've held her like a baby while she sobbed because she didn't understand what was happening to her.

I'm a heart mom. I know my way around a hospital room. I know more about the heart than I ever thought I would. I own and can use more medical equipment than I ever thought I would. I have a bond with my heart child that is so close I can't even explain it. We have walked through it together, every step. Every single one of the many appointments, we have kept each other company and held each other's hands. We have both comforted each other. We have spent nights snuggled up together watching movies in a hospital bed. We've spent more time singing in the car together. We've laughed and cried in the bathroom more times than I care to remember. We've played "Doctor Mae" and "Mommy Mae." We've danced. We know each other in a way that is almost weird. I often feel bad that I don't have the same relationship with my other kids, but at the same time I'm grateful that I didn't have to form the same relationship with them. But, through it all, we've been so blessed.

Being a heart mom isn't easy, and it never will be. Even when Mae is an adult and fully in charge of her own life and health care, I will still worry. I am the one who remembers what it was like to hear her diagnosis for the first time. I am the one who fought for my unborn baby. I am the one who took her to the hospital every other day after she was born. I will

remember all of the hard appointments. I will remember the surgeries and recoveries, when she will forget. I will forever be a heart mom.

Here is THE thing though. I realized today, as I was fighting against letting my heart mom title define me, it's okay to let it define me — it does define me. Because this life is the only life we get, and this is the life that we've been given. My family was assigned this job, to be one of the many heart families out there. I've been struggling with that concept for almost four years. I'm slowly learning how to accept it, how to be strong, how to cope and most importantly how to use it for good. My biggest assignment in life is being a heart mom and helping my daughter to be a strong heart warrior.

At 6, She Was a Pioneering Heart Patient. Nearly 7 Decades Later, She Fully Appreciates It.

Reprinted From [American Heart Association News](#)

From the time his daughter Cindy was diagnosed with a heart defect in the 1950s until the day he died more than half a century later, Kenneth Winn carried in his wallet a special piece of paper.

As the years passed, the paper grew tattered; the sketch on it, more faded. But he held on to what her cardiologist had drawn for him – a way to understand, even at its most basic, why his little girl's heart beat so quickly, why she sometimes turned blue, why even non-exertive playing wore her out. And why groundbreaking surgery – one of the first in the country on a child her age – would save her life.

For the early part of her childhood, Cindy Allen-Stuckey was in and out of hospitals while doctors sought to find the cause of her symptoms. They ruled out pneumonia and cystic fibrosis. Finally, when she was 3, doctors at a children's hospital in Indianapolis recognized her heart issues. The first was a heart murmur.

Soon after, she was diagnosed with an atrial septal defect and anomalous pulmonary venous drainage. Or, as her dad told her: "You have arteries on one side but none on the other, and a hole between the chambers."

He then showed her the sketch her cardiologist had painstakingly drawn so her parents could understand what their little girl was undergoing. Cindy had surgery when she was 6. Had they waited any longer, doctors said, she likely would have been bedridden by age 12.

The surgery went well. Subsequent notes through months and years that followed (and which Cindy tracked down after an unexpected heart scare several years ago) tell how she was symptom-free and growing normally. But in the hospital immediately after surgery, recovery played out quite differently than it would have today. In 2024, her parents would be able to stay with her. In 1956, visiting hours were limited to one hour every Sunday, and 20 minutes every Wednesday.

That was tough on her. When she came home after nine days in the hospital, she didn't want to talk about that or anything else about the surgery. "I'd been different from everyone else for six years and I didn't want to be different again," she said.

So, her parents didn't speak of it either. In elementary school, she cringed when the circulatory system came up in health class and teachers talked about the heart. She avoided the topic as best she could.

She grew up, married for the first time at age 19, had a child, got her undergraduate and master's degrees, and taught first grade – not coincidentally, to children the same age she was when she had surgery.

She told her first husband about the surgery once, but they didn't talk about it again. When her son, Brandon Allen, was born, she made certain that doctors checked for every possible heart issue he might have. (He had none.)

She's been married 36 years to her second husband, Tim Stuckey. "Somewhere along the way I told him I'd had heart surgery," she said, "and that was probably the whole conversation."

A few years ago, Cindy's heart began racing. Tim took her to her physician, who gave her the all-clear, which a precautionary electrocardiogram confirmed. A technician, seeking as much background information as possible on her heart, tracked down the notes from her surgery decades earlier.

Cindy's own research led to watching a documentary about the earliest heart surgery performed on children in 1944 at Johns Hopkins University. Turns out her surgeon, Dr. Harris B. Shumacker Jr., trained under that surgeon and performed the first heart surgery at Riley Children's Hospital in 1956 – the year Cindy had hers. "It made me realize this was a huge event for me and for Riley Hospital," she said. "I truly feel like a walking miracle."

Around then, Cindy learned one other significant piece of information: The times she felt abandoned by her parents after surgery, which included one day they didn't show up at all – the empty feelings that followed her into adulthood – weren't because they didn't care. "I finally asked my mother why they weren't there," Cindy said. "She started to cry and told me the doctor said I was so upset when she and my dad left that he thought it best they not come at all."

That was a breakthrough, one that – along with so many other thoughts and experiences – she shared with Kathy Adams, her friend since 1988. They discovered that each had surgery as children in the mid-1950s; Adams' surgery was on her eye.

"We talked about the phrase 'wounded healer' to describe people who have been through a lot and now feel their mission is to help other people," Adams said. "That is Cindy. She's a wounded healer. She helps others reach their highest potential."

Cindy has written a book that includes how her heart challenges as a child helped shape her. She is also a motivational speaker who talks about how what she endured helped her become the person she is today. She ends her talks by asking audience members to

reach under their seats. "I've placed a sketch of my dad there," she said, "holding the piece of paper with my heart drawn on it."



[Learn More](#)

After 2 Open-Heart Surgeries, She Got a Transplant – at Age 2

Reprinted From [American Heart Association News](#)

Tamika LeBlanc was 21 weeks pregnant with her first child when someone from her doctor's office in Garden Grove, California, called. They wanted her to have another ultrasound.

"We didn't get a great picture of the heart," she'd been told, prompting LeBlanc to think she was headed in for routine imaging. The ultrasound tech snapped photo after photo. It took longer than her first visit. As it dragged on, LeBlanc began to worry. Then the doctor came in to explain what the pictures showed.

Her unborn baby had heterotaxy syndrome, a rare condition marked by abnormal arrangement of organs. Congenital heart defects are the most common type of birth defect in children and often affect babies with heterotaxy syndrome. LeBlanc's baby had an underdeveloped heart with one ventricle and one atrium, so the defect meant her heart had two instead of four chambers.

Two days later, she went to see Dr. Nita Doshi, the medical director of fetal cardiology at the Children's Hospital of Orange County to learn more about her daughter's prognosis. Doshi explained that there would be no way to fully repair the child's heart. Their best option involved at least three surgeries in her first few years. However, even then, the girl may not live past her fifth birthday. LeBlanc left knowing the odds were long, but Doshi also left her feeling optimistic that her daughter could beat those odds.

When Olivia Gail LeBlanc was born on Aug. 23, 2017, Tamika held her daughter for a few seconds before she was taken for evaluation by pediatric cardiologists. Olivia underwent her first open-heart surgery at 18 days old.

Olivia had her second open-heart surgery when she was 5 months old. The best-case scenario was for Olivia to wait until she was 4 to 6 for her third open-heart surgery. But in April 2019 – at age 2 1/2 – she went into heart failure.

Her problems were so severe that she wasn't a candidate for the third planned surgery. Doshi had Olivia evaluated for a heart transplant. While she was waiting for a heart to become available, Olivia's heart stopped. She was in cardiac arrest. Doctors performed chest compressions for 45 minutes, then used a heart-lung machine to keep her alive.

Getting on a transplant list can be tricky because a patient has to be sick enough to need a new organ yet healthy enough that they'll likely thrive once they receive it. Olivia's health yo-yoed, causing her to go on and off the list starting Nov. 22, 2019.

She received a new heart on Jan. 26, 2020. Olivia had to learn how to walk and eat again. She's had other challenges, such as a vocal cord getting paralyzed during one of her intubations. "A heart transplantation is not a cure. It is a different and equally involved heart condition and complex journey," Doshi said. "Olivia is a true heart warrior and continues to inspire us with her strength, perseverance and courage."

Now approaching her 7th birthday, Olivia "has so much energy and just doesn't stop," Tamika said. Olivia takes horseback riding lessons, dance lessons and is learning to cook. "We say she has a supercharged heart," Tamika said.

The family started a nonprofit, the OG Life, named for Olivia Gail, aimed at helping families whose children are dealing with life-threatening heart conditions. This year, Olivia is serving as an American Heart Association national Heart Walk ambassador

"It's important to tell Olivia's story to give families hope," Tamika said. "In five years, I want to tell you that Olivia is still running around with her supercharged heart and there is more light being shed on heart defects and we've discovered new treatments to help our kids live longer."



HEART FAMILIES:
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OR TIPS

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[Share Helpful Advice](#)

CHD Resources

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- [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](#)
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Bull & Oyster Sponsorships Open!

Sponsorship opportunities are available for KHT's [2024 Little Hands, Big Hearts Bull & Oyster Bash](#)! We offer various sponsorship options at different price points, all of which help us to provide programs, resources, and support to Heart Warriors and their families year round.

All Little Hands, Big Hearts Bull & Oyster Bash Sponsors will receive: Opportunity to provide items for silent auction and/or raffles Acknowledgement on social media Recognition in Annual Impact Report							
	HOST SPONSOR \$7,000 <i>Exclusive!</i>	SIGNATURE SPONSOR \$5,000 <i>Exclusive!</i>	GOLD SPONSOR \$4,000 <i>Available: 3</i>	SILVER SPONSOR \$3,000 <i>Available: 5</i>	BAR SPONSOR \$2,000 <i>Available: 3</i>	DJ SPONSOR \$1,000 <i>Available: 5</i>	HERO SPONSOR \$500 <i>Unlimited</i>
Name in electronic program	LOGO	LOGO	LOGO	LOGO	LOGO	LOGO	
Signage displayed at event					BAR	DJ BOOTH	LISTED
Tickets to Bull & Oyster Bash 1 table = 10 tickets	VIP Table x2	VIP Table x2	VIP Table x2	VIP Table	Table	Table	Tickets x2
Name on event banner	LOGO	LOGO	LOGO	LOGO			
Entry into Tiny Beats Jackpot: 50/50 Raffle for Heart Warriors Drawing at Bull & Oyster Bash	x3	x2					
Verbal recognition during event							
Opportunity to provide info with all prizes & auction items							
Name displayed in Heart Dedication video at event	LOGO	LOGO	LOGO	LOGO			
Opportunity to set up info booth							
Logo listed as "hosted by" in all promotional materials							
Logo included on/with all prizes							
Opportunity to provide banner or sign							
Option to speak at event							

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