



SEPTEMBER 2023



Welcome to our newsletter, HeartStrings!

We are so excited to finally have a vessel to bring to you all the great things KHT is doing, as well as news from the Heart Community and ways you can help.

Congenital Heart Defects/Disease is the leading cause of birth defects – 1 in 100 babies born will have a CHD. Of those babies with CHD, 25% of them will need surgery to survive at some point during childhood. Although CHD is the #1 birth defect in the US, funding not only for research, but support for families is extremely underfunded. With your support, we can be a resource for many families both local and beyond. Because of you, The Krueger Hat Trick Foundation has been able to donate over \$150,000 since we started less than 3 years ago.

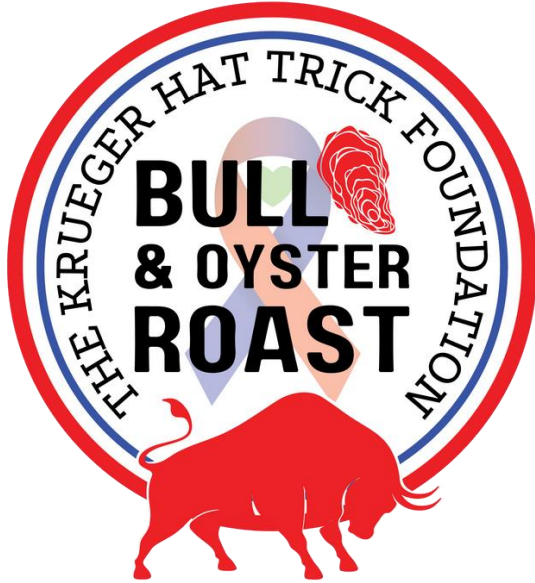
These donations have gone to amazing Heart Families not just across the country, but worldwide. They have also gone to hospital programs like Beads of Courage that inspire Heart Warriors and their families as they travel through their Journey. These donations have also been used to help fund Heart Family respite centers where families can go during their child's heart surgery, as well as pediatric waiting rooms so Heart

Warriors have somewhere to enjoy their time before their procedure. We are over the moon about all we have been able to accomplish in our short time; and we are also immensely humbled and appreciative of what you have allowed us to do. It is because of you and others in our community that have allowed KHT to help so many.

As a Heart Mom, I can tell you firsthand that this journey is not easy and often times feels extremely lonely, however you have ensured that other Heart Families don't feel so alone. And for that we thank you and hope you continue to support our mission to ensure that no one walks the Heart Journey alone.



UPCOMING EVENT SPOTLIGHT



We celebrate the strength of Heart Warriors each year at our Annual Bull & Oyster Roast in support of The Krueger Hat Trick Foundation (KHT).

Join us for KHT's 3rd Annual Bull & Oyster Roast on Friday, October 20 at Martin's West in Baltimore, MD from 7:00-11:00 PM! It will be a night of delicious food, great music, fun games, and charity! With oysters on the half shell, BBQ, open bar, and DJ Bobby - you do not want to miss this!

[View Full Details & Buy Tickets!](#)

[Become A Sponsor!](#)

HEART WARRIOR OF THE MONTH



Braxxleigh was diagnosed with Ventricular Septal Defect while mom was still pregnant with her. After Braxxleigh was born, at 3 months old, she had her first open heart surgery to repair her VSD. At 4 months old, Braxxleigh had open heart surgery number 2 to repair her mitral valve (a valve that pumps blood from one heart chamber to another). Unfortunately, the repair failed and at 8 months old Braxxleigh had open heart surgery number 3 to replace her mitral valve with a mechanical valve. As she grows, Braxxleigh will need additional surgeries to replace the valve with larger ones to fit her growing heart. A special fact about Braxxleigh is that she absolutely loves cows. Although

she does not talk much, she can tell you what almost all barn animals say! Lets congratulate Braxxleigh on her courageous journey!!

Share Your Heart Warrior Story

CHD NEWS & ARTICLES

LeBron James' son Bronny, 18, diagnosed with congenital heart defect after cardiac arrest

Reprinted from [Today.com](https://www.today.com/health/lebron-james-son-bronny-18-diagnosed-congenital-heart-defect-after-cardiac-arrest-rcna111111)

One month after Bronny James, the oldest son of NBA superstar LeBron James, suffered cardiac arrest, his family has answers as to why. In a statement given to NBC News by the James family spokesperson, the cause for the sudden cardiac arrest was identified as an "anatomically and functionally significant congenital heart defect."

"After a comprehensive initial evaluation at Cedars-Sinai Medical Center led by Dr. Merije Chukumerije and follow-up evaluations at the Mayo Clinic led by Dr. Michael J. Ackerman and Atlantic Health/Morristown Medical Center led by Dr. Matthew W. Martinez, the probable cause of Mr. James' sudden cardiac arrest (SCA) has been identified. It is an anatomically and functionally significant Congenital Heart Defect which can and will be treated," the statement reads.

"We are very confident in Bronny's full recovery and return to basketball in the very near future. We will continue to provide updates to media and respectfully reiterate the family's request for privacy."

James suffered cardiac arrest during a workout for the University of Southern California basketball team on July 24, 2023 and had to be rushed to the hospital, according to a statement from a family spokesperson. "Yesterday while practicing Bronny James suffered a cardiac arrest," the spokesperson said in a statement on July 25. "Medical staff was able to treat Bronny and take him to the hospital.

"We ask for respect and privacy for the James family and we will update media when there is more information," the statement continued. "LeBron and Savannah wish to publicly send their deepest thanks and appreciation to the USC medical and athletic staff for their incredible work and dedication to the safety of their athletes."

Bronny James is the oldest of LeBron James' three children and currently a freshman at USC. James, 18, is a freshman on the USC basketball team after being one of the nation's top recruits as a senior for Sierra Canyon School in Los Angeles. In March, he played in the prestigious McDonald's All-American Game featuring the nation's top high school players.

The 6-foot-3 guard is part of a heralded freshman class at USC. Buffalo Bills safety Damar Hamlin, who has made an [incredible return](#) to the field after suffering a [cardiac arrest](#) during a game in January, expressed his support for James one day after the incident occurred. "Prayers to Bronny & The James family as well," he [tweeted](#). "Here for you guys just like you have been for me my entire process."

James [announced his commitment to the Trojans](#) in May, keeping him in the Los Angeles area, where his father is a star for the Lakers. Following his son's announcement, LeBron James told reporters that he believed Bronny was the first person from his family to go to college. The elder James jumped straight to the NBA from high school in Ohio in 2003. "This is an incredible thing," James said, [according to NBC Sports](#). "Obviously, his dad didn't go to school. His mom didn't go to college. It's super-cool. ... USC is getting a great kid. "He's there to play basketball, (but) they're going to be super surprised at how great a kid he is, even though they've been recruiting him for a while," James said. James, 38, has also expressed his wish to one day play with his son in the NBA. Bronny will be eligible for the NBA Draft following his freshman season.

Bronny is the oldest of James' three children with his wife, Savannah. The couple's younger son, Bryce, 16, is also an elite basketball prospect who plays for Sierra Canyon, and they share 8-year-old daughter, Zhuri Nova.

As people born with congenital heart defects now live longer, challenges evolve over time

Reprinted from [American Heart Association Newsroom](#)

Nearly 40,000 infants are born with a [congenital heart defect](#) (CHD) each year in the United States and thanks to research and medical advances, most people with CHD now survive through adulthood. According to the American Heart Association, the world's leading nonprofit organization focused on heart and brain health for all, adults now outnumber children among the more than 2.4 million people living with CHD in the U.S. "Congenital heart defects occur when people are born with structural abnormalities of the heart or blood vessels involving the heart. Surgery and other medical interventions are often required to address these issues," said Anitha S. John, M.D., Ph.D., FAHA,

volunteer chair of the American Heart Association's Council on Lifelong Congenital Heart Disease and Heart Health in the Young. "It's important to note that the majority of patients, even those with complex congenital heart defects, survive to adulthood and will need specialty heart care throughout their lives. However, beyond health and medical issues, many people living with CHDs face other challenges, especially as they transition into adulthood."

A series of scientific statements recently published by the American Heart Association outline several of these obstacles:

Psychological Care

["Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease"](#), published in the Association's [Circulation: Cardiovascular Quality and Outcomes](#) journal, reviews potential psychological and social challenges that occur from infancy through adulthood among people born with heart defects and the types of mental health care that may be beneficial.

- According to the new statement, children with more complex CHDs have a 5-times higher rate of receiving an anxiety diagnosis in their lifetime compared to children without CHD.
- For adults with CHD, the rate of experiencing a mood or anxiety disorder in their lifetime is about 50%, compared to about 30% for adults in the general population.
- The statement advocates for mental health assessment and support to be part of comprehensive care for all people with CHD rather than a special service that is offered only in some places or special circumstances.

Social Determinants of Health

["Understanding and Addressing the Impact of Social Determinants of Health and Resultant Health Disparities Across the Lifespan in Congenital Heart Disease,"](#) published in the [Journal of the American Heart Association](#) (JAHA), recognizes that disparities driven by social determinants of health limit access to the lifelong specialty care needed by people living with CHDs.

- Specialty care services are concentrated in urban areas. This can make access difficult for those who live in rural or smaller communities, as well as for those who may not have transportation or who lack flexibility in taking off time from work. Insurance status also plays a part in who has access to specialty care.
- Access may also be limited in home monitoring and visitation programs and programs to support nutrition, growth and cognitive development (such as school-based outreach), In addition, these programs may have varying levels of cultural competence for supporting underrepresented populations.
- The statements note a of lack of specialty providers to support the growing number of adults with CHD continues to grow. There are fewer than 500

board-certified specialists in adult congenital heart disease in the U.S., and they are primarily located at specialty heart centers in urban areas.

Transitioning to Adulthood

[“Advances in Managing Transition to Adulthood for Adolescents with Congenital Heart Disease: A Practical Approach to Transition Program Design,”](#) also published in JAHA, suggests key aspects of care to help children with CHDs successfully transition to adult-oriented health care.

- Young people living with CHDs may not seek care as they become adults until they are facing a health crisis.
- Extended time without routine care can have a significant impact on their long-term health and quality of life.
- The statement calls for clinicians to gain a broader understanding of transition needs and barriers to successful transition, to minimize worsening health disparities for people with low socioeconomic status and those from historically under-resourced communities.

“Many people living with CHDs have tremendous resilience in the face of multiple challenges throughout their lifetime. We must do our part to improve their experiences through better awareness of those challenges, access to specialty care and recognition of the unique physiological and psychological impacts of their condition,” said John, who is an associate professor of pediatrics at George Washington University and medical director of the Washington Adult Congenital Heart Program at Children’s National Hospital, both in Washington, D.C. “It is important to involve individuals and families in research and in decision-making at every step.”

Young girl who endured heart defect and stroke is now a healthy adult

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

Seeing Shelby Lombardo's white blood cell counts periodically spike, her pediatrician thought the then-4-year-old had leukemia. But a test for the disease came back negative. Other doctors didn't know what was wrong with Lombardo. So, they sent her home with antibiotics without a definitive diagnosis.

Lombardo's mother, Misty McDougal, knew something was at the root of the problems. Something was making Lombardo sick far too often. She took her daughter to another pediatrician in their Chattanooga, Tennessee, area.

Listening to Lombardo's heart, the doctor said he heard a possible murmur. Thinking the child was just nervous, he told McDougal to bring her back in two weeks. The doctor

detected the heart abnormality again at the follow-up visit, so he recommended that Lombardo get checked out by a cardiologist. The specialist told McDougal he'd never seen anything quite this bad: Lombardo had a congenital heart defect that caused a rare mitral valve cleft and several large holes in her heart.

"As a mom, it was the most heart-wrenching thing I had ever gone through," McDougal said. "You're looking at your child and you're thinking she's just absolutely perfect. ... She's your heart and soul." Around her fifth birthday, Lombardo had open-heart surgery to repair the valve and the three holes.

About 18 months later, the first grader was getting ready for school when the left side of her body went numb. Unsure what was happening, McDougal carried her daughter into the pediatrician's office. The girl turned out to be having a stroke, and she spent several days in the hospital.

Doctors later found that Lombardo has a genetic blood-clotting disorder that likely caused the stroke; her mother and brother have the disorder, too. Months of physical therapy helped her make a full recovery. Still, for about an entire year of childhood she missed out on playground activities. She also grew up knowing her heart problems made her different from her classmates; she lacked the carefree joy of being a kid.

"I had to sit inside or on the sidewalk," Lombardo recalled. "There were so many things that I had to be cautious about at a young age. You have to grow up really quickly." At 12, Lombardo got a clean bill of health from her cardiologist.

She's now 24, married and living in Jasper, Tennessee. She sees a cardiologist annually and eats a heart-healthy diet with limited fat. She remains active, including taking walks with her dogs: Opal, a Chihuahua and dachshund mix, and Scotty, a terrier.

Lombardo recently shared her story at an American Heart Association event. Her message is rooted in her mother's quest for a correct diagnosis, as she encourages everyone to thoroughly investigate any concerns they have about their health.

"I think the biggest takeaway is to, yes, listen to your body, but also get second opinions," Lombardo said. "If you think something's wrong, there's a chance that it could be. "You shouldn't have any doubts when it comes to your health," she said. "Especially women. We put everyone else first."

McDougal advises parents to trust their gut and keep pursuing answers about their child's health if they're concerned about the quality of care they're getting. "Had I not continued down that path, my daughter could have died," McDougal said.



DID YOU KNOW

More than 1 million children and 1.4 million adults are living with CHD.

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!

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