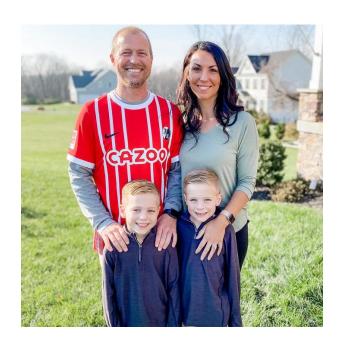


NOVEMBER 2024









Dear Supporters,

As we reflect on this season of gratitude, I am filled with immense thankfulness for your unwavering support of The Krueger Hat Trick Foundation. Thanks to your generosity, we've been able to donate to countless Heart Families, as well as local children's hospitals, providing comfort kits, meals, Beads of Courage, and more to brighten the toughest days. Your kindness ensures no one faces the Heart Journey alone.

Looking ahead, we hope you'll join us for Giving Tuesday on December 3rd to continue funding these vital programs. Every gift helps supply families with travel support, housing assistance, and

encouragement to navigate this challenging journey.

We also invite you to celebrate the season with us at the <u>Santa Brunch</u> at Twain's Tavern on December 8th, a family-friendly event filled with holiday cheer. And don't forget to mark your calendars for our exciting 2025 events, including the <u>Hearts</u> for Hope Family Happy Hour + Cornhole Tournament and the <u>Green Hearts Open Charity Golf Tournament</u>. Full details can be found at <u>thekht.org/events</u>.

Thank you for making our work possible and for being a light in the lives of those we serve. Together, we are making a lasting difference.

With heartfelt gratitude, Katelin Krueger

Upcoming Events





SANTA BRUNCH

Sunday, December 8, 2024 Twain's Tavern | Pasadena, MD

Buy Tickets!

FAIRWAY FORTUNE

50/50 Raffle for Tiny ChampionsMonday, June 9, 2024

Enter To Win!





HEARTS FOR HOPE

Family Happy Hour & Cornhole Tournament

Sunday, June 8, 2025 1:00 PM - 6:00 PM Twain's Tavern | Pasadena, MD

Join Us!

GREEN HEARTS OPEN

Charity Golf Tournament

Monday, June 9, 2025 Compass Pointe Golf Courses | Pasadena, MD

Register Now!

Heart Warrior Of the Month





Meet Patrick

Meet Patrick who is 3 and a half years old. His Heart Journey began when he was diagnosed with Hypoplastic left Heart Syndrome (HLHS) during a routine sonogram. Patrick was taken to the NICU immediately after he was born and had his first open-heart surgery when he was just 4 days old. Patrick was intubated for 2 weeks and spent an additional 4 weeks in the PICU with a feeding tube. He was finally sent home from the hospital, but unfortunately his heart journey continued 2 months later when he underwent a second open-heart surgery. After 2 weeks Patrick was discharged and was able to come home to his loving family. Patrick is growing and developing like the little warrior he is. Patrick loves playing with his dogs and loves being outside in the sunshine. Patrick's parents describe him as a happy little boy that will never give up. He is a true Heart Warrior!

Share Your Heart Warrior Story

CHD News & Articles

New Stents for Infants Mean Kids Could Avoid Series of Open Heart Operations

Reprinted From NBC News

The Food and Drug Administration recently approved a heart stent made specifically for infants and young children, a device that could help kids born with certain congenital heart defects avoid a series of open heart operations over their childhoods.

About 40,000 babies are born with congenital heart defects in the U.S. each year, according to the Centers for Disease Control and Prevention. In some cases, those defects are treated with stents, which prop open blood vessels, ensuring that blood can properly flow through them.

Typically, when infants and young children need stents, surgeons trim or modify adult-size stents and squeeze them into the tiny vessels of infants' hearts, which are about the size of a walnut. (An adult's heart is about the size of a fist.)

"What we've been doing for the past three decades is kind of jerry-rigging these adult stents and making them work for our patients," said Dr. Evan Zahn, a pediatric cardiologist and director of the Guerin Congenital Heart program at Cedars Sinai Medical Center in Los Angeles. "You can imagine that is less than ideal — they're too big."

This means that as the child grows older and their blood vessels get bigger, stents have to be replaced, often with open heart surgery, Zahn said.

"It's not unusual to have kids who are going into middle school who've had four or five or even six open heart surgeries," he said. "Their survival is great, but the amount of what I call therapeutic trauma that they have to go through is quite a burden."

The Minima stent, from the California-based biotech company Renata, is designed to grow with the child as he or she ages. Zahn is the company's chief medical officer. Instead of surgery, the size of the stent can be adjusted with a minimally invasive procedure through a blood vessel in the groin. Patients are usually able to go home about a day later, compared with around seven days for open heart surgery, including some days in the ICU.

Dr. Shabana Shahanavaz, pediatric cardiologist and director of the cardiac catheterization lab at Cincinnati Children's Hospital, said that in her 15 years of practice she's never seen a stent that was specifically manufactured for babies.

"That is mind-boggling to think that it wasn't there before," said Shahanavaz, who consults for Renata.

laire Wasserman and Ashley Louise, mothers to 8-month-old twins Raphael and Antonia Wasserman, were waiting desperately for the stent to be approved.

Raphael was born with a congenital heart defect and had open heart surgery when he was just days old. But over the next several months, Raphael became sicker as the largest blood vessel in his body narrowed. His heart was struggling to pump blood, and he urgently needed another procedure.

"It became this kind of race with time," Louise said. "How long can he wait putting off having this surgery if we are able to get to this point when the stent is approved."

The approval came just in time for Raphael, who became one of the first babies to receive the device. Zahn was Raphael's surgeon.

"I was definitely a little nervous as a physician who's using something new on somebody's baby," he said. "No matter how long you do it you're never not nervous when you're doing something that's relatively new realizing that you have somebody's most precious possession on the table with you."

Dr. Michael Argilla, a pediatric cardiologist and director of the pediatric catheterization laboratory at NYU Langone Health in New York City, said, "The word game-changer is thrown around a lot, but this stent really does change the frame of reference for a lot of our work, which is pretty amazing."

The FDA approved the Minima stent to treat two heart conditions: coarctation, or narrowing of the aorta, which is the largest blood vessel in the body; and stenosis, or narrowing and hardening, of the pulmonary artery, which pumps blood from the heart to the lungs.

Shahanavaz said that with further testing, it's possible that the stent will be approved to treat other congenital heart defects as well.

Since the surgery, Raphael is doing well in his recovery.

"It felt really amazing actually to witness medicine in progress and technology changing your life in a very real way," Louise said. "He's not going to have to have a stent replacement every three years for the next 20 years."

Modern Medicine is Changing the Prognosis for Kids with Down Syndrome and Heart Defects

Reprinted From American Heart Association News

Evelyn Hamm was born with a hole in the middle of her heart. But her parents and her doctors expected it.

During her 20-week anatomy scan, doctors detected the congenital heart condition, an atrioventricular septal defect. While uncommon, the defect is very common among children born with another condition – Trisomy 21, also known as Down syndrome. So common, in fact, it was the presence of this defect that alerted doctors to Evelyn's extra chromosome.

"We did not do prenatal genetic testing," said Rachel Hamm, who was in her late 20s when she became pregnant with Evelyn, her first child. Initially, the news that her baby was facing two serious health conditions "was overwhelming."

But during the last few months of her pregnancy, Rachel and her team of doctors had two things families of children with Down syndrome did not have decades ago: time to prepare, and a wealth of knowledge about how to treat conditions that once signaled an early death.

Advances in cardiac treatment and care over the past several decades have led to greatly improved long-term survival rates for children born with heart defects – including those with Down syndrome.

"Prenatal testing has allowed us to diagnose genetic syndromes and congenital heart defects sooner so that we can treat them sooner," said Dr. Shaun Setty, medical director of pediatric and adult congenital cardiac surgery at Miller's Children's Hospital and Long Beach Memorial Medical Center in Long Beach, California. Setty co-authored a recently published American Heart Association scientific statement on congenital heart defects in children with Trisomy 21.

"We're now operating on smaller and smaller babies," he said. "In the past, we would wait until the baby was a certain size before we would perform surgery. We now know we want to operate on them sooner because the patients will have better longevity and outcomes." Evelyn had open-heart surgery to repair the hole just four months after she was born. Three years later, her heart is doing great – and so is she, her mother said. Doctors told Rachel that Evelyn's future is "really up to her. She does not have to sit out of sports. She gets to be a typical kid and do whatever she wants to do."

Children born with Trisomy 21 have an extra copy of chromosome 21, which changes how their bodies and brains develop. About 1 in 800 children are born with Down syndrome in the U.S. each year, according to the AHA report. Up to half of them have some type of congenital heart defect, along with significant physical, neurodevelopmental, psychosocial and functional conditions that can further complicate their health and quality of life.

There are a wide variety of heart defects that affect children with Down syndrome, but most are either a hole or holes in the heart like Evelyn had. Others may have some type of abnormal heart valve, Setty said. For example, instead of two valves connecting the upper and lower chambers of the heart, there may be one common valve.

"In atrioventricular septal defects, the inside of the heart doesn't form correctly," he said. "We know there is a correlation between Trisomy 21 and the genetic mechanisms of how hearts are formed. What we don't have figured out are the exact mechanisms. The more we look into it, the more complex it is."

Treating children with Down syndrome for the myriad conditions that affect them often involves another level of complexity: negotiating the health care system to find all the specialists they might need. Children with Down syndrome and congenital heart defects may have gastrointestinal, respiratory or neurologic issues, along with endocrine disorders such as diabetes or thyroid dysfunction. They also may have blood disorders, certain types of cancer and vision or hearing issues.

Medical care centers specifically for people with Down syndrome are starting to emerge across the country. They allow families to get all the care they need in one place, saving time, stress and money.

"It not only relieves stress for families, but allows for a whole patient evaluation," Setty said. "Having an integrated system of care allows children to be seen earlier and ensures the correct specialist will see them at the right time. When a family has to navigate all of this on their own, it makes it very difficult. When care is coordinated, it also allows specialists to talk to each other so they can make sure things are not missed."

No such center exists near Helena, Alabama, where Rachel and Blair Hamm are raising Evelyn, who is now 3. Even before Evelyn was born, Rachel began researching medical options, switching hospital systems and spending hours speaking to Evelyn's pediatrician about what to expect.

"I was her center of care," Rachel said. "I was her coordinator."
In addition to the heart defect, Evelyn developed pulmonary hypertension, or high blood pressure in the lungs, which has since resolved. This condition affects up to about half of children with Down syndrome and heart defects. She also has an underactive thyroid, which her mother said is easily managed.

"She's an otherwise healthy little girl. We're very thankful for that," Rachel said. But other children with her condition aren't so lucky, and Rachel has made it her mission to advocate for them, as well as for her daughter. She sits on a steering committee working to bring a Down syndrome medical center to nearby Birmingham and is president of the Junior Board of Directors for Down Syndrome Alabama.

While enormous progress has been made in how children with Down syndrome are treated, Rachel said there needs to be a broader understanding of the condition across medical professionals, in particular when delivering a diagnosis to families.

"Down Syndrome Alabama works to help physicians deliver a compassionate diagnosis," she said. "I was not given a compassionate diagnosis. The way I was spoken to, they

were putting limitations on Evelyn before she was even born. Physicians need to understand that these children are people. They are more than just a diagnosis."

DID YOU KNOW

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



Learn More

Anaya's Story: A New Pulmonary Valve, a New Life

Reprinted From Children's Hospital of Philadelphia

Anaya is in many ways a typical toddler. She loves finger paints and swinging – so much that her parents, Linet and Reji, put a swing in their family room. Sometimes, her big emotions evoke the familiar "terrible twos." But in one important way, Anaya is not so typical – at two years old, she's already made history.

Anaya is the first patient in the world to have a MASA polymeric pulmonary valve implanted in her heart.

In May 2023, Anaya became the first human patient to have to have a MASA polymeric pulmonary valve implanted in her heart. Cardiothoracic surgeon Katsuhide Maeda, MD, PhD, performed the procedure at Children's Hospital of Philadelphia (CHOP), the first step in an early feasibility clinical study that hopes to make groundbreaking progress in the treatment for congenital heart defects.

The MASA valve is more durable and consistent in quality than homograft valves currently in use, which are made of human tissue and can fail quickly. Anaya's encouraging post-surgery progress is a promising development for the clinical trial.

"Frequent cardiac surgery can influence normal physical as well as mental growth in children," says Dr. Maeda. "Hopefully, this new conduit will last a long time, and it will avoid further frequent surgical interventions."

Life-changing news connects the family to CHOP

When Linet went for her 20-week anatomical scan in March 2021, she and Reji were devastated to hear that their unborn daughter had tetralogy of Fallot (TOF), a congenital heart defect characterized by, among other issues, a ventricular septal defect, a hole between the lower chambers of the heart, and pulmonary stenosis, a narrowing of the pulmonary valve that affects blood flow from the heart to the lungs.

Doctors at their local hospital referred the northern New Jersey couple to CHOP cardiologist Michele Cohen, DO. "From the very start, Dr. Cohen has been so helpful and given us confidence," Linet says. "Anaya loves to see her whenever we have an appointment."

Because her daughter's heart defect was diagnosed prenatally, Linet gave birth in July 2021 in CHOP's Garbose Family Special Delivery Unit (SDU) in the Richard D. Wood Jr. Center for Fetal Diagnosis and Treatment so Anaya could receive expert care immediately. Before going home, doctors inserted a temporary patent ductus arteriosus (PDA) stent to connect her aorta to her pulmonary artery to increase blood flow to the lungs. This gave her time to grow before her first heart surgery to implant the homograft valve.

First heart surgery at 10 months old

When she was 10 months old, in June 2022, Dr. Maeda performed Anaya's first openheart surgery to implant a homograft, or a pulmonary valve made of human tissue.

An echocardiogram in December 2022 showed that the valve had begun to fail, and a second homograft surgery was scheduled for April 2023, less than a year after the first. But in March, Dr. Maeda called Linet and Reji to ask if they wanted to enroll Anaya in a clinical trial to implant a new MASA polymeric pulmonary valve.

The MASA valve has several important benefits. It's made of a material designed not to be rejected by the body's immune system. And it can be manufactured with consistent quality, in different sizes to fit people of all ages. But it had never before been implanted in a human. Anaya would be the first.

A groundbreaking clinical trial offers new hope

Clinical trials depend on a series of approval processes before getting underway, which made the timing of Anaya's surgery uncertain. Dr. Maeda believed it was safe for her to wait for the trial to be approved.

Both Linet and Reji work in the pharmaceutical industry on clinical trials, so they're familiar with the protocols. "We have some understanding of the pros and cons," says Reji. "Of course, it's a different matter when it's our own daughter." Dr. Maeda gave them reading material to review, and after days of deliberation, they ultimately decided to participate in the trial.

The road ahead for Anaya

Anaya's surgery was a success, allowing her to return to normal life as an energetic toddler.

Anaya had the MASA valve implanted in May 2023. The surgery was a success; the clinical team expects the valve to last at least 10 years. Linet and Reji are amazed that their daughter's rough early road has not dampened her sunny disposition or boundless toddler energy.

Anaya has had two open-heart surgeries in her first two years of life. At her last checkup Dr. Cohen was happy to hear a clear, strong heartbeat, with only a faint murmur. "I've been waiting to hear something like that," says Linet. "It made me quite emotional."

Meanwhile, the early feasibility clinical trial continues, at 10 hospitals around the U.S.

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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Corporate sponsorships are now open! By becoming a sponsor, you'll enjoy year-round recognition while helping us achieve and exceed our ambitious goals for the year. Your generosity makes a real impact, and we deeply appreciate your support and compassion. Click the link below to join us as a sponsor and make a difference!

THE KRUEGER HAT TRICK FOUNDATION

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*To be included in Hearts for Hope & Green Hearts Open, sponsorship must be purchased by May

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BRAND EXPOSURE		2 To 1 To			1.5 × 5 × 5 × 5 × 5
Name on KHT Heartstrings Newsletter	LOGO	LOGO	LOGO	•	•
Featured social media posts for one rolling year	12	12	6	Y	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	h1 (2)			ide	
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 + Cornhole Tournament Sunday in June	10 tickets	8 tickets	6 tickets	4 tickets	
Green Hearts Open Charity Golf Tournament Menday in June	2 foursomes	2 foursomes	1 foursome	1 foursome	
Entry into Fairway Fortune: 50/50 Raffle for Tiny Champions Drawing at Golf Tournament	x3	×2	•	*	•
Little Hearts Big Hopes Bull & Oyster Bash Saturday in September	2 tables	2 tables	1 table	1 table	
Santa Brunch Weekend in December	10 tickets	8 tickets	6 tickets	4 tickets	

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