



# BEAT BY BEAT

Four families recall how they made it through the heart transplant process and are now living life in gratitude for their donors. By Heather R. Johnson

**W**HEN HEART PATIENTS talk about their experiences, they often describe it as a journey — a heart journey. It often follows a circuitous path that's filled with stumbles, hardships and, yes, progress. They make major lifestyle changes. They start taking new meds. They undergo surgeries. They enter cardiac rehab. They feel tired. They feel better than they have in years.

Occasionally, a heart journey ends at a cliff with no bridge in sight. There's no procedure to fix the problem and no amount of medication or exercise to make the heart stronger.

For the few who stand at the edge of

that scary precipice, only a heart transplant will take them to the other side. These patients get a new chance at life thanks to someone's decision to donate their heart after death. Dozens of Mended Hearts and Mended *Little* Hearts members have approached this cliff, looked over the ledge and made it across.

Here, four families share their heart transplant journeys — from the diagnosis to the anxiety-ridden waiting period, to surgery and recovery. They endured multiple surgeries, infections, medication side effects and other obstacles, but all of them survived the journey and now honor the lives of their donor families with grace and positivity.

Photos: Gaughan Family and Eddle Pearce

# DIAGNOSIS

## THE NEWS NO ONE WANTS TO HEAR

### Madie

"I knew almost immediately something was wrong," says Marcey Gaughan, when she recalls her Level 2 ultrasound. "The technician wasn't talking to us like they had with previous ultrasounds."

Their doctor soon justified the unease that Marcey and her husband, Matt, had been feeling. He informed them that their unborn baby had Hypoplastic Left Heart Syndrome (HLHS). "We felt such guilt," says Marcey. "The doctors assured us it wasn't because of something we did."

Doctors typically treat HLHS with three surgeries, often beginning within the first two weeks of birth. The surgeries don't cure the condition, but rather increase blood flow and restore heart function by letting the right ventricle do the work. Unfortunately, Madison, who goes by "Madie," had multiple organ failures right after she was born. Because of this, her heart wasn't



strong enough to survive those surgeries.

"The doctors told us a heart transplant might be required," says Matt. With Madie fighting for her life at Children's Hospital of Wisconsin in Milwaukee, doctors put her on the transplant list. Marcey and Matt prayed.

Madie Gaughan was born with Hypoplastic Left Heart Syndrome. After several organs began failing shortly after birth, her doctors put her on the transplant list.

### Ayla

Catherine Campbell and her husband, Michael, experienced a similar shock when they went for her Level 2 ultrasound. Excited friends and family waited by their phones, eager to hear whether the Campbells would have a boy or a girl. Once the nurse at UVA Medical Center in Charlottesville, Virginia, began talking to them about their unborn baby's condition, Catherine and Michael turned their ringers off.

They learned that their daughter, Ayla, had Hypoplastic Right Heart Syndrome and would need a similar number of surgeries as Madie to survive. "My husband almost passed out," Catherine says. "You don't even think of

something like this as a possibility."

When Ayla was four months old, she had her second surgery. She soon developed a blood clot, and her tiny heart stopped. Complications from the clot included arrhythmias, a stroke, seizures and a leaky heart valve. Rather than proceed with the third surgery, Ayla's doctors put her on the waiting list at UVA Children's Hospital in Charlottesville, Virginia, for a new heart.

After two surgeries to repair Ayla's Hypoplastic Right Heart Syndrome, her body wasn't strong enough to survive the third surgery she needed. Instead, she was placed on the waiting list for a new heart.



# DIAGNOSIS:



Sandra Barnes and her daughter Caroline Tart were both born with congenital heart defects that led both to have heart transplants. Barnes's sister, Donna, also had a heart transplant, but died shortly after.

## Sandra and Caroline: Mother & Daughter in Need of New Hearts

Unlike Ayla and Madie, Sandra Barnes, then 46, had lived most of her life with a heart condition. Doctors diagnosed her with a congenital heart block at age 19. Her sister, Donna, and daughter, Caroline Tart, also had heart conditions.

Donna died soon after receiving her heart transplant, at 46. That loss served as a wake-up call for Sandra and Caroline. "We knew whatever it was that we all had was serious," says Caroline, "and we would need to look for the same signs."

For Sandra, those signs came over the next three years as her health deteriorated. "I got weaker and weaker. I dreaded walking up the steps to work," she says. During her next two stays at UNC Medical Center in Chapel Hill, North Carolina, doctors began discussing

transplants with her. During her third visit, her physician put her on the national waiting list for a heart.

When Sandra got her transplant, Caroline was 15 years old and already had a pacemaker. "I knew I was on the same path [as my mother]," she says. "I just didn't know when."

Caroline, who was diagnosed with restrictive cardiomyopathy when she was 9 years old, continued through high school and college with intermittent heart-related illnesses. She started teaching, but fatigue, nausea and swelling plagued her. About a year into her teaching job, doctors diagnosed her with heart failure. Caroline was in such a fragile state that doctors told her she could not leave the hospital until she received a new heart.



## Michael Strane: No Prior Symptoms

For years, Michael Strane hiked, biked and rock climbed around his southern California home and beyond without a single symptom of heart disease. In July 2008, he suffered a massive heart attack while mountain biking with his friends.

When the then-34-year-old geologist got to the emergency room, doctors discovered that his left anterior descending artery was 100% blocked. Damage was so severe that a bypass failed. Michael received an emergency bi-ventricular assist device (an implantable pump used when both sides of the heart are failing) to keep his heart functioning.

Over the next month and a half, Michael endured internal bleeding, a

hospital-borne infection, three strokes and pneumonia. When he awoke from a medically induced coma, it was September. "I missed all of August 2008," he says. "I had a lot of trouble with that."

He spent the next few weeks relearning how to stand, swallow and talk — and gaining enough strength to survive a heart transplant surgery. "After I woke up, I lived hour to hour," he says. "I focused on things like getting out of bed and sitting in a chair for 20 minutes."

Not long after Michael woke from the coma, a wound left from the BiVAD procedure became infected. But after his white blood cell count returned to normal levels, doctors deemed him to be strong enough for transplant surgery. On September 24, 2008, doctors placed Michael on the transplant list. Seven hours later, doctors found an almost 100% match.

Geologist Michael Strane suffered a massive heart attack while mountain biking. After several failed attempts to repair his heart, he was placed on the waiting list for a new heart.

Top: Caroline Tart | Bottom: Michael Strane

# WAITING:

## WHEN DAYS FEEL LIKE YEARS

The need for organ donors consistently outpaces demand. Wait times vary from days to years. Factors that affect wait time include how well a donor matches with the recipient, the severity of the recipient's illness and how many donors are available in the patient's local area. Organ size is also crucial to the success of a transplant. United Network for Organ Sharing (UNOS) reports that only slightly more than 50% of people on the waiting list receive an organ within five years.

During the waiting period, a transplant team regularly monitors the patient to make sure he or she remains healthy enough for a transplant. Heart patients typically keep their eyes on their phones during this time. The hospital can call at any hour of the day or night with news of a match. When the call comes, the patient has to immediately stop eating and drinking and get ready for surgery. Many hospitals use pagers to alert the patient to call the hospital.



## Little Girls, Big Hearts: Madie and Ayla

Fortunately, Children's Hospital of Wisconsin uses both phones *and* pagers. On January 29, 2013, Marcey Gaughan got a call at work from hospital staff. "Did you get a page?" the nurse asked. "For the first time, I had forgot to put it on," Marcey recalls.

The hospital had found a suitable heart for Madie, and staff wanted to get her ready for surgery that afternoon. Marcey and Matt brought Madie straight to the hospital and spent a precious few hours with her before nurses took her away for the surgery.

For the Gaughans, the life-changing phone call came at the end of a rocky three months and three days. Madie had already endured two open-heart surgeries during that short time to help keep her tiny heart functioning.

Madie was taken into surgery at 2:30 p.m. and was back in her room by 10:30 that night. "They couldn't close her chest for a couple of days because the donor heart was twice the size of Madie's," says her mother.

Because the matching process is based on body weight and heart size, typically surgeons can transplant the heart of an older person into a younger patient. With

Madie Gaughan's donor heart was twice the size of the heart it was replacing. Physicians couldn't close her chest for several days after surgery, her mother, Marcey, says.

children, doctors can place a heart from a donor who is two times larger by body weight into most children with heart failure, which allows for a few more potential matches. One study also showed an improved mortality rate among infants and children who received hearts from an oversized donor compared to the same size or an undersized donor.

Unlike Madie, Ayla and her family waited at home for close to a year for the perfect heart. The leaky valve that developed after Ayla's second surgery had gotten progressively worse, to the point where she couldn't toddle across the room without wheezing and fighting for breath. When she was 3, doctors recommended putting Ayla on the transplant list, and the Campbells agreed. "It was scary listing her so young," says Catherine. "But we were grateful to be able to wait at home for the most perfect heart."



# WAITING:



## From Blur to Boredom: Sandra and Caroline

Caroline's mother, Sandra, was 46 when her heart problems escalated from bad to worse. Doctors at UNC Medical Center put Sandra on the national waiting list on July 10, 2006. One week later, they found a match.

"It was harder on my family than it was for me," Sandra says. "Once I found out, I turned it over to God. I said, 'Whatever you decide, I'm good with.'"

Sandra's daughter, Caroline, was a freshman in high school when her mom went through heart transplant surgery. Several years later, when Caroline's own heart weakened, doctors wouldn't let her leave the hospital until she received a heart transplant. She waited two long months.

Too sick to go home, but not



← Caroline had to wait two months in the hospital for a donor match. She stayed busy by visiting with friends and hanging out with a therapy dog.

bedridden, the then-24-year-old had a lot of time to kill. She stayed busy by visiting with friends, talking with her doctor and going on Starbucks trips with nurses.

During one of those trips, a nurse told her to watch for a doctor in green scrubs. A visit by a doctor in green scrubs meant the hospital found a donor heart, and it was time to get ready for surgery.

One evening at about 6 o'clock, a cardiologist, accompanied by a surgeon in green scrubs, came into her room. She knew it was time. "My mom almost passed out," she says. "I felt my stomach drop but didn't freak out. Everything went very quickly after that."

Her mother helped her wash her hair and call family members. Among the commotion, Caroline asked for a few minutes alone: "I wanted to pray for my donor family." At 11 p.m., she was wheeled away for surgery.



## HEART TRANSPLANT FACTS

Since 1988, more than 65,000 heart transplants have occurred in the U.S., according to UNOS. The top reasons people need heart transplants include:

- Coronary heart disease
- Congenital heart defects
- Viral infections that affect the heart
- Weak heart valves and muscles, which can become damaged by alcohol, pregnancy and certain medicines

## Seven Hours: Michael Strane

Michael Strane didn't have to wait long at all for a new heart — he was only on the waiting list for seven hours. "I hardly had a chance to wrap my head around what was happening," he says. Dr. Mark Cunningham of Keck Medical Center of USC performed Michael's transplant.

Michael spent about another month in the hospital recovering. Again, he set small goals. "After the transplant, it was all about reaching milestones," he says. "Walk around the room twice. Take meds without a nurse helping me."

He also set a goal to walk out of the hospital — no wheelchair. He did it. "My brother took me on the elevator down to the main floor, and we walked right out the front door. No one said anything."

Top: Caroline Tart | Bottom: kiefepix

# RECOVERY:

## Slow and Steady: Madie and Ayla

Dr. Robert Jaquiss, codirector of the heart center and division director of pediatric and congenital cardiothoracic surgery at Children's Health in Dallas, says infants and small children are less likely to reject their donor hearts than adults. Unlike grownups, children younger than age 2 can also receive transplants from across blood types, which means a wider net for potential matches.

Madie, a newborn at the time of her surgery, accepted her new heart but would not eat. "Her body knew she couldn't eat and breathe at the same time," says her mother, Marcey. Doctors inserted a G-tube, which delivers nutrition directly to the stomach, to help her as she regained her health.

Otherwise, Madie recovered well. "She looked like a Disney princess," says Marcey. "She had such rosy cheeks. I never realized how pale she was until I looked back at pictures from before her surgery." Today, Madie is about to turn 5 years old. She still receives occupational, physical and speech therapy, but is almost caught up with children her age.

Ayla Campbell had a "rough couple of months" after her transplant surgery. Her body started forming fluids, which put Ayla in constant pain. She had four invasive surgeries in four weeks, including re-opening her chest plate to fight an infection. Ayla's doctor, Dr. Thomas L'Ecuyer, says such ups and downs are typical of the recovery process, and complications tend to lessen after three months.

Today, at age 5, Ayla still has some trouble talking. She uses a speech device and sign language to compensate and is undergoing



therapy to strengthen a weak arm.

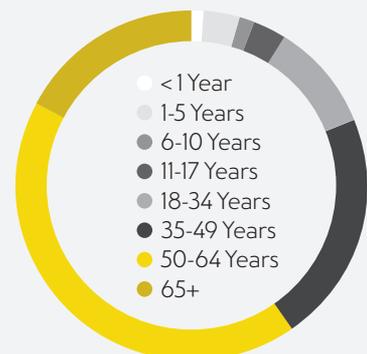
Overall, though, Catherine says Ayla is "doing amazing." The family gets daily joy from watching their daughter swim and play sports. "Now that she has the energy, she's always go, go, go," says Catherine. "I thank the donor for giving her the chance."

While helping Ayla work through developmental issues, Ayla's mother, Catherine, says the family focuses on the good. "Find the positive in everything, even when times are tough. Also, never forget these kids are amazing. They can get through so much. They've surprised the doctors many times."

Ayla uses a speech device and sign language to communicate and is "doing amazing," her mother reports. She recently threw the first pitch at a Richmond Flying Squirrels Minor League Baseball game.

## HEART TRANSPLANTS: BY THE NUMBERS

In 2016, 3,191 people — from newborns to older adults — received heart transplants, according to the United Network for Organ Sharing (UNOS). Adults age 50 to 64 made up the largest share at 42%, followed by 35- to 49-year-olds (21.7%).





It took Sandra Barnes and her daughter, Caroline Tart, about a year to feel back to normal after their heart transplant surgeries.



**As long as I've lived, I've had a heart problem. It's nice not being sick and worrying so much.**

— Caroline Tart



### Sandra and Caroline

Heart transplant surgery requires an extended, challenging recovery period. During the critical first year, rejection is the biggest risk. Sandra didn't have rejection issues, but she developed kidney problems requiring dialysis. She also lost bone density from taking prednisone, which can weaken bones over time.

A second chance at life comes with new demands as well. Patients take immunosuppressant medications for life. They also have frequent heart biopsies in the months after surgery to determine whether the body is accepting the new heart. "You'll get to know your doctor and nurses very well because of the regular checkups and monitoring of medications," Dr. Jaquiss says.

Because immunosuppressant drugs can increase skin cancer risk, Sandra stays out of the sun as much as possible. "God has truly blessed me," she says. "As a teacher, I'm around sickness all the time, but I don't get sick a lot. I'm very lucky."

In July 2017, Sandra celebrated 11 years with her new heart. She says it took her about a year to feel back to "where she needed to be." Now she can tackle

almost any activity. "I've got a young heart. I just don't have the young bones to go with it," she says with a laugh.

Sandra's physical recovery was taxing — "Some days I didn't want to walk, but the staff pushed me to get better," she says — but the emotional recovery was just as hard. "It took me a long time to get over the fact that someone had to die in order for me to live," she says.

Sandra wrote her donor family at her 10-year anniversary. To date, she hasn't received a reply, but she honors their gift. "Keep a positive attitude, be grateful for what you have, and take care of it," she says. "Eat right, and take your meds — the rate of rejection because people won't take their meds is astronomical."

Sandra's daughter, Caroline, was walking within 48 hours of her own surgery. Like her mother, Caroline took about a year to feel "normal" — but when she did, it was an even better normal than before: "As long as I've lived, I've had a heart problem," she says. "It's nice not being sick and worrying so much. I'm able to keep up with my friends and run and try to be healthy. And I have energy to do my job."

# RECOVERY:

## PATIENTS HOLD THEIR “NATIVE” HEART

Out of roughly 4,000 people who need heart transplants, only about 2,000 actually receive one. What’s even more rare? A heart transplant recipient getting to see and hold their “native” heart.

But in a lab at Baylor University Medical Center Dallas, William C. “Bill” Roberts, M.D., allows patients to do exactly that. Through Baylor’s Heart to Heart program, Dr. Roberts helps heart transplant recipients understand what caused their heart disease, and more importantly, how to take care of their donated heart.

“So few people are lucky enough to receive a heart transplant,” says Dr. Roberts, who spent much of his career studying heart disease at the National Institutes of Health. “I want them to be empowered to take care of their donor heart as best they can.”



Charles Lightner recently underwent a heart transplant at Baylor University Medical Center Dallas. Through the hospital’s Heart to Heart program, Lightner got to see and hold his “native” heart — and learn how to care for his donor heart. Here, Andrea and Charles Lightner, along with their daughter, Chasite, stand with Dr. Roberts in his lab.

## Michael Strane

Transplant patients can go on to live fairly active lives. How well they recover depends in part on a patient’s health before surgery. “For children and adults, the majority lead a fairly normal quality of life,” Dr. Jaquiss says.

Michael was an athlete before his heart attack. Today, nine years after receiving his new heart, he is almost back to his previous fitness level. Beta blockers keep him from maxing out his heart rate, but he has the fitness to hike, mountain bike, rock climb and finish 100-mile bike rides. “I’ve done everything I can to live as normal a life as possible,” he says.

Research shows Michael and others can look forward to more years of bike rides. A 2015 transplant patient study published in *Journal of Thoracic Disease* reports a five-year survival rate of 72.5%, up from 62.7% in the 1980s. Long-term survival rates also continue to climb. UNOS estimates about one of every six

Michael Strane says he honors his heart donor by living his life the best that he can.

heart recipients transplanted before 1994 survive 20 years or longer.

New immunosuppressive drugs, which allow for individually tailored regimens, contribute to this success, the report states, because doctors can better control organ rejection and drug side effects. “Someone in 2017 has a better outlook than at any time in history,” says Dr. Jaquiss.

Like Sandra, Michael wrote his donor family, but hasn’t heard back. He’s OK with that. “The greatest memorial is to live the rest of my life the best I can.” ❤️



Top: Melanie Medina | Bottom: Michael Strane