STANDING STRONG

Karin’s aortic aneurysm could have killed her. Instead, it helped her siblings avoid a similar fate.

A Second Chance at Life

What’s it like to receive a heart transplant? Four families share their stories.

PLUS:

- Hurricane Harvey not stopping Mended Little Hearts event in Houston
- A snowbird brings new life to a dying Mended Hearts chapter
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At age 3, Ayla Campbell couldn’t walk across the room to welcome her daddy home from work without wheezing. A heart transplant saved her life. Read her story, along with those of three other heart transplant recipients, on page 10.

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

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Mended Hearts members gather in Nashville for learning, networking and fireworks.

22 One Woman’s Diagnosis Helps Her Siblings Avoid Tragedy
After an aortic aneurism nearly killed her, Karin Bertozzi sought to find out why. Her discovery shed light on a genetic condition hiding in several relatives.

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On the Cover: Mended Hearts member Karin Bertozzi took some time out from her family’s summer vacation to Grand Cayman for a gorgeous photo shoot near the ocean. Though she’s the picture of health here, in 2015, she underwent a 12-hour emergency open-heart surgery for an aortic aneurysm — the same thing that took actor John Ritter’s life.
What is Repatha®?

Repatha® is an injectable prescription medicine called a PCSK9 inhibitor. Repatha® is used:

- Along with diet and maximally tolerated statin therapy in adults with atherosclerotic heart or blood vessel problems, who need additional lowering of LDL cholesterol.

The effect of Repatha® on heart problems, such as heart attacks, stroke, or death, has not been determined.

Ask your doctor if Repatha® can get you on the path to further lowering your LDL

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Do not use Repatha® if you are allergic to evolocumab or to any of the ingredients in Repatha®.

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Tell your healthcare provider or pharmacist about any prescription and over-the-counter medicines you are taking or plan to take, including natural or herbal remedies.

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• Repatha® may cause allergic reactions. Call your healthcare provider or go to the nearest hospital emergency room right away if you have any symptoms of an allergic reaction including a severe rash, redness, severe itching, a swollen face, or trouble breathing.
• The most common side effects of Repatha® include: runny nose, sore throat, symptoms of the common cold, flu or flu-like symptoms, back pain, and redness, pain, or bruising at the injection site.

You are encouraged to report negative side effects of prescription drugs to the FDA.
Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of Patient Information on next page.

Need help paying for Repatha®?
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REPATHA® (ri-PAth-a) (evolocumab)
Injection, for Subcutaneous Use

What is REPATHA?
REPATHA is an injectable prescription medicine called a PCSK9 inhibitor. REPATHA is used:
• along with diet and maximally tolerated statin therapy in adults with heterozygous familial hypercholesterolemia (an inherited condition that causes high levels of LDL or atherosclerotic heart or blood vessel problems, who need additional lowering of LDL cholesterol).
• along with diet and other LDL lowering therapies in people with homozygous familial hypercholesterolemia (an inherited condition that causes high levels of LDL), who need additional lowering of LDL cholesterol.

The effect of REPATHA on heart problems such as heart attacks, stroke, or death is not known.

It is not known if REPATHA is safe and effective in children with homozygous familial hypercholesterolemia (HoFH) who are younger than 13 years of age or in children who do not have HoFH.

Who should not use REPATHA?
Do not use REPATHA if you are allergic to evolocumab or to any of the ingredients in REPATHA. See the end of this leaflet for a complete list of ingredients in REPATHA.

What should I tell my healthcare provider before using REPATHA? Before you start using REPATHA, tell your healthcare provider about all your medical conditions, including allergies, and if you:
• are allergic to rubber or latex. The needle covers on the single-use prefilled syringes and within the needle caps on the single-use prefilled SureClick® autoinjectors contain dry natural rubber. The single-use Pushtronex™ system (on-body infusor with prefilled cartridge) is not made with natural rubber latex.
• are pregnant or plan to become pregnant. It is not known if REPATHA will harm your unborn baby. Tell your healthcare provider if you become pregnant while taking REPATHA.
• are breastfeeding or plan to breastfeed. You and your healthcare provider should decide if you will take REPATHA or breastfeed. You should not both without talking to your healthcare provider first.

Tell your healthcare provider or pharmacist about any prescription and over-the-counter medicines you are taking or plan to take, including natural or herbal remedies.

How should I use REPATHA?
• See the detailed “Instructions for Use” that comes with this patient information about the right way to prepare and administer REPATHA.
• Use REPATHA exactly as your healthcare provider tells you to use it.
• REPATHA is administered under the skin (subcutaneously), every 2 weeks or 1 time each month.
• REPATHA comes as a single-use (1 time) prefilled autoinjector (SureClick® autoinjector), as a single-use prefilled syringe, or as a single-use Pushtronex™ system (on-body infusor with prefilled cartridge). Your healthcare provider will prescribe the type and dose that is best for you.
• If your healthcare provider prescribes you the monthly dose, you may use:
  • a single-use on-body infusor with prefilled cartridge over 9 minutes, or
  • 3 separate injections in a row, using a different single-use prefilled syringe or single-use prefilled autoinjector for each injection. Give all of these injections within 30 minutes.

• if your healthcare provider decides that you or a caregiver can administer REPATHA, you or your caregiver should receive training on the right way to prepare and administer REPATHA. Do not try to administer REPATHA until you have been shown the right way by your healthcare provider or nurse.
• Do not administer REPATHA together with other injectable medicines at the same injection site.
• Always check the label of your single-use prefilled autoinjector, single-use prefilled syringe, or single-use on-body infusor with prefilled cartridge to make sure you have the correct medicine and the correct dose of REPATHA before each administration.

REPATHA may cause allergic reactions. Call your healthcare provider or go to the nearest hospital emergency room right away if you have any symptoms of an allergic reaction including a severe rash, redness, severe itching, a swollen face, or trouble breathing.

The most common side effects of REPATHA include: runny nose, sore throat, symptoms of the common cold, flu or flu-like symptoms, back pain, and redness, pain, or bruising at the injection site.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of REPATHA. Ask your healthcare provider or pharmacist for more information.

Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about the safe and effective use of REPATHA.
Medicines are sometimes prescribed for purposes other than those listed in Patient Information leaflets. Do not use REPATHA for a condition for which it was not prescribed. Do not give REPATHA to other people, even if they have the same symptoms that you have. It may harm them.

This Patient Information leaflet summarizes the most important information about REPATHA. If you would like more information, talk with your healthcare provider. You can ask your pharmacist or healthcare provider for information about REPATHA that is written for healthcare professionals.

For more information about REPATHA, go to www.REPATHA.com or call 1-844-REPATHA (1-844-737-2842).

What are the ingredients in REPATHA?
• Active Ingredient: evolocumab
• Inactive Ingredients: proline, glacial acetic acid, polysorbate 80, water for injection, and sodium hydroxide.

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Expanding Our Reach

If you’ve picked up this issue of Heartbeat from the coffee table in your doctor’s waiting room, thank you! While Heartbeat has been in circulation for quite some time, the readership has been limited to members of Mended Hearts and Mended Little Hearts. But we’re trying a little experiment with several issues in 2017. We’re working with physicians to get Heartbeat in front of a broader audience — YOU!

A quick introduction: Together, Mended Hearts and Mended Little Hearts make up the largest peer-to-peer cardiovascular support network in the world. We are a national and community-based nonprofit organization that offers the gift of hope to patients and families dealing with heart disease — whether it’s acquired or congenital. Founded in 1951 with four members, we have grown to more than 20,000 members in the U.S.

Those four original members had a motto: “It’s great to be alive — and to help others!” They realized that surviving a major heart event came with a responsibility: to help other heart patients. Members today continue living out this mission to connect those who’ve “been there” with those who are just beginning their heart journey.

And Heartbeat magazine, the official publication for Mended Hearts and Mended Little Hearts, is the pulse that keeps these friendships beating. In each issue, we offer in-depth feature stories about heart patients who are thriving, medical news and helpful tips to keep your heart healthy.

We hope you enjoy this issue of Heartbeat. Please check out our websites — www.MendedHearts.org and www.MendedLittleHearts.org — to see previous issues and learn more about us. Have a question about something you’ve read in this magazine, or about our organization? We’d love to hear from you. Email editor@mendedhearts.org.

Donnette Smith
President

Mended Hearts members have a mission to connect those who’ve ‘been there’ with those who are just beginning their heart journey.

Donnette Smith
Mended Little Hearts Symposium Is a Go for Houston

Despite record flooding from Hurricane Harvey, the Mended Little Hearts Congenital Heart Defects Symposium is still set to take place at Texas Children’s Hospital in Houston, September 22 – 23.

“We’ve spoken many times with staff at Texas Children’s, and they are enthusiastic about making sure the Symposium happens,” says Jodi Lemacks, Director of Mended Little Hearts. Texas Children’s Hospital and the Houston Marriott Medical Center Hotel experienced only minor leaks caused by the storm, according to a CBS News report.

Houston’s two main airports — George Bush Intercontinental and William P. Hobby — are also open.

Attendees can expect a packed agenda. Highlights include:

- Panel discussion on transitioning from pediatric to adult CHD care
- Keynote address from Michael Montgomery, former Green Bay Packer and Founder of The Heartbeat Away Foundation
- Presentations on innovations in CHD surgery, and regenerative medicine approaches for CHD

“Hosting this conference in Houston is so important right now,” Lemacks says. “We were told that will help the morale and economy, so I believe it will be a very positive event.” Lemacks also noted that MLH leaders are preparing 250 Bravery Bags full of items such as toiletries and other necessities that they will then donate to shelters in Houston. — MM

43 Million
That’s the number of adults in the United States providing unpaid care to another adult or to a child. The overall economic value of this care amounts to $470 billion annually. As our population ages and life expectancy continues to expand, these totals will continue trending upward.

— Source: AARP
HEART HERO

Fredonia Williams:

Mended Hearts Volunteer of the Year

At the core of Mended Hearts is education. It’s about teaching new heart disease patients that they can get better, that life will go on and that there are lots of people who live the promise of recovery and renewal.

So few should be surprised to hear that the 2017 Mended Hearts Volunteer of the Year is herself an accomplished educator. Fredonia B. Williams, Ed.D., began her career as a French and English teacher, later earned her doctorate and ascended the ranks to become a high school principal. This resident of Huntsville, Alabama, knows how to teach and lead.

The criteria for this particular accolade include participation on boards and other service in support of the Mended Hearts mission. Dr. Williams serves as the National Visiting Chair for Mended Hearts and recently completed a four-year term as Regional Director on the national board. She is currently an Assistant Regional Director (Southern Region) of Mended Hearts while also making cardiac health awareness and recovery a part of her sorority alumnae group’s community service (Delta Sigma Theta). She is a Go Red Ambassador for Huntsville Hospital. In addition, she was tapped to serve on the Novartis Heart Failure task force and worked with a research team at Duke University to develop smartphone apps for cardiac patients.

Meanwhile, she’s helped the MH Southern Region grow in ways that are both pragmatic and inspired. “We look at area hospitals and identify which have heart surgery and rehabilitation programs,” she says, detailing how she then cold calls those hospitals’ administrators and cardiac clinicians, makes presentations and explains how an active MH program effectively reduces patient re-admissions and related costs. In some cases, the hospitals cover MH membership fees for a year to kick off the program.

But Dr. Williams also knows that a MH chapter can’t be a one-size-fits-all proposition. “The strength of the program depends on the people,” she says. “In some situations it might help to have co-presidents, kind of like a buddy system. And look at your members to determine meeting times and locations.”

She is an educator who remembers being a new student. “Everyone goes through an emotional change, a fear of the unknown with heart surgery,” she says. “I share with them how I learned to control this condition. There still was a lot left to live for.” — RK
NURSING

Better-Educated Nurses Mean Healthier Patients

The Affordable Care Act included funding ($200 million) to promote nurse education, helping to bring more practitioners into caregiving and to raise the education levels and credentials of people already in nursing. This wasn’t a jobs program; the idea was to improve care and create healthier patients.

That’s an important goal for cardiac patients, as study after study shows that a well-educated nursing workforce is linked to lower mortality rates, fewer medication errors and overall positive outcomes — including fewer hospital re-admissions. More advanced training is beneficial for several reasons, not the least of which is helping nurses manage increasingly sophisticated healthcare technologies, including the use of electronic medical records.

Some important statistics to consider are:
- The number of registered nurses (RNs, who require either an Associate’s or Bachelor’s degree) rose from 2.6 million in 2008 to 2.8 million by 2015, according to the Health Resources and Services Administration.
- Multiple studies show that increasing the number of RNs with four-year degrees by 10% correlates with about a 10% drop in patient mortality rates.
- The portion of all nurses with a Bachelor’s degree or higher is between 55% and 61%.
- Ideally, the number of nurses with four-year degrees or higher should rise to 80%, according to a report from the Robert Wood Johnson Foundation (“The Future of Nursing”).

Several studies rationalize that reduced re-admission rates for patients could pay for nurses’ increased training. For patients who are hospital shopping, finding nurse training data isn’t easy, but the correlations cited above strongly suggest that hospitals with well-ranked cardiac departments are likely to have better-educated nurses. — RK
Your cardiologist is listening

If you have been limiting your work or your activities because of your chronic angina, be sure to talk about it with your cardiologist.

For tips on how to talk with your cardiologist, information about living better with angina, and support and stories from people just like you—including Donnette—visit www.SpeakFromTheHeart.com.

"I realized that by talking only about the number of attacks, I wasn’t telling my cardiologist the whole story."

Donnette, angina patient

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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

When 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.
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.

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.
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.
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 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.”

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.
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 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.

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.”

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
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%).
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.”
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 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.”

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

Top: Melanie Medina | Bottom: Michael Strane

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.”

Top: Melanie Medina | Bottom: Michael Strane
SPARKS FLY at Mended Hearts Annual Conference

Mended Hearts members gather in Nashville for learning, networking and fireworks. By Heartbeat Editors
The Gaylord Opryland Hotel & Resort provided the perfect backdrop for the 2017 Mended Hearts Annual Conference. The patriotic-themed event was planned for July 2–7 so that attendees could not only learn from speakers and network with one another, but also enjoy fireworks as one big community.

“I’m always humbled by the breadth of the journeys and stories that I hear by being around other Mended Hearts members,” says Larry Haffner, a heart valve patient from the St. Louis, Missouri, area. With more than 230 members and other friends in attendance, there were plenty of heart stories to share.

“There’s always a lot to learn about health and cardiac issues, and I want to continue to be involved, increasingly, with Mended Hearts in any way I can help,” says Haffner, who was recently appointed to the Mended Hearts Budget Committee.

Honoring Dedicated Members
Every other year at the conference, Mended Hearts introduces the newly elected Executive Committee and announces winners of several awards. The event also features three days of robust educational programming with speakers covering many topics related to heart disease, patient/family services and chapter growth.

Newly re-inaugurated President Donnette Smith had the pleasure of presenting these awards, including the “Mended Heart of the Year” award to Dr. Fredonia Williams (see separate article). Smith noted that all the award winners — and for that matter, everyone in attendance — represented the highest ideals of Mended Hearts’ mission and vision. She also expressed her gratitude and enthusiasm for the privilege of serving as Mended Hearts President for the next two years.

This year’s event also included an opening presentation, “The Vision Thing: Where Do We Go From Here?” by Executive Director Norm Linsky, who honored three long-time Mended Hearts leaders who passed away in recent months: Raul Fernandez, Frank Cecco and Bob Scott. “Mended Hearts is what it is because men and women of their caliber — and yours — dedicate countless hours of service to live out our mission of helping others,” Linsky said.

Linsky also outlined a vision for Mended Hearts, which is based on a book called Forces for Good: The Six Practices of High-Impact Non-Profits, by Leslie R. Crutchfield and Heather McLeod Grant. He stressed that Mended Hearts and Mended Little Hearts already have these practices in place, and have the building blocks for tremendous future growth and service.
And the Winner Is...

The following chapters, partners and individuals were honored during the Mended Hearts Awards Ceremony. The event was part of the 2017 national conference. Be sure to check with your local chapter leaders to find out who won the many regional awards. Congratulations to all nominees and winners!

**President’s Cup**
Recognized for outstanding performance in support of the Mended Hearts’ mission:

1-39 Members
Chapter 362, Southeast Texas, Sugarland (Houston)

40-99 Members
Chapter 380, Boise, Idaho

100+ Members
Chapter 379, Gastonia, North Carolina

**Hospital of the Year**
Recognized for allowing access to heart patients; catheterization patients and family visiting; meeting space; and more. Marvin Keyser accepted the award on behalf of the hospital.

**Memorial Regional Hospital, Hollywood, Florida**

**Sydney & Helen Shuman Nurse Recognition**
Recognized for dedication and support of nurses in cardiac care. The winners are drawn from chapter nominations, and two awards of $250 are given at local chapter presentations. This is a nationally endowed award.

**Cherry C Ramsey, RN, BS, C. RN**
Cookeville Regional Medical Center, Tennessee Chapter 127

**Gina H. Pettigrew, RN**
Conroe Regional Hospital, Texas Chapter 245

**Mary M. Amato Educational Award**
Supports students who are future health care leaders in treating heart disease. Applicants must be currently enrolled in college, technical/trade school or university. This is a $500 Award to a relative of a Mended Hearts member. This is a nationally endowed award.

**Piper A.E. Smith**, Microbiology Major at the University of Montana in Missoula. Granddaughter of Randy Gay, Chapter 324 in Missoula.

**Newsletter Awards**
Winners are selected based on appearance, content, inclusion of the president’s report, digital version and quality articles from members and clinicians.

**Newsletter (Monthly)**
Honorable Mention
CardioActivities
Chapter 62, San Diego, California
Editor: Ed Marrone (Jill Bene, Chapter President, accepted the award.)

**Newsletter (Monthly)**
Winner
Heart2Heart
Chapter 11, Louisville, Kentucky
Editor: Sandy Larimore

**Newsletter (Quarterly)**
Winner
Heartline
Chapter 230, Pontiac, Michigan
Editor: Shirley Kell

**Mended Heart of the Year**
This award honors someone who demonstrates outstanding service to the mission, nationally and regionally. It also recognizes the winner’s length of service; participation on national committees and boards or task forces. (Read more about Dr. Williams on page 7 of this issue.)

**Dr. Fredonia B. Williams**
Chapter 260
Huntsville, Alabama

**Photos: Marcia Baker**
Main Attractions
The week's highlight was a presentation by Alden Harken, M.D., the son of Mended Hearts founder Dwight Harken, M.D. Alden Harken's inspiring speech focused on the role of empathy in human relationships and recovery from traumatic events such as a heart attack.

During his presentation, Dr. Harken quoted Katherine Graham, former editor of the Washington Post, who said, “The luckiest people in the world are those who are doing something that they think is important and that everyone else thinks is important.” He then told the crowd: “That’s you all!”

On behalf of everyone in attendance, Donnette Smith thanked Dr. Harken for his presentation and noted that his was one of the most moving events in Mended Hearts’ nearly 70-year history. In conclusion, she surprised Dr. Harken by presenting him with Mended Hearts’ highest award, the Dwight Emery Harken, M.D., Award, named in honor of his father. There wasn’t a dry eye in the house.

Other speakers included John Shannon, B.S. CEP, who spoke about mindful movement following sternotomy; Philip Johnston, Pharm.D., who answered audience questions about medication adherence; and JoAnn Lindenfeld, M.D., FHFSA, who spoke about heart failure and the challenges of managing multiple medications. Their presentations were excellent, informative and appreciated by all.

Julia Carter, a retired teacher from Aiken, South Carolina (Chapter 294), says she was glad she attended. “After our first conference, we decided not to miss any of these great events,” Carter says. This was her fifth time attending. She says the biggest takeaways from this year’s conference were learning how to advocate for Mended Hearts, how the TAVR procedure provides an important new option for heart valve patients and “how hard working our staff and members are. They are truly inspiring.”

Alden Harken, M.D., won the 2017 Harken Award, named for his father, Dwight E. Harken, M.D. The late Dwight Harken founded Mended Hearts in 1951 with four of his post-surgical heart patients. Donnette Smith, President of Mended Hearts, presented the award to Alden Harken.

I’m always humbled by the breadth of the journeys and stories that I hear by being around other Mended Hearts members.
— Larry Haffner

The conference gave members a chance to meet the newly elected Executive Committee. From left: Gordon “Gus” Littlefield, Treasurer; Donnette Smith, President; Patrick Farrant, Vice President; Millie Henn, Executive Vice President, and Angel Olvera, Vice President of Mended Little Hearts. They were joined by Mended Hearts Executive Director Norm Linsky.
After an aortic aneurism nearly killed her, Karin Bertozzi sought to find out why. Her discovery shed light on a genetic condition hiding in several relatives. By Scotty Brewington
At the age of just 46, Karin Bertozzi, a yoga instructor and fit mother of three, fainted in the middle of her local grocery store. That’s the last thing she remembers until four days later.

Just after she fainted, Bertozzi was rushed by ambulance to Suburban Hospital in Bethesda, Maryland, where medical staff originally suspected a stroke. Very quickly, though, she was diagnosed with an ascending aortic aneurysm with a dissection measuring 5 centimeters. It was about to rupture, which likely would have killed her.

Bertozzi underwent a 12-hour emergency open-heart surgery to replace her damaged aorta and repair her aortic valve. For 18 days, she remained in the intensive care unit, where she fought several complications: blood clots, heart rhythm problems and even a MRSA scare (MRSA is a drug-resistant bacterial infection). During that time, she also began having heart-rhythm issues, so doctors performed another surgery to implant a dual-chamber pacemaker.

“When I finally woke up, I thought I had been in a car accident,” says Bertozzi. “When my husband and surgeon said I had open heart surgery, I didn’t believe them. For me, there were no warning signs. I had always been athletic. I had taught two yoga classes that morning — and never had high blood pressure or high cholesterol. I had done everything right.”

What Is an Aortic Aneurysm?
The aorta is the largest artery in the body. It begins in the left ventricle and runs through the chest and abdomen. Aneurysms grow slowly in the aorta, weakening and dilating the artery wall. Although most people are never aware of an aortic aneurysm, at times they can burst or rupture, which can be fatal.

Aortic aneurysms are the primary cause of nearly 10,000 deaths and a contributing cause in more than 17,000 deaths in the United States, according to the Centers for Disease Control and Prevention.
of the heart and descends all the way down into the abdomen.

An aneurysm is caused by a weakness in the aorta, which causes the aortic walls to bulge out. When an aneurysm causes a tear in the aortic wall, it’s called a dissection. If this bursts, it can lead to uncontrolled bleeding and death.

When the aneurysm occurs in the portion of the heart that rises up out of the ventricle, it is called an aortic aneurysm. If this happens toward the abdominal area, it’s called an abdominal aortic aneurysm.

Most aneurysms occur in 70- to 80-year-old men — not healthy, asymptomatic women in their 40s. To try and understand why this happened to her, Bertozzi worked with her doctors to examine her family history. She knew that her paternal grandfather had died in his sleep at age 52 of a cardiac event and that her father had suffered from an abdominal aneurysm before succumbing to cancer.

“I think my surgeon knew pretty early on that it had to be genetic. After my event, we started connecting the dots,” she says.

Bertozzi was able to find her grandfather’s autopsy, which showed that he had died of the same type of aneurysm she had. Her cardiac surgeon, Philip Corcoran, M.D., suspected that a genetic connective-tissue disorder might be to blame. He referred her to have genetic testing done at Johns Hopkins in Baltimore. She has since undergone genetic testing there, as well as through The John Ritter Foundation for Aortic Health (named after the actor who died suddenly of an acute aortic dissection) and at the University of Texas.

The results of genetic testing were inconclusive. Bertozzi did not test positive for one of the handful of “named” connective-tissue disorders. Instead, hers is one of the thousands of “unnamed” disorders, and therefore, there is not...
currently a specific gene that can be identified through genetic testing.

Since her aneurysm in October 2014, Bertozzi’s three older brothers, as well as her own three children, have been scanned for aneurysms with an echocardiogram. Two of Bertozzi’s brothers had aneurysms large enough that they required open-heart surgery. Her third brother also presented with a smaller aneurism that his doctors are monitoring.

Bertozzi’s children, as well as all of her nieces and nephews, are also scanned annually.

In total, all three of Bertozzi’s siblings and one uncle presented with a dilation of the aorta and signs of the same, unnamed genetic connective-tissue disorder.

“My family is unique in that we all have this and are all still alive, which makes us a unique grouping for geneticists to follow,” Bertozzi says. “I always joke with my doctors that once they are able to isolate the gene that causes the connective-tissue disease in our family, we should get to name it.”

Be Proactive

According to Dr. Corcoran, there are certain types of syndromes that tend to run in families that can be associated with the familial propensity of developing weakness in the tissue walls of the aorta. The most common genetic connective-tissue disorder is Marfan Syndrome. (This is not the disorder that runs in Bertozzi’s family.)

Though inherited disorders like Bertozzi’s are uncommon, they can occur. The incidence of classic Marfan Syndrome, for example, is about one in 10,000. This means that approximately 200,000 people have this predisposition in the U.S.

Bertozzi’s disorder is even less common, but it’s still out there.

“I ask my patients, ‘Are your mom and dad alive and well? What about your sisters and brothers? If not, did they have known cardiovascular problems?’” Dr. Corcoran says. “These cardiac diseases tend to run in the family and need investigating. It’s important to know your family history.”
Investigating possible cardiac disease could be as simple as a chest X-ray, a CT scan of the chest or a non-invasive echocardiogram — all of which are relatively easy and cost-effective ways to look at the aorta, Dr. Corcoran says.

Symptoms of a possible cardiac condition are shortness of breath, difficulty breathing, crushing pain that doesn’t go away after several minutes, chest pains while exercising, pain that radiates to the back, chest pain at rest or a burning chest pain that radiates to the jaw and fingers, causing them to become numb.

Bertozzi had the benefit of being close to the hospital, and EMS was able to respond rapidly. In cardiac situations, time is of the absolute essence, says Dr. Corcoran.

“Cardiac prognosis has dramatically improved in recent years. Back in the day, heart attacks had a close to 66% fatality rate,” he explains. “Now, if we can get the artery open in less than 90 minutes, we have a good chance of saving the patient. Every hour that passes with an undisgnosed condition like Karin’s, mortality rates can double.”

By being proactively screened, Bertozzi’s siblings were able to have elective surgery rather than suffer from a rupture and dissection of the aorta or other acute cardiac events, which ultimately caused the untimely deaths of John Ritter, Albert Einstein, Lucille Ball and Alan Thicke.

“Four members of Karin’s family were proactively screened and intervened upon, which hopefully saved their lives,” Dr. Corcoran says.

“I had taught two yoga classes that morning — and never had high blood pressure or high cholesterol. I had done everything right.”  
— Karin Bertozzi

Paying It Forward
For Bertozzi, this life-changing heart event has served as a springboard for her to help others going through similar traumas. She remembers a Mended Hearts visitor named John, himself a heart patient 20 years earlier, who visited her every day while she was in the hospital.

“I was really touched by his dedication. He checked on me everyday,” she says. “My husband and Mom were there with me, but they were filled with so much worry. And the doctors and nurses are focused on saving your life. John was a quiet cheerleader, reminding me that I could do this. I could get my life back.”

Today, Bertozzi serves as a visitor and patient advocate with her local Mended Hearts chapter in Washington, D.C. She visits with patients at Suburban Hospital every Friday — sometimes more — after completing her daily cardiac rehab at the hospital.

“I’m in a community of other heart patients and I draw support from that. I wanted to give back to people in the same situation I had been in,” she says. “It’s one of the highlights of my week. When I stand in front of a heart patient, I have a story to tell. I can say I know what it feels like to be on these medications, what it feels like to sneeze for the first time with an incision.”

Bertozzi also has a message for everyone, even those outside of the heart community.

“I did all the right things — I ate right, exercised, didn’t smoke — but you just can’t escape your genetics,” she says. “If you know someone in your family has had a heart event, find out what it was. Being proactive is much better than being totally blindsided in the ICU and trying to wrap your brain around it. Become educated on your family history and be aware of your genetics. Knowledge is power!”

Aortic aneurysms have taken the lives of several celebrities, including John Ritter, Alan Thicke, Lucille Ball and Albert Einstein.
STEVE PERELL GETS SO MUCH OUT OF MENDED HEARTS, HE INCLUDED IT IN HIS MOVE FROM NYACK, NEW YORK, TO LAKE WORTH, FLORIDA. BUT THIS WASN'T JUST ABOUT TRANSFERING FROM ONE CHAPTER TO ANOTHER. PERELL HAD TO RESTART A CHAPTER THAT HAD CEASED OPERATIONS.

“My wife and I were snowbirds who decided to fully relocate to Florida,” he says. “Then I received a letter that said this chapter had disbanded. I immediately made phone calls to Marvin and the hospital.”

“Marvin” is Marvin Keyser, the Mended Hearts Regional Director in the Southern Region and a certified patient advocate. The hospital is JFK Medical Center, a 460-bed facility in Atlantis, Florida, which specializes in cardiovascular care and is where the previous chapter had been based. He says the chapter’s decline was partially due to misunderstandings and “the leadership had aged out.”

Reviving the chapter took work, but Perell was up for the job. A retired high school social studies department chairperson, he knew how to set up the organization and to establish relationships with hospital staff.

He first contacted a hospital administrator and recruited a core group of MH volunteers. “The rebirth would not have been possible without the great efforts of former Chapter 206 President RoseMarie Yersy and newcomers Denise Widzgowski and Ann Kritzer,” says Perell. They went through old files to connect with people who had been involved in the past, then held elections to form a four-person board, as is required.

Perell says rekindling relationships with administrators, nurses, therapists and physicians expedited the process for accomplishing the main goal: to visit patients.

“Here in Florida, the previous chapter had been immersed in paperwork,” he explains. “But documenting everything isn’t our business. We try to keep it simple, to just focus on making people happy.”

Perell says volunteer dedication to the mission is necessary for success. “If you have that, you can deal with ups, downs, politics and planning.” With that managed, he says he gets to experience, as a MH volunteer, something similar to what he remembers from his teaching days: “When I assure a patient who’s recently had a cardiac event that their life isn’t over, their face lights up.” — RK
Two MLH Moms Share a Goal... and More

Two moms in the leadership of Mended Little Hearts of Houston have a remarkable number of things in common. But one difference – the age of their children – makes their friendship especially valuable.

Beth Gray came into her MLH involvement by way of a stepchild, now age 21, whose congenital heart condition is a relatively rare double inlet left ventricle (it was corrected through surgery at age 2). Emily Schaffhausen’s 9-year-old daughter was diagnosed with the very same condition days after birth and has also been treated with surgery. And while their children were born 12 years apart, the women have known each other since grade school.

Gray and Schaffhausen founded their MLH chapter in 2014 when a similar, unaffiliated organization folded. Both families, along with thousands of others, benefit from being in the epicenter of cardiac care, with world-renowned congenital heart defect (CHD) specialists at Texas Children’s and Children’s Memorial Hermann hospitals in Houston. But despite so many skilled providers in these institutions, MLH served an otherwise unmet need for their families.

“The hospitals can only do so much,” says Schaffhausen. “MLH is there to help the whole family. Cardiologists know they can’t do that.”

The partnership between families and healthcare providers can be seen in the mix of attendees planning to attend the Mended Little Hearts CHD Symposium in Houston this September. Gray says at least 30% will be doctors and nurses.

That dialog is increasingly important for all CHD patients who age into adulthood, as Gray’s family is now experiencing.

“There’s a bigger teen survivor population than ever before,” she observes, pointing out that adult CHD cardiology is a whole different ball game. “There is the potential for other organs to be affected,” she says. Fortunately, Texas Children’s and Houston Methodist hospitals have instituted programs to address the need for appropriate transition of care.

In the meantime, both Gray and Schaffhausen work with their teams of volunteers to help out children, mostly infants, and their families who are first grappling with CHD. “These are the families who need us most,” she says. “This is our mission.” — RK
Gifts From the Heart

Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from May 2017 through August 4, 2017.

In Memory of:
Madeline Bocuzzi
Dr. and Mrs. Edward Portnay
Robert “Bobby” Brown
Bill and Leigh Goodwyn
Kenneth Elder
Phoenix Suns
Gene Kulawik
Mended Hearts Chapter #290
Robert “Skipper” Perry
Shaun and Annette Dreyer
Patrick K. Suess
Tony Popmaeier
Marylou Magrino
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Cathy and Dan Boswick
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Ana-Maria Hurtado-Quinn
Carmela LaMonica
Mark Melnick and Family
Holly Pavia
Kathleen Rasso and Family
Steven and Claudia Thaler
Steve and Lil Trilling
Minetta Wallingford
Gaston Smikle
Dr. and Mrs. Edward Portnay
In Honor/Recognition/Celebration of:
Eryn Abernathy
Shannon Drinkwater
Rohit Loomba and Parinda Shah – in celebration of their wedding!
Maggie Raskin

Linda Mason
Michael Capaldi
Patient Advocacy Network:
In honor of Claude Ballin’s 90th Birthday!
Allen and Linda Greenbaum
In memory of Dan Cantone
Deborah and Frank Klesenski-Rispoli
In memory of Robert L. Easton
Margaret LeHew
Donation Towards Shipping Costs For Heartguides:
Mended Hearts Chapter #38
Mended Hearts Chapter #42
Mended Hearts Chapter #51
Mended Hearts Chapter #111
Mended Hearts Chapter #165
Mended Hearts Chapter #179
Mended Hearts Chapter #294

In Lieu of Expense Reimbursement:
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Millie Henn
Julie Jezowski
Ron Manriquez

Mary M. Amato Memorial Education Fund:
In memory of Joseph R. and Mary M. Amato
Anna Amato
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Neil and Nancy McDonald
Jenny Sondag for Sean, Adam, Linda, Missy, Becky, Eileen, Carrie, Eva, Jenny, Barb, Mary and Erin Thurman Law Firm
Marsha Ward
In Honor/Recognition/Celebration of:
Friendship House Staff
Wendy Carr
Jonah Mayer in celebration of his Bar Mitzvah!
Giacomo and the Mejia Family
Evely Danielle Redwine in celebration of her 8- and 9-month birthdays!
Amy Mason

2017 CHD Symposium:
Mended Little Hearts of Amarillo
Mended Little Hearts of Baltimore
Mended Little Hearts of the Bay Area
Mended Little Hearts of Columbus
Mended Little Hearts of Dallas
Mended Little Hearts of Dayton
Mended Little Hearts of Fort Worth
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Mended Little Hearts of South Central Pennsylvania
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Mended Little Hearts of Washington, D.C.

General Donations:
Evelyn Cavicchio
Grove School’s National Honor Society
Mended Little Hearts of South Central Pennsylvania
Origami Owl Custom Jewelry
Cynthia Ragan
Berence Yanez

Historical Hearts

Mended Hearts Chapter Anniversaries: September – October 2017

5 years
• Bellingham, Washington · Chapter 382 · Western Region

20 years
• Auburn, Alabama · Chapter 211 · Southern Region

35 years
• Cleveland, Ohio · Chapter 138 · Central Region
• Duluth, Minnesota · Chapter 104 · Midwest Region
• Medford, Oregon · Chapter 137 · Western Region

45 years
• Jackson, Mississippi · Chapter 76 · Southern Region
The Mended Little Hearts Congenital Heart Defects Symposium is set for September 22–23 in Houston, Texas. On Friday, there will be a “CHD According to Me” transition panel, followed by an “Out of this World” reception where you can come dressed as a character from outer space. (Darth Vader may even make an appearance.) Saturday will feature a tour of Texas Children’s Hospital, followed by a full day of outstanding speakers discussing CHD topics. A group outing to an Astros game is also on the agenda. Stay tuned for more information!