EXTREME MAKEOVER: HEART ATTACK EDITION

3 survivors swap heart-stopping habits for clean eating, lower-stress jobs and more exercise — even marathon training

Changes you can make today to lower your risk for heart attack & stroke

PLUS:
▷ A teen’s sudden cardiac death prompts new AED & CPR law
▷ Hands-only CPR training — during your layover
▷ Mission Viejo chapter shares secrets to its success
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Based on Heartbeat magazine, the app features all of the articles from each issue, as well as Mended Hearts and Mended Little Hearts news, videos, stories from survivors and more. App users can save their favorite stories, share them on social media, contact their regional representatives and post comments about the stories throughout the app. Updated with each issue of Heartbeat, the app is a great way to stay up-to-date wherever you are.

Available on iPhones as well as Android and Google devices, Heartbeat Now is a tool to supplement our members’ experience as givers of hope to heart disease patients and caregivers. Stay involved and connect with us whether you’re at home, on the go, or volunteering as a Mended Hearts or Mended Little Hearts member! As always, we aim to help our members pave the way toward happy, healthy post-diagnosis living.

Download the Heartbeat Now mobile app from your device’s app store today!
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On the Cover: After a heart attack nearly killed him, Mended Hearts member Mike Anthony lost 80 pounds and has run four marathons. His friend Tom Tumminello shot the cover photo of Mike running near a lake at Harriman State Park in New York.
As someone who has survived breast cancer as well as heart disease, I have participated in events such as the Susan G. Komen three-day walk. My daughter, who's also a heart survivor, often participates with me. It's wonderful to feel the excitement in the air and see people on the side of the road, cheering for the cancer survivors. But it does make me wonder: Why aren't heart disease survivors that excited? We should be!

Our walks and events should be celebrations. I want to see a band, cheerleaders, pom-poms, fired-up people saying, “You survived this heart attack, and you don't have to have another one! You're a survivor!” There's life after heart disease — and life during heart disease. We should be grateful and excited about that.

All too often, people who have survived heart disease focus on the fact that they can't go to their favorite burger joint as often as they'd like or that they need to quit smoking or cut down on caffeine, but think, instead, about how fortunate we are to be alive and have the option to change our habits. On page 16, you'll meet three survivors who did just that. Each looked at heart disease not as an obstacle but as a reason to make huge, positive life changes for their health. Their stories are inspiring (and exciting!).

We should also be grateful that we live in a time when technologies and treatments are improving every day. I was recently fortunate enough to witness a transcatheter aortic valve replacement. I stood at the foot of the operating table, holding my breath, and watched as they replaced the valve in the woman's still-beating heart. When they blew up the balloon to position the valve, I could see that valve actually beating, working perfectly in this woman’s heart. She had a new valve in an instant. I wanted to start cheering. It was the most incredible thing I've ever seen in my life.

I want people to feel that enthusiasm every day. We have new treatments that weren’t available even 25 years ago and so many others will be introduced in our lifetime. Living as a survivor is not a burden, it’s a blessing. Grab your pom-poms, and let’s cheer for each other.

Donnette Smith
President
Mended Hearts
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

Watch Donnette’s video
Conferences Hit the Road

Every day, every week, every month, every year... Mended Hearts and Mended Little Hearts volunteers help heart patients and families along their heart journeys. Whether the patient or family is working to accept a difficult diagnosis or deal with an intimidating surgery, you are there to tell them about your journey and help them get through theirs.

The people who organize, lead, visit and welcome shell-shocked patients who still can’t quite believe they’re sitting in a heart survivors support meeting — these are people who deserve to be celebrated.

For the first time, we’re bringing the National Education and Training Conference to you, to do just that. We’re coming to celebrate your achievements and offer new ideas. We want to learn about your challenges and hear your thoughts on where our organization is heading.

The National Education and Training Conference will happen in six cities this year. Hopefully, one of them is within a manageable drive or an affordable flight from your hometown.

Here’s what we have to offer:
• Growing your membership
• Creating programs to attract more people
• Building stronger hospital relationships
• Driving awareness through social media and marketing
• New ways to engage patients
• The latest treatment options and medications
• Networking with other heart patients and caregivers
• Regional awards
• Lots more!

The registration is a bargain: just $50 for two days of ideas and opportunities to share your successes and pick up new ways to grow a chapter or group. Think of it as a mobile town hall with great refreshments — and a passel of people who love the same things you do. I hope I get to see you there.

Michele Packard-Milam, CAE
Executive Director
Mended Hearts
For over 60 years, Mended Hearts has been helping heart patients live healthier lives. And your financial support makes a huge difference in how we do this. Here are a few ways you can help.

- **Seasonal Campaigns.** June 5 is our National Day of Giving. We honor Mended Hearts’ founder Dr. Dwight Harken’s birthday by using contributions to fund projects and educational initiatives at Mended Hearts and Mended Little Hearts. In November, “the month of giving,” we host the “Thanks for Giving” campaign where we ask friends of the organizations to help support our mission.

- **Planned Giving.** To include a gift to Mended Hearts or Mended Little Hearts in your will, discuss the matter with your estate planner or attorney.

- **Honor a Loved One.** Give a donation in honor of someone you find brave or inspiring. Their name will be printed in the “Gifts from the Heart” section of Heartbeat magazine.

- **Use AmazonSmile Instead of Amazon to Shop.** Select Mended Hearts as your charity and AmazonSmile will donate 0.5% of your purchases to Mended Hearts.

- **Donate to a Combined Federal Campaign.** Support Mended Hearts by donating to a CFC. Be sure to designate #24730.

- **Use Goodsearch Instead of Google.** Register for “Mended Hearts” on Goodsearch, a charity-fueled search engine, and every time you complete a web search, Goodsearch will donate $.01 to Mended Hearts.

Remember, you can donate any time online at www.MendedHearts.org

Thank you for your support!
The Dr. Will Hear You Now

Your physician may soon have a handy new tool to better hear the sounds of your heart and lungs. Eko Core, which was recently approved by the FDA, is an adapter that attaches to the stethoscope and amplifies the sound. Your doctor then streams your heartbeat data to your electronic health record, where he or she can then analyze the audio file, compare it to previous recordings to detect any changes and even share it with a specialist if necessary.

“The beauty of the Eko Core is that it captures heart sounds in a streamlined way that has never been done before, interfacing seamlessly into our traditional exam without requiring any extra effort,” says John Chorba, M.D., a cardiologist at U.C. San Francisco. “It really is a wonderfully simple idea with the potential to be a real game-changer.”

Its founders say Eko Core has the potential to reduce the number of unnecessary referrals, patient anxiety and expensive testing. It can be used in a number of settings, including primary care, pediatrics, cardiology, telemedicine and even medical education.

In 2015, Eko was selected to present at SXSW Health, the Aspen Ideas Festival, CES and the United Nation’s 70th Anniversary Celebration. It also ranked No. 5 on Time magazine’s best inventions of 2015. — Melanie Medina
Life didn’t begin easy for Katy Portell. Born with four congenital heart defects, surgeons transplanted a donor’s heart valve into her heart when she was just four years old. But today, Katy, 25, is living her dream as a volunteer coordinator at Southwest Transplant Alliance (STA), telling her story and encouraging organ and tissue donation.

Katy connected with Mended Hearts in 2007 while living in Alaska with her family. While picking up T-shirts for an upcoming Heart Walk, they were invited to a Mended Hearts meeting where they happened to be inaugurating Alaska’s first Mended Little Hearts group.

“We dove right in and became part of that group, meeting monthly and doing hospital visits,” Portell says.

Portell eventually relocated to Houston. There, she met a group of passionate members of The Woodlands, Texas Chapter 341 of Mended Hearts who wanted to start a Mended Little Hearts group.

“My Mom and I helped them with the groundwork and eventually a great group of moms came on and ran with it,” Portell says. “They formed Mended Little Hearts of Houston in 2014.”

Though Katy continues to support the Houston group, she moved to Dallas over a year ago to pursue her dream job promoting tissue and organ donation with STA. Soon after settling in, she reached out to Mended Little Hearts in Dallas and has been involved ever since.

Mended Little Hearts of Dallas works closely with Children’s Medical Center, where they host monthly meetings for families in the heart center and conduct regular visits.

For Portell, Mended Little Hearts is about hope, but also awareness. “My goal is to bring hope to parents who are just learning that their child has a congenital heart defect. I feel blessed as a child who has come through surgeries and hospital stays and is now able to tell them my story,” she says. “I also want to advocate for adult patients because it’s very important for families to hear that as a child grows, their care must continue.”

Portell hopes to be a role model, showing kids they can grow up and pursue their own dreams, remaining strong by eating well, exercising and keeping up with their cardiac care.

“Getting involved is how I connected with my heart story in the first place,” she says. “Now it’s a part of who I am and a passion. I will always have this, which can be scary, but there is incredible medical care out there for us now. It’s important for kids to grow up knowing that they are not alone.” — Scotty Fletcher

Tech Talk
Did you know you can access Mended Hearts resources on your phone? Read this magazine with the “Heartbeat Now” app or learn to navigate life after a heart event with the “Mended Hearts HeartGuide” app. Both are available on your iPhone or Android.
SUDDEN CARDIAC ARREST

A Heart Attack ≠ Sudden Cardiac Arrest

ONE minute, Francee Levin was talking with a teacher at Colleton County Middle School, where she held a poetry residency. The next, she was lying unconscious in an intensive care unit. In between she died. Twice.

Francee Levin didn’t suffer a near-fatal heart attack. She experienced sudden cardiac death — in her case, with no symptoms and no known cause.

Loss of heart function, or sudden cardiac arrest (SCA), causes sudden cardiac death (SCD). According to the American Heart Association, up to 80 percent of people who suffer SCD have coronary heart disease. Other risk factors include age, hypertension, an enlarged heart, elevated cholesterol, glucose intolerance, smoking and excess weight.

Aside from the fact that she was over age 55, Levin had none these risk factors and no family history of heart disease. She did have good luck. Two school nurses and a resource officer used CPR and an automated external defibrillator (AED) to keep her alive. EMTs quickly airlifted Levin to a major medical center in Charleston, South Carolina.

Despite a grim prognosis, Levin not only survived SCD and a nine-day coma, but regained full memory and physical function. The event did leave her with a weakened heart, which she continues to work on in cardiac rehab.

Levin’s story proves the importance of defibrillation when treating a person experiencing sudden cardiac arrest. “To work well, defibrillation must be done within minutes of SCA. With every minute that passes, the chances of surviving SCA drop rapidly,” the National Heart, Lung and Blood Institute reports. EMTs often have and use defibrillators. Many public places, such as shopping malls, airports, airplanes and hotels have automated external defibrillators that the public can use.

Levin believes even more public places should have AEDs. “This happens a lot more frequently than people realize,” says Levin. “If we had more defibrillators, we could save a lot more lives.” — Heather R. Johnson

Staying on Track
About 74% of heart patients reported that activity trackers — like fitness bands, blood pressure/ heart rate apps and food trackers — helped them cope with their condition, according to a survey by HealthMine, a Dallas-based health technology company. The downside? Only about 31% of heart patients use these devices.
Hands-Only CPR Saves Lives

Each year, more than 300,000 U.S. adults die from sudden cardiac arrest outside the hospital, according to the American Heart Association (AHA). Some of these deaths could be prevented if bystanders were able to perform CPR. But many times, people nearby don’t do conventional CPR — which includes mouth-to-mouth resuscitation and chest compressions — because they’re afraid they’ll hurt the victim, or because they’re not confident in their skills.

To help alleviate that fear, the AHA issued a call-to-action for bystanders to use chest-compression-only CPR. The AHA’s recommendations:

1. Tell someone to call 9-1-1, or make the call yourself
2. Start chest compressions in the center of the victim’s chest

Another tip from the AHA: Do the chest compressions to the beat of the Bee Gees’ Stayin’ Alive. The AHA has had several clever campaigns to get the word out about hands-only CPR, including videos featuring actor, comedian and physician Ken Jeong channeling his inner-John Travolta as he helps administer hands-only CPR to the iconic disco tune. They’ve also installed kiosks at several major U.S. airports so that people can learn and practice hands-only during a layover.

And for 2016, the AHA is taking their call-to-action mobile. The association will head to Florida, Georgia, Virginia, West Virginia, Ohio and Indiana with mobile demonstrations. Exact locations in each state will be posted on www.heart.org in August.

An important caveat: Hands-only CPR is not recommended for children, says Wendy Sue Swanson, M.D. with Seattle Children’s Hospital. CPR for infants younger than 12 months consists of doing 30 chest compressions (with your fingers) and then two gentle, 1-second rescue breaths, then 30 compressions again. Repeat.

For children younger than 8 years old, the CPR ratio is 30 compressions for every two breaths. This is the same compression-to-breath ratio as infants. However, the position of your hands for compression is different.

— Melanie Medina
We can’t control our genes, but we can control many lifestyle factors that contribute to heart attacks and strokes. By Heather R. Johnson
While we can’t control everything about our health, there’s plenty that each of us can do to prevent heart disease and stroke. And Million Hearts — a national initiative to prevent 1 million heart attacks and strokes by 2017 — is on a mission to educate people about those things that are within our power to control.

Their mission is needed: about 1.5 million heart attacks and strokes occur every year in the United States, according to Million Hearts, which is co-led by the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare & Medicaid Services. And one out of every six health care dollars is spent on cardiovascular disease, according to CDC data.

The good news is that with a combination of good habits and good health care, we can all reduce our heart attack risk no matter what our genes say. “This is something that we can absolutely do if we work together,” says Janet Wright, M.D., Million Hearts executive director. Read these ABC’S to help you control your risk factors.

A is for Aspirin (when appropriate)

The American Heart Association and other organizations recommend that heart attack survivors and people at high risk for heart attack take a low-dose aspirin. Aspirin thins the blood and prevents the blood clots that contribute to heart attack and stroke.

Aspirin may reduce the odds of heart attack or stroke for those who smoke or suffer from coronary artery disease, diabetes, high blood pressure or high cholesterol. However, those who haven’t had a heart attack should only take aspirin if a health care professional says it’s safe.

**GENETIC RISK FACTORS FOR HEART DISEASE AND STROKE**

In addition to environmental and lifestyle factors, genetics and other influences can increase a person’s risk for heart attack and stroke. For instance, African Americans have the highest rate of high blood pressure, which can lead to heart attack or stroke, of all ethnicities, according to Million Hearts. Low-income individuals also suffer high blood pressure, high cholesterol, heart attack and stroke more often than their higher-income peers. Those in the Southeast region of the U.S. have the highest stroke death rates.

One risk factor for heart disease that runs in families is high cholesterol. Familial hypercholesterolemia (FH) is a genetic disorder characterized by high cholesterol levels, especially “bad” LDL cholesterol. “FH is underdiagnosed and undertreated,” says Million Hearts executive director Janet Wright, M.D. “Experts and primary care doctors that manage this condition say that you don’t find an individual with FH; you find a family.”

Dr. Wright says that those treated for FH, usually with a statin, can reduce their cholesterol—and their heart attack risk—to that of the normal population. “This is a great example of how better detection and better treatment can save people from having heart attacks at an early age,” Dr. Wright says.
When your heart has to work overtime because of high blood pressure, you’re more likely to suffer a heart attack or stroke. The higher those numbers go, the higher the risk. To control blood pressure, first, monitor it regularly. And don’t just rely on a routine doctor visit, Dr. Wright says. Check your blood pressure at home, at your local pharmacy, or some other non-medical venue. A medical setting, despite good equipment and intentions, may not give the most accurate reading.

“Most of us get a little bit stressed when we go into the doctor’s office, even for something routine,” says Dr. Wright. “Blood pressure is a dynamic and sensitive indicator, so a little bit of stress can falsely elevate the numbers.” By monitoring blood pressure in a “no-pressure” environment, people get a comprehensive view of their blood pressure, which they can then pass on to the doctor.

To bring those numbers down, adopt a healthy lifestyle and talk with your doctor about medication. Of the one in three U.S. adults with high blood pressure, only about half have it under control. Lifestyle changes can go a long way toward upping that percentage.

With cholesterol, one can definitely have too much of a good thing. Our bodies need some amount of cholesterol to make hormones and digest fatty foods. But too much cholesterol can build up in artery walls and cause heart disease.

The lifestyle changes to control blood pressure — such as a healthy diet and
exercising — can also help reduce LDL cholesterol and triglyceride levels, and raise “good” (HDL) cholesterol. Studies have shown that healthful dietary changes can cut cholesterol by 20 to 30 percent.

When diet and exercise aren't enough, doctors often recommend medication. Cholesterol-lowering drugs include statins, niacin, bile-acid resins, fibric acid derivatives and cholesterol-absorption inhibitors. Some drugs provide a combination of treatments.

Statins can quickly reduce LDL cholesterol by 50 percent or more and raise HDL cholesterol by as much as 15 percent. This is great news when it comes to reducing heart attack risk. Despite the benefits, of the 71 million people eligible for statins, only a little over half take them. Many people fear or can't tolerate the side effects. Others don't want to take a pill every day or can't afford to.

Dr. Wright advises individuals to consider medication if their doctor recommends it. (Ask for a generic version, which will cut down the cost.) “[Statins] are extremely effective with few side effects,” says Dr. Wright. “Use of these drugs is associated with fewer heart attacks and strokes.”

**S Means Stop Smoking**

It’s easy to advise someone to quit smoking. It’s not so easy to do it. But quitting tobacco for good has so many benefits. The American Cancer Society reports that within a year after quitting, heart rate and blood pressure drop; the carbon monoxide level in the blood returns to normal; circulation and lung function improve; coughing and shortness of breath decrease; and, most importantly, the excess risk of coronary heart disease drops to half that of a continuing smoker.

A 2004 Surgeon General’s report showed that smoking impacts nearly every organ in the body. Smoking contributes to a host of diseases, from stroke and dental problems to reproductive health, chronic obstructive pulmonary disease (COPD) and heart disease.

Smokefree.gov helps smokers build a “quit plan” that includes the following:

- Set a quit date.
- Consider why you want to quit.
- Understand your smoking triggers.
- Understand what causes cravings.
- Ditch the reminders, such as ashtrays, and clean your car and clothes.
- Tell friends and family so they can support you.

Although a number of resources exist to help smokers quit, and the number of smokers has dropped since the Surgeon General released the first report that warned of the health hazards of smoking 50 years ago, health care providers can do more.

“We’re seeing progress, but we’d like to see more health care providers go beyond asking about smoking status to actually helping their patients quit,” Dr. Wright says. “Million Hearts is directing its efforts in this ‘assist’ step by providing a standardized protocol that helps smokers get the counseling and medication that can help them quit.”

Dr. Wright says meeting the Million Hearts goal will be a collaborative effort among patients, health care providers and non-profits. And she’s hopeful about realizing the vision of cutting the number of heart attacks and strokes by a million: “We can knock heart disease off as the nation’s number one killer.”
The American Heart Association reports that 50,000 to 100,000 advanced heart failure (AHF) patients in the United States could benefit from a left ventricular assist device (LVAD) — a mechanical device that is designed to restore blood flow throughout the body when the heart is too weak to pump blood adequately on its own. (An LVAD is also commonly referred to as a “heart pump.”) Without an LVAD, AHF patients could have poor prospects for survival and significantly limited lifestyles. Unfortunately, LVAD awareness is low among both patients and physicians, and patients often die without ever knowing that an LVAD may have been a treatment option for them.

Mended Hearts, Inc. is actively working to improve awareness and education around all heart failure treatment options, including LVADs. In mid-February, Mended Hearts launched a new, national contest called “Thanks to an LVAD” to recognize individuals who are living with LVADs and help educate and inspire others with AHF.

“Advanced heart failure is an extremely frightening and debilitating condition with very few treatment options,” said Michele Packard-Milam, CAE, executive director of Mended Hearts. “Studies have shown that LVADs can help extend the lives of some heart-failure patients and improve their quality of life, but there is not enough awareness about these devices. We created this national contest to capture the stories of real LVAD recipients — both to celebrate them and to make other heart-failure patients aware of LVADs as a treatment option.”

Through the “Thanks to an LVAD” Video Contest website (www.ThanksLVAD.com), anyone who has received an LVAD is invited to submit a short video (30 seconds or less) in which they are joined by at least one friend or loved one sharing what they believe is the best thing about the recipient having received an LVAD.

“We’re not looking for anything fancy,” said Packard-Milam. “Record the video on your iPhone, iPad or digital home video camera. The important thing is to share your story.”

Every video entry will trigger a $100 donation to Mended Hearts from St. Jude Medical, which is sponsoring the cost of the campaign. Based on participation, grants and donations could total as much as $25,000.

Contest entries will be accepted until 11:59 p.m. Pacific Time on April 12, 2016. A panel of judges will select five winning videos based on specific criteria. Winners will be highlighted through media and social media campaigns to help educate others.

Submit a video, learn more about heart failure, LVADs and contest rules by going to www.ThanksLVAD.com today. We look forward to hearing your story! 😊

1. American Heart Association, HeartMate II: A Reliable Destination; Feb. 2010
2. Ibid.
Three Mended Hearts members share how their heart attack prompted major lifestyle changes. By Heather R. Johnson
Heart attack survivors face a host of challenges after they come home from the hospital. Not only are there procedures to recover from, there may also be new medications to manage, and depression, fear and anxiety to wrestle with. On top of all that, the patient’s doctor may also recommend drastic lifestyle changes.

For many patients, it’s those lifestyle changes that are the hardest to conquer. It’s not easy for anyone to overhaul their diet, quit smoking or start an exercise routine, and yet some heart patients are tackling all of these at the same time. For heart attack survivors, though, these changes are critical to reducing their risk of a second heart attack.

By focusing on what’s to be gained — more energy, weight loss, a healthy heart — people can, over time, make the changes that lead to better health and longevity. Here are three Mended Hearts members who overhauled their lifestyles. Let their stories inspire you to make those healthy changes you may be avoiding.

**Mike Anthony: From overweight and overworked to vegan marathoner**

Mike Anthony, a member of Mended Hearts Chapter 140 in Bergen County, N.J., had a near-fatal heart attack in 2007, not long after his 40th birthday. While working stressful 14- to 16-hour days as a film location manager, Anthony gained 80 pounds and exercised only sporadically. After finishing a long stint managing the film *What Happens in Vegas*, Anthony got his wake-up call: a heart attack.

“My heart stopped when they were getting me ready for emergency stenting,” says Anthony. “It was a very shocking morning.”

Doctors implanted four stents total. “I thought my life was over,” he says. “The doctor said I had severe coronary artery disease. I didn’t want to accept that fate.”

Determined to slow the progression of his disease, Anthony entered cardiac rehabilitation and studied plans outlined by Drs. Dean Ornish, Caldwell Esselstyn and Joel Furman. “They all emphasize a plant-based diet — fruits and vegetables, high fiber, no meat or dairy, and little or no fat,” Anthony says.

He understood the benefits of veganism, but it took time for him to fully adapt to the diet and the lifestyle. “When I heard about athletes like Rich Roll and Scott Jurek, I realized you can be vegan and strong,” he says. “Then I could accept it.”

With two of America’s top ultra endurance athletes as inspiration, Anthony adopted a plant-based diet and

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I truly believe your body can heal itself if you eat well, engage in physical activity and rest.

— Mike Anthony

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Paul Maher: From take-out to clean eating king

He drank, smoked, didn’t exercise and had heart disease in his family, but at age 41, Paul Maher showed no signs of heart disease, until he went into full cardiac arrest at home. “It was a perfect storm,” he says.

About eight days after an ambulance rushed Maher to the hospital, surgeons performed quintuple bypass surgery. A few days later, they implanted a defibrillator. Two weeks post-heart attack, Virginia Hospital in Arlington, Va., discharged Maher with a lengthy list of prescriptions and advice. Now what?

Maher quickly fell back into his usual routine. He quit smoking, but only moderately cleaned up his diet. He did not, however, stop drinking, which later triggered symptoms of atrial fibrillation (Afib). The second Afib episode required a hospital stay. “That was the turning point,” he says. “I realized that I was the only one responsible for my health. I’ve got to do this.”

He immediately overhauled his eating habits to a diet of mainly fresh vegetables and fruits with few processed foods. He also started exercising six days a week. “When I met my wife, I didn’t own tennis shoes,” he says.

That soon changed, as Maher spent up to an hour a day cycling, running and sometimes swimming. He started entering sprint triathlons and 5K running events. “Always having a goal helps me stay active,” he says.
When he’s not training for an event, he spends at least 30 minutes a day with either a P90X workout or some other activity. Regular exercise and a little less overtime helps him keep stress at bay.

Eight and a half years post-heart attack, Maher takes only 10mg of Lipitor and aspirin. Although Maher’s young children only know their healthy dad, the shift didn’t come without effort. “The biggest obstacle was accepting the fact that I had to change,” he says. “I tried to skirt the lines of just doing enough, eating healthy just enough, only drinking sometimes. I realized that’s not enough. I had to fully commit to be healthy.”

**Shirley Kell: New year, new life**

Shirley Kell rang in 1997 with a heart attack. She had no symptoms but knew something didn’t feel right. Dr. James O’Neill, of Clarkston Medical Group in Clarkston, Mich., did “every heart test known to man,” she says, but couldn’t find anything wrong. And then a blood enzyme test came back positive. Three days later, she had quadruple bypass surgery.

When Kell got home from the hospital, she went into a lifestyle change frenzy. “I read every label in the grocery store, recorded every calorie I ate and walked on a treadmill every day for an hour,” Kell says. She stayed in cardiac rehab for nine-and-a-half years.

Over time, Kell wore out the belt on her treadmill. She later relaxed a bit in her strict, low-fat, low-calorie diet. She gained back most of the 50 pounds she lost. Yet, she redefined her life in other ways, letting go of an unhealthy relationship and retiring from her longtime job at General Motors. Kell’s kids, who she raised as a single mom, grew up and gained some independence. She started volunteering for the American Heart Association, Mended Hearts and organizations that help the homeless.

With her life streamlined, Kell is beginning to renew her focus on diet and exercise. She recently dove into a 21-day challenge that requires lots of vegetables and lean protein and no dairy, grains, sugar or fruit. She also spends lots of time in her garden. “I do everything I did before except shovel snow,” she says.

Of all the challenges, however, learning how to manage stress took the most focus. “There’s so much stress for anybody who works and raises kids,” she says. “I love my solitude now. I love going to lunch or dinner with friends, but home is my sanctuary. And helping others makes a world of difference.”

**The GoToGuide on Heart Attacks** — provided with this issue of Heartbeat and online at www.MendedHearts.org — is a simple guide for patients and caregivers. Learn the signs and symptoms of a heart attack, how heart attacks are treated, what to do if you think you’re having a heart attack, where to find resources and more. The GoToGuide is made possible by our sponsor, AstraZeneca.
A Matter of Time, Life and Death

Gwyneth Griffin’s death may have been prevented had others been equipped to take quick action. By Heather Elise Duge
First, there was the shortness of breath. It happened on an ordinary day for 12-year-old Gwyneth Griffin of Stafford, Va. She had a mild heart murmur and was born with a congenital heart defect — bicuspid aortic valve with stenosis — but she saw her cardiologist regularly and was cleared to do all the activities she loved: ballet, jazz, lyrical and her favorite, Irish dancing.

“Gwyneth could dance all day long, no matter where she was — at the grocery store, at school or in her room at home,” her mother, Jennifer Griffin, says.

Gwyneth’s cardiologist thought the shortness of breath could be from the demands of the middle schooler’s busy schedule. Several months later, Gwyneth and her father, Joel, attended a healthy teen-living event at her middle school. Joel went to watch his younger daughter at field day, while Gwyneth joined her friends at the track. After she ran one lap around the track, Gwyneth collapsed.

No one was able to perform CPR, so her friends immediately sent students to find the principal, a nurse, an automatic external defibrillator (AED) and Gwyneth’s dad.

“My husband arrived at the scene to find Gwyneth with no pulse,” Jennifer says. Normally, the school had an AED at the back of the gym. That one couldn’t be found, so someone ran to get the school’s second AED, which was in the front office.

When Joel got the AED, he followed the instructions and shocked Gwyneth twice. She regained her pulse.

Gwyneth spent seven weeks in the hospital as physicians worked to repair her organ systems. Her heart wasn’t strong enough for her to be taken off of sedation. The only way to give her a fighting chance was to put her on Extracorporeal Membrane Oxygenation (ECMO) — a machine that takes over the work of the heart and lungs.

Ultimately, it was determined that Gwyneth suffered a devastating and unrecoverable brain injury caused by the amount of time that passed after she collapsed. She passed away in 2012 at the age of 13.

“All of this was because, in the period of time between her collapse and my arrival on the scene, no one did anything,” Joel says in an American Heart Association video about his daughter.

CPR Training, AEDs Are Essential
Gwyneth’s story is a parent’s worst nightmare. Healthy, active teens aren’t supposed to collapse from sudden cardiac arrest (SCA). When the unthinkable does happen, time is of the essence. Quick action in the form of CPR or the use of an AED can help prevent sudden cardiac arrest from causing sudden cardiac death (SCD). Had those around Gwyneth started CPR immediately, her story may have turned out differently.

“More widespread training in CPR and availability of AEDs remarkably reduce the chance of SCA becoming SCD,” says Dr. William Scott, Professor of Pediatrics/Cardiology and Associate Vice Chairman at UT Southwestern Medical Center in Dallas. (Dr. Scott was not involved in Gwyneth’s care.)

“Research has already shown that
Sudden Cardiac Arrest in CHD Patients

William Scott, M.D., who is a Professor of Pediatrics/Cardiology and Associate Vice Chairman at UT Southwestern Medical Center in Dallas, says there are many causes of sudden cardiac death in children who have congenital heart defects. The causes generally fall into one of two groups: problems with the heart’s structure, or with its rhythm.

Structural problems “include complicated defects at birth, such as hypoplastic left heart syndrome, and those that present later in life, such as hypertrophic cardiomyopathy and Marfan syndrome,” says Dr. Scott, who works at Children’s Health.

Regarding the second group, he says, “Most of the arrhythmias are inherited, such as long QT syndrome, although some are not typically inherited — an example being Wolff-Parkinson-White syndrome.”

Also, arrhythmias may arise late after surgery for CHD. “For example, patients with Tetralogy of Fallot may be at higher risk for sudden death many years after surgery,” he explains.

Know the Warning Signs of Heart Disease

To prevent Sudden Cardiac Death in children with Congenital Heart Defects, early detection is key. If an individual is known to be at high risk for SCD, a defibrillator (ICD) can be implanted. Parents should ensure that their children have routine checkups with a primary care doctor and be aware of these potential warning signs of heart disease:

- Family history of premature death (sudden or otherwise)
- Family history of heart disease in surviving relatives, significant disability from cardiovascular disease in close relatives younger than 50 years, or specific knowledge of the occurrence of conditions (i.e., hypertrophic cardiomyopathy, long QT syndrome, Marfan syndrome or clinically important arrhythmias)
- Personal history of heart murmur
- Personal history of systemic hypertension
- Personal history of excessive fatigue
- Personal history of syncope, or excessive/progressive shortness of breath or chest pain/discomfort, particularly if present with exertion

SCD occurs much less often in communities where there is widespread training in CPR and readily available AEDs.”

The Griffins are working hard to increase CPR training and the number of AEDs in communities. Their work has resulted in Gwyneth’s Law, which was passed in Virginia in 2013.

Gwyneth’s Law has three components:
- AED placement in all schools
- CPR training for teachers
- CPR training as a high school graduation requirement

The governor of Virginia signed the law in March 2013, with the first two components going into effect immediately. Since the law was passed, four lives have been saved as a result of people receiving CPR training. The student-training component of Gwyneth’s Law is on track to be enacted in Virginia in the 2016-17 school year, and the state should have 75,000 trained individuals by next year. So far, 27 states require students to be CPR Trained. One of these is Maryland, where a child saved his sibling at home within one week of CPR training.

In December 2015, Gwyneth’s Gift Foundation — the actionable arm of Gwyneth’s Law — officially became a 501c3 non-profit organization. Through the Foundation, Jennifer and Joel focus on helping underprivileged and rural schools gain access and funding for AEDs. They also continue to advocate for the awareness and importance of CPR training for everyone. Scholarships will be provided to high school students and will one day include medical students studying cardiology, traumatic brain injury and neurology.

“Gwyneth’s death is hard to live with,” Jennifer says. “We will always wonder if she would have lived had things been different. It only takes one person to step up and do something to save a life.”
For new heart patients, life can quickly become overwhelming. They hear unfamiliar medical terms, undergo complicated procedures, take new medications and begin making major lifestyle changes.

But here’s the good news. Mended Hearts helps patients navigate through the new path life has put them on — and the new HeartGuide is their map. Inside the guide, patients will find easy-to-understand information on heart disease, risk factors, common tests and therapies, depression and medications. There are also sections for caregivers, tools and notes, and glossary and resources. It’s even available online in an interactive format and will soon be offered as an app for smartphones and tablets.

What’s more, the HeartGuide was created by the Mended Hearts medical advisory board with input from members — patients like Dr. Fredonia Williams, Southern Regional Director and National Visiting Chair. As a heart failure patient, she understands the fear that comes with a new diagnosis. “The HeartGuide is indeed the journey to a healthy heart,” she says. “This is where it starts.”

The HeartGuide app is now available for free in the app store.

Order copies of the HeartGuide for your chapter in the Officer Portal at www.mendedhearts.org. There is no cost for the guides or for shipping.

The New HeartGuide Is Here!

The new HeartGuide is made possible by our sponsors: Amgen Cardiovasclar, AstraZeneca, Bristol-Myers Squibb, Pfizer, Daiichi-Sankyo Lilly, Gilead, Janssen and Novartis Pharmaceuticals.
Strong Link to Hospital Is Key to Mission Viejo Chapter’s Success

For Dennis Galloway, serving as president of Mended Hearts Mission Viejo Chapter 216 is more than just a job. It’s personal.

“I got involved with Mended Hearts back in 2008 after having a quadruple bypass and aortic valve replacement,” Galloway says. “When I was in the hospital, I received a visit from Mended Hearts and I appreciated it so much, as did my family. I wanted to give back to my community.”

This year, the California chapter, which has 140 active members, is celebrating its 28th year. Members include those who have had a heart procedure themselves, as well as family, caregivers and others who are interested in heart disease and care.

The chapter has more than 20 accredited visitors who do several hundred visits each year, along with hundreds of phone calls and personal follow-ups with heart patients at Mission Hospital. Galloway himself has been an accredited visitor for eight years.

“When you visit a patient and they see you walking in — knowing that you have walked in their shoes and that you are back at it and healthy — it gives them hope,” Galloway says.

The chapter meets monthly and hosts an annual holiday gala as a thank you event for its many volunteers. It raises money through an annual fundraiser — Night Out with the Angels, which is held with the Los Angeles Angels of Anaheim baseball team. Chapter 216 is also one of the beneficiaries of a large golf tournament held locally every year.

Over the years, the chapter has donated close to $100,000 worth of equipment to the cardiac rehabilitation center at Mission Hospital and has provided several automated external defibrillators (AEDs) to various recreational centers and schools in Orange County. The generous group also awards a nursing scholarship to a nurse in the cardiac CICU and telemetry units and scholarships for continued education for the hospital’s...
The chapter has a website (www.mendedhearts216.org) and a monthly newsletter, *The Ticker Talker*, where it shares information about events, medical advances, members and general heart health. Galloway credits the chapter’s success to its strong relationship with Mission Hospital.

“The nurses, surgeons and cardiologists are all very supportive of our mission and very involved,” Galloway says. “We couldn’t do it without them and all of our volunteers. It’s critical to build and keep those relationships and let people in the community know we are here for them.”

The chapter holds its monthly meetings at the hospital’s cardiac center and various physicians and other specialists, as well as pharmaceutical and medical device companies, often present at the meetings.

“Our members love to learn about new technologies and solutions,” Galloway says. “Having knowledgeable industry leaders talk to our members is a big part of our educational piece.”

The Mission Viejo chapter has also mentored other area hospitals like St. Joseph Health’s St. Mary in Apple Valley, helping them develop their own Mended Hearts chapters.

Though this year marks the end of Galloway’s term as president, he plans to remain on the board of directors and will continue visiting patients.

“I’ll never give up the visits,” Galloway says. “The patients give back to us as much as we give to them. It helps us heal, too.” — Scotty Fletcher
MENDED LITTLE HEARTS GROUP SPOTLIGHT

Social Media, Word-of-Mouth Spur MLH of West Michigan’s Growth

MENDED LITTLE HEARTS of West Michigan, the state’s only group, began in 2011 when three moms of kids with congenital heart defects found each other on Facebook. Today, the group has grown to 250 members.

“We really grew through word of mouth,” says Jenna Wood, lead coordinator of the group and one of its original members. “We met with our local children’s hospital and they agreed it was needed. They really helped us spread the word.”

Wood began her journey with MLH when her youngest son, Zachary, now 7, was diagnosed in utero with a heart defect.

“At the time, we knew no children with heart defects and we felt really alone,” she says. “When my son was three, I met two other moms who were going through the same thing and lived in my area. We met for dinner one night and decided to start our own group.”

Today, the group delivers Bravery Bags to Helen DeVos Children’s Hospital filled with a care notebook, puzzle books, playing cards, a superhero pillow and a black sharpie for kids to get “autographs” from their doctors and nurses. The hospital staff gives the bags to patients having open-heart surgery and other procedures. There is also a prenatal Bravery Bag that includes an infant sleeper and hat, as well as information for parents so they are aware of the group before they have the baby.

The Michigan group held its first 5K run/walk fundraiser this year, which it plans to continue, and also has many members participate in the Fifth Third River Bank Run in Grand Rapids. “Many of our members are active runners and ask for sponsorships from friends, family and local businesses,” Wood says. “My husband ran in honor of our son.”

The group meets once a month, with presenters from Helen DeVos and the University of Michigan Health System each presenting twice a year on different therapy options and various hospital programs. For the past four years, the group has hosted a huge potluck dinner for members in honor of Congenital Heart Defect Awareness Week.

These kinds of events are important so that families and children can get to know each other, Wood says. “Families are very relieved and happy to hear that there are other people out there experiencing what they are experiencing,” she says. “The kids get to know each other and so do their siblings, which is important, too.”

Some of the hospital’s doctors and nurses also attend the annual party, allowing the kids to see them out in the “real world” and realize that they are people, too, Wood explains.

“Our hospitals recognize there is a need in our area and they are very supportive,” Wood says. “Our goal is to raise awareness and to let every family dealing with heart defects in Michigan know we are here to offer help, support and hope.”
Gifts From the Heart

Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from December 23, 2015 – February 26, 2016.

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**Historical Hearts**

**Chapter Anniversaries March/April 2016**

**5 Years**

- Columbus, OH – Chapter 371 – Midwest Region

**10 Years**

- Woonsocket, RI – Chapter 338 – Northeast Region
- Portland, ME – Chapter 339 – Northeast Region

**15 Years**

- Rancho Mirage, CA – Chapter 281 – Western Region

**25 Years**

- Lima, OH – Chapter 111 – Central Region

**40 Years**

- Washington, D.C. – Chapter 94 – Mid-Atlantic Region

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**50 Years**

- Rochester, NY – Chapter 50 – Northeast Region

**Mended Little Hearts Anniversaries March – May 2016**

**5 Years**

- Mended Little Hearts of the Rocky Mountains - Denver, CO - Southwest Region
- Mississippi Gulf Coast Mended Little Hearts - Gulfport, MS - Southern Region
Mended Hearts is the largest cardiovascular peer-to-peer support network in the world. We have 300 chapters and satellites in nearly every state. Our community-based organization is built upon the principles of service, charity and partnership.

To find out more about our services and to locate a chapter near you, reach out to one of our Mended Hearts Regional Directors listed below or go online at mendedhearts.org.

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