FEELING GOOD AGAIN

Cardiac rehab can get heart patients back to work (and play) — yet many don’t participate

PLUS:
- Who’s at risk for blood clots? (Kids can get them, too!)
- Mended Hearts makes it easier to form chapters
- MLH of Milwaukee’s cool approach to leadership

Check out the winners of Mended Little Hearts’ Rock Your Scar photo contest
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You can now read Heartbeat magazine on the go with the Heartbeat Now app, available on iPhones as well as Android and Google devices. The app features everything you love about the magazine and more. With the app, you can:

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Updated with each issue of Heartbeat, the app is a great way to stay up-to-date on Mended Hearts and Mended Little Hearts news wherever you are!
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On the Cover: Not long after suffering a heart attack, Willa Welter, a member of Mended Hearts Chapter 183, in Cape Girardeau, Mo., was able to return to work as a manager/stylist at Great Clips. She credits cardiac rehab with giving her the confidence to exercise. Flip to page 8 to see what Welter and other members have to say about the role of cardiac rehab in their recovery.
What Are You Waiting For?

Heartbeat readers, I have a challenge for you. Become a Mended Hearts or Mended Little Hearts accredited visitor today, if you’re not already one. Face-to-face visits with heart patients and their loved ones are the backbone of our organization, and we need more visitors among our ranks in order to grow.

But visiting is about more than the organization. It’s about helping other human beings when they’re most vulnerable.

I offer up this challenge as both a patient and an accredited visitor. I clearly remember going to the hospital in 1988 for my first open heart surgery. I was 40 years old and very active; my kids were still in school and I was working full time. But I thought my life was over.

As I lay in that hospital bed, scared out of my mind, I got a knock on the door. It was a Mended Hearts visitor who’d been through the same surgery I was about to have. This gentleman had had his surgery two years prior, and he was fit and healthy — back at his job and playing golf.

If this man hadn’t come in that room and been able to answer my questions from a patient’s perspective, I don’t think I could have gone through with the surgery. It was like he had thrown me a life preserver. That visit inspired me to become a visitor.

I know there are barriers to visiting: we don’t have time. We’re shy. We don’t know how. These are easier to overcome than you think. Training is online and generally takes three hours. Once you’re accredited, you can visit as often as you have time — it doesn’t have to be an all-day affair. You can also shadow a more seasoned visitor as long as you’d like until you feel comfortable doing it on your own.

Help Mended Hearts and Mended Little Hearts do what we do best — help others! Get started by going to our website for details: www.mendedhearts.org.

Donnette Smith
President
Mended Hearts
The Irony of Rehab

IN THIS ISSUE, WE LEARN THAT REHAB DRASTICALLY REDUCES the risk of a second MI, further cardiac events and rehospitalizations.

Even so, rehab is underutilized. Rehab is not consistently prescribed by many physicians, and when it is prescribed, most patients do not go. In fact, doctors don’t refer patients to rehab if they don’t think the patient is likely to go. And patients who start rehab often don’t complete it:

- Only 14-35% of MI survivors and 31% of Medicare patients who undergo coronary bypass surgery participate in rehab.*
- Only 5.4% of eligible older patients who had experienced a heart attack completed 36 or more sessions.
- Certain people, including the higher-risk groups listed below, are less likely to be referred to, participate in, or complete the program:
  - People with multiple illnesses
  - Women - rehab referral and participation rates are worse in women.
  - Only 31% of eligible women are referred (compared to 42% of men).
  - Only 50.1% of women attended rehab, versus 60.4% of men.
  - People of color: Black women are nearly 60% less likely to be referred to and enroll in rehab than white women.
  - The elderly
  - Those with low socio-economic status

How can this be? There are many barriers to rehab. Transportation, insurance, inconvenience and perhaps even fear. But what a difference 36 sessions can make.

How can we make this better? Emphasize rehab more during visits? Help patients understand that rehab is something they should demand, even if their doctor doesn’t offer it? You tell me, and I will tell the CDC and Million Hearts, who are working hard to solve this puzzle.

Michele Packard-Milam
Executive Director
Mended Hearts

*Data cited in this column is from Million Hearts.
Beat Your Odds of AFib and Stroke

Mended Hearts has partnered with the National Stroke Association to create a web-based game about atrial fibrillation (AFib). *Beating Your Odds* has five mini games that will educate you on disease awareness, recognition of stroke signs and symptoms, treatment options, shared-decision making and medication adherence. Download your virtual rewards after each game. To play the game, go to MendedHearts.org/education/afib-and-stroke.

Can a FitBit Save Your Life?

Doctors at a New Jersey ER recently used data from a patient’s personal activity tracker — in this case a FitBit — and smartphone to determine the time his heart arrhythmia (atrial fibrillation, or AFib) started. This allowed the doctors to figure out which treatment he would need to get his heartbeat under control. The patient was safely treated and discharged home with instructions to make an appointment with a cardiologist.

This is the first reported case of doctors using data from an activity tracker/smartphone system to help in their decision-making. And while activity trackers aren’t approved medical devices, this case shows their potential in providing ER physicians with objective clinical information about the patient.
For Shannan Pearsall, coordinator of Mended Little Hearts of Long Island, volunteering isn’t just something she does. It’s in her blood.

As the daughter of a volunteer firefighter, serving her community comes naturally. Pearsall also has a younger brother who is a congenital heart disease (CHD) survivor. When her first son, Aidan, was born with a heart defect, she knew just how to give back.

Not only has Pearsall served as coordinator of MLH of Long Island since its 2011 inception, she also served on the awareness committee and recently took on the role of social media chair. “It wasn’t necessarily my comfort zone, but I was willing to learn,” she says. Her daily posts announce upcoming events, news, and messages for the “I am 1 in 110” campaign to raise awareness of the number of kids born with CHD. She uses #PowerOfPictures and #RockYourScar hashtags to drive home the “1 in 110” message.

Pearsall manages her MLH duties around a part-time job, caring for two sons, and even more volunteer work — running a family advisory council for her local hospital. “It’s an extension of Mended Little Hearts,” she says. “I know the impact of family-centered rounds and why it’s important for parents to advocate for their children.”

How does she do it all? Excellent time management. “When my kids go to bed, I get on the computer,” she says. “I plan social media posts ahead as much as I can. I also have my mobile office — my car — where I check e-mail when waiting outside of my kids’ school. If it’s important enough, you’ll find the time.”

When her schedule becomes especially overwhelming, she receives plenty of reminders of why she gives her time. “I will either get a call from my son’s cardiologist or an e-mail from a family in need,” she says. Then I remember why I’m doing this. This family is going through the worst period that I went through eight years ago. In that moment, everything else that’s stressful just disappears. You feel for the family and travel back to that moment in your own life. It re-energizes you to keep going forward.” — Heather Johnson
New Staff, New Promotions

We are pleased to announce new staff members and promotions.

**Member Services Coordinator**

Jessica Iga earned her stripes in several positions over 10 years at American Heart Association, where she worked in corporate relations, charitable estate planning, regional affiliate support and customer service. Jessica started in the Dallas office in February 2016.

**Director of Patient Advocacy**

Andrea Baer is the first Director of Patient Advocacy and started her position in February 2016. Baer is an accomplished volunteer who has given thousands of hours of service to Mended Hearts (as a member of the Executive Committee and Board) and to Mended Little Hearts. She is a tireless and energetic leader who oversaw the creation and implementation of Mended Little Hearts’ first strategic plan and who has provided vision and focus during the greatest period of growth MLH has ever had. Baer will work from her home in Pennsylvania.

**Accounts Receivable/Data Entry Clerk**

Heather Freeman joined Mended Hearts as a part-time accounts receivable data entry clerk in February 2016. Freeman is a recent graduate from Texas A&M University-Texarkana and has recently moved to Dallas to attend the Southern Methodist University to complete a Master’s degree. Heather has previously worked in customer service and real-estate operations where she acquired skills in accounting and data management.

**Manager of Field Communications**

Mandy Sandkuhler, a well-respected staff member, handles a tremendous amount of work and member interactions with kindness, knowledge, ability and aplomb. Her natural journalism skills made her the absolute best candidate for managing our magazine. Under her leadership and work with our new publisher, Heartbeat magazine has become a dynamic, delightful expression of our mission. Sandkuhler works from her home in Atlanta, Georgia.
New HeartGuide Wins National Award

We can now use the words “award winning” when talking about the new Mended Hearts Heart-Guide. The guide, which offers easy-to-understand information on heart disease, risk factors, common tests and therapies, depression and medications, underwent a major redesign in 2015 and recently won a prestigious national award from the Center for Plain Language, a nonprofit organization that helps government agencies and businesses write clearly.

The HeartGuide won an Award of Distinction in the center’s ClearMark competition. The award will be presented at an awards ceremony this May at the National Press Club in Washington, D.C. Judging was based on:

• Understanding audience needs
• Style or voice
• Structure and content
• Information design and navigation
• Pictures, graphics and charts
• Overall effectiveness in plain writing

Mended Hearts leaders took great care to ensure patients would be able to clearly understand the information in the HeartGuide by asking members and our medical advisory board to provide input on the guide. We thank everyone who contributed to the HeartGuide!
The physical and emotional benefits of cardiac rehab are undeniable. So why aren’t more heart patients participating? By Heather R. Johnson

Six days after Willa Welter had a heart attack, she began rehab at Southeast Health in Cape Girardeau, Mo. Welter worked closely with Anita Smith, manager of Cardiac/Pulmonary Rehab at the hospital.
Jake Gray had always considered himself to be in pretty good shape. Having worked in North Carolina’s textile industry for much of his adult life, Gray was used to maneuvering heavy machinery on his own.

“I did all this stuff myself. I was hands-on — a one-man show,” Gray says.

He stayed busy outside of work, too. “I’ve played golf all my life and walked. I was not a sedentary person,” says Gray, President of Mended Hearts Chapter 379 in Gastonia, N.C.

That’s why Gray was so surprised and scared when he wound up in cardiac rehab at CaroMont Regional Hospital after undergoing a CABG surgery there in 2011. “I was despondent,” Gray says. “It was kind of a, ‘I wonder what’s going to happen to me’ situation. You’re really worried about your future.”

That all changed for Gray when Susan Murphy, the manager of CaroMont’s cardiac rehab facility, gave him a glimpse of hope. “The Lord sometimes sends people in your way who say the right thing at the right time, and Susan was that person,” Gray says. He was on the treadmill and wasn’t feeling well when Murphy placed her hand on his arm and told him, “You’re going to be OK.”

“That sounds pretty simple,” Gray says. “It sounds like a normal thing to say in the normal course of what they do, but this was a very sincere situation.”

Murphy was right, too. After 36 weeks of cardiac rehab, Gray’s heart function had increased by 63%. He lost 25 pounds (and has kept it off for five years), and the 75-year-old still hits the gym three times a week. “I think cardiac rehab is one of the best things I did for myself.”

“[Cardiac rehab] helps when you’re in a group of people who have had the same type of cardiac experiences, seeing that they’re going through the same things that you are.” — Dr. Jeffrey Schussler

What Is Cardiac Rehab?
Gray could be considered the poster boy for cardiac rehab. His experience illustrates what happens when caring medical staff such as registered nurses, exercise specialists, nutritionists and others work in concert to help patients regain their full physical, emotional and psychosocial health.

Cardiac rehab can also boost a patients’ confidence. Six days after Willa Welter, a member of Mended Hearts Chapter 183, in Cape Girardeau, Mo., had a heart attack, she began rehab at Southeast Hospital. A little over a month later, her heart function, or ejection fraction, had increased from 32% to 54%.

(‘A healthy adult has an ejection fraction of about 55% to 70%.’)

“When I first went in, I was scared to death that I would have another heart attack,” Welter says. “They got me to walk around a track, use the machines, and they were always there to answer questions.”

The physical therapists didn’t just watch Welter walk around the track. They walked with her, coaching her with each lap. “They always said, ‘You’ve got this. You can do this,’” says Welter. “They gave me my confidence back.”

Cardiac rehab staff members support patients in nearly when he first began cardiac rehab, Jake Gray says he was “despondent.” But after completing a 36-week long program, he says it was one of the best things he’s ever done for himself.

During his cardiac rehab workouts, Gray befriended Susan Murphy, the facility’s nurse manager. Murphy gave Gray the confidence to continue his workouts.
every step of their recovery. They prepare tailored exercise regimens, monitor vital signs during exercise and teach patients how to gauge their activity level. They also create healthy eating plans, assist with smoking cessation, help manage stress levels and medications — and teach patients how to cope with depression, anger and other emotions that may arise during recovery. Patients also get to meet others who are on their own road to recovery through cardiac rehab.

**Why Patients Are Missing Out**

Despite the overall health benefits for heart attack survivors and patients with coronary artery disease or congestive heart failure, participation in cardiac rehab remains relatively low. Fewer than 20% of eligible patients receive cardiac rehab, according to many sources. And women, minorities and people in rural areas have especially low participation rates.

That’s the bad news.

The good news is that the percentage of referrals seems to be improving. A 2014 study in the *Journal of the American College of Cardiology* indicated an 81% referral rate for heart attack patients, the focus of the study.

Mary Ann McLaughlin, M.D., cardiologist and medical director of the cardiac health program at Mount Sinai Hospital in New York City, agrees that surgeons, cardiologists and general practitioners don’t recommend cardiac rehab as often as they should. Surgeons, for example, may only focus on the mechanical problem, which they “fixed.” General practitioners have too much to cover in too little time during an office visit. “They are so time-crunched these days,” says Dr. McLaughlin. “They have such a short time period to go over medications and other issues that they may not have time to talk about rehab.”

One way researchers have found that hospitals and staff can overcome physician referral obstacles is through an automatic referral system, along with trained clinical staff who can help increase enrollment rates of cardiac rehabilitation.

**What about cardiac rehab and exercise for children and adults with congenital heart defects?** Look for details about this in an upcoming issue of *Heartbeat*, where experts and Mended Little Hearts families will weigh in.

**WHAT THE LONDON BUS SYSTEM MEANS TO YOUR HEART**

Prior to the 1940s, recovery after a heart attack was simply bed rest. In the ’50s, though, that slowly started to change, thanks in part to a seminal study by Jerry Morris, a Scottish epidemiologist. He conducted a large study that found that the drivers of double-decker buses in London, who were mostly sedentary during their work, had higher rates of cardiovascular disease than the ticket counters, who had to climb the stairs. He later expanded the study to postal service workers and found that those who delivered mail by bike or on foot had lower rates of cardiovascular disease than those who worked behind the counter.
At CaroMont Regional Hospital, where Gray was treated, heart patients are invited to go to an orientation for cardiac rehab. That’s how Gray learned about it. “I figured it couldn’t do anything but help me,” Gray says.

At Southeast Hospital in Cape Girardeau, Missouri, cardiac rehab managers offer a phased approach. Heart patients begin with an inpatient cardiac rehab program, after which they are allowed to participate in a 12-week outpatient program if the patients choose to do so. “We try to get them into rehab within the first couple weeks so they don’t lose interest,” says Anita Smith, manager of Cardiac/Pulmonary Rehab at Southeast Health.

Barriers to Participation

According to a study conducted by American College of Cardiology, only half of the women referred to cardiac rehab actually attend. Many theories exist on women’s reluctance, but some experts suspect that women have too many demands at home. “They’re taking care of older parents, or children, and feel that they can’t participate,” Dr. McLaughlin says. “Part of the reason they ended up with a heart problem is because they were taking care of everyone else before themselves. This is a good reminder that women have to take time out.”

Lack of access, especially for patients that live in rural areas, as well as a lack of time and money, also pose barriers, either real or perceived. Many hospitals try to accommodate time-crunched and working patients with extended hours and satellite facilities. “We’ll refer patients to a rehab facility that’s closest to where they live,” says Smith of Southeast Health. “Our foundation also provides gas cards to the heart program, which eases the burden for some patients.”

Lack of insurance coverage for cardiac rehab is a concern for some heart patients. Most insurance companies cover as many as 36 sessions for those who meet eligibility requirements, but they may only cover a portion of the cost. To accommodate patients whose insurance

The American Heart Association reports that cardiac rehab has been shown to reduce morbidity and mortality by nearly 25% compared with usual care.
benefits don’t cover cardiac rehab, or only cover a portion of it, many hospitals offer a reduced self-pay rate and other arrangements. “We try to work with a person’s income level,” says Smith. “We’ll do what we can to get you in here and make the most of the time we have.”

Home-based cardiac rehab programs, although rare, and not always supported by insurers, can potentially address transportation, family and work-related barriers to participation. The patient would also need to be especially motivated. However, researchers do recognize home-based programs as a viable alternative to help patients stick to an exercise program.

Role of Smartphones in Cardiac Rehab

One promising new development for cardiac rehab ties in with one of society’s most relied-upon devices: the smartphone. Patients that used a special smartphone app and web-based portal in addition to traditional cardiac rehab lost four times more weight than patients that used cardiac rehab alone. The findings, which were presented this year at the American College of Cardiology’s 65th Annual Scientific Session, suggest that the accountability that comes from frequent reporting through the app played a key role in improved dietary habits and slightly more exercise. And when it comes to heart patients, every little bit helps to prevent future cardiac events.

Cardiac rehab — with or without the help of your smartphone — offers clear, proven health benefits for heart patients. As more physicians prescribe cardiac rehab, and as more healthcare facilities address barriers to access, we can expect more heart patients to reap the benefits of cardiac rehab. The Mended Hearts community can help the cause by sharing their cardiac rehab success stories.

Welter’s 36-week stint ended long ago, but she continues to attend cardiac rehab three times a week. “I feel safe there,” she says. “From day one they treated me like family. All heart patients should do this because of the benefits it gives you in the long run.”

Heart attack survivor Willa Welter, of Mended Hearts Chapter 183, in Cape Girardeau, Mo., was able to get back to her job as a stylist at a hair salon thanks in part to her steady recovery during cardiac rehab.

Photo courtesy of Southeast Health

YOU MIGHT BE A CARDIAC REHAB CANDIDATE IF…

Many doctors will recommend cardiac rehab for patients with one of the following:

- A recent heart attack
- Stable angina (chest pain)
- Congestive heart failure
- Angioplasty or cardiac stenting
- Coronary artery bypass surgery, heart valve repair or replacement, including left ventricular assist devices (LVAD)
- Heart transplants or those waiting for transplants

Photo by Cheryl Howard, Southeast Health

Heart attack survivor Willa Welter, of Mended Hearts Chapter 183, in Cape Girardeau, Mo., was able to get back to her job as a stylist at a hair salon thanks in part to her steady recovery during cardiac rehab.

Photo courtesy of Southeast Health
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

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.

Watch Donnette’s video

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TREATING

BLOOD CLOTS

REQUIRES FAST ACTION

Heart patients young and old are at risk for blood clots, including those with congenital heart defects. Know the warning signs and get medical help fast if you think you have one. By Scotty Fletcher

People who have been still for a long period of time, such as surgical patients, are at risk for blood clots. Compression socks or stockings help prevent clots from forming.
When Lucien Dusablon, of Mended Hearts Chapter 338 in Woonsocket, R.I., noticed the toes on his left foot were changing colors, he thought it was just a symptom of his diabetes.

Dusablon, who became a member of Mended Hearts in 2010 after recovering from a blocked artery, has suffered from diabetes for many years and chalked the discoloration and leg pain up to the disease.

“I thought it was the diabetes, but when the doctor did a sonogram on my leg, he saw that I had a blood clot behind my left knee,” Dusablon says.

Dusablon was immediately admitted to the hospital and given blood thinners. He stayed hospitalized for six days until the clot dissipated and he regained feeling in his leg.

“When the clot dissolved and the bottom of my leg got the rush of blood it needed, it was very painful,” says Dusablon.

What Are Blood Clots?
A blood clot is a gelatinous mass of blood that changes from liquid form to a semisolid state. Blood clots can be life-saving when they help stop bleeding — for instance after an injury. But when they form inside a vein and don’t dissolve on their own, blood clots can get into the bloodstream and block the flow of blood to the heart or brain, leading to a heart attack or stroke. Clots can also form when plaque deposits in the blood vessel walls rupture.

In the medical field, a blood clot is known as VTE, or Venous Thromboembolism. If the clot forms in the leg or another deep vein, it is called Deep Veinous Thrombosis or DVT.

A blood clot that breaks loose and travels to the lungs is a Pulmonary Embolism or PE. This typically occurs after someone has been still for a long period of time, such as during a long flight or surgery, and can be deadly. DVT is the main cause of pulmonary emboli.

Blood clots become dangerous when they get into the bloodstream because they can block the flow of blood to the heart or brain and cause a heart attack or stroke.

Who’s At Risk?
Though VTE is most common in adults 60 and older, blood clots can occur at any age, including in children. Clotting
Hospitalization for a medical illness

Personal history of a clotting disorder or previous DVT

Obesity

Cancer and cancer treatments

S

vein thrombosis) and PE (pulmonary embolism). A DVT is a blood clot that can also increase their risk. Some people have additional conditions that may not always experience symptoms.

If you have any of these symptoms, it is an emergency and you should seek medical help immediately. If you have any of these symptoms, it is an emergency and you should seek medical help immediately.

Though further work-up and treatment may depend on other factors, the standard treatment for blood clots is to put the patient on blood thinners for several months, Dr. Glaser says.

Seeking Treatment

The primary method of diagnosing DVTs is an ultrasound examination of the leg veins called a lower extremity venous duplex.

This exam checks the leg for clots and tells the patient’s doctor where the clot is, how extensive it is, and in some cases, how long it has been there. It can also be used to follow-up with patients with existing clots to see if they are improving, stable or worsening.

The lower extremity venous duplex is typically performed by a trained ultrasound technologist and uses an ultrasound probe to directly check the veins in the legs. The exam involves no radiation exposure and can be done in a variety of locations. It is typically interpreted by physicians with special training such as radiologists, vascular surgeons, cardiologists and certified vascular medicine experts.

“The presentation of DVT can vary, but one of the most common presentations is leg pain,” says Dr. Joseph Glaser, a nuclear medicine and vascular ultrasound specialist with Radiologic Associates, PC. “The patient’s legs may be swollen or discolored, but that doesn’t always happen. If you speak to your doctor about persistent leg pain and they send you for one of these exams, it is a potential emergency and should not be delayed so that if a clot is found, treatment can be promptly started.”

Children and Blood Clots

Though blood clots are more common in adults, children are also at risk for developing clots — especially kids with congenital heart defects. About 1 in 10,000 children get blood clots, including as many as 1 in 200 children in hospitals, according to Johns Hopkins University School of Medicine.

Lindsey Bilodeau’s daughter, Madeleine, was born with a several heart defects: Ebstein’s anomaly (which involves a malformed tricuspid valve), ventricular septal defect and coarctation of the aorta. Madeleine had her first heart surgery just five days after she was born. One month after surgery, her parents noticed that her heart rate and breathing were elevated and pushed
doctors to do an echocardiogram, which uses sound waves to produce images of the heart.

The test revealed that a blood clot had formed on top of the Gore-Tex patch that had been used to repair Madeleine’s tricuspid valve. Within 24 hours of doctors finding the clot, Madeleine was back in surgery to remove it.

“It was the most urgent we had seen the doctors react,” says Bilodeau of Mended Little Hearts of Little Rock, Ark. “They said that if the clot were to break off, she could have brain damage or a stroke, which could be fatal.”

Madeleine, who will be three in December, has not had another clot since and is on a preventative aspirin regimen.

Jennifer DeBouver, MLH Bereavement Chair, lost her son, Asher, to blood clots he developed from his pic line after heart surgery. He was just six weeks old.

“Asher was born with several congenital heart defects, but the clots turned out to be a bigger issue than all of the heart conditions combined,” she says. “Once he developed the clots, the hematologist came in and said that even though blood clots in infant heart patients is somewhat common, there is little research on how to best treat them.”

Today, Jennifer and her husband run a foundation — The Asher James Congenital Heart Disease & Thrombosis Foundation to spread awareness and fund research on children’s blood clots.

(Above, above right) Children born with congenital heart defects are at a higher risk for developing blood clots than others. Madeleine Bilodeau, who has Ebstein’s anomaly, ventricular septal defect and a repaired coarctation, developed a blood clot one month after her first heart surgery. Bilodeau recovered from the clot and will celebrate her third birthday in December.

Jennifer DeBouver lost her son, Asher, to blood clots he developed from his pic line after heart surgery. The DeBouver family now runs The Asher James Congenital Heart Disease & Thrombosis Foundation to spread awareness and fund research on children’s blood clots.

— Jennifer DeBouver

A blood clot may not be the first thing that comes to mind, and doctors often misdiagnose the symptoms [in children] as a cold or the flu.

— Jennifer DeBouver
Heart Disease & Thrombosis Foundation — to spread awareness and fund research on children’s blood clots.

The foundation worked with a hematologist to create a card that explains the warning signs and risks of blood clots in children. They partner with Mended Little Hearts of Chicago to include the cards in hospital Bravery Bags for parents of children with congenital heart defects.

“A blood clot may not be the first thing that comes to mind and doctors often misdiagnose the symptoms as a cold or the flu,” says DeBouver. “We wanted to give parents a heads-up so that they can recognize the signs and symptoms.”

The cards, which are currently distributed to five hospitals in Chicago, are available through the foundation’s website at www.asherjamesfoundation.org.

Don’t Wait. Be Proactive!
In May of 2008, after feeling unusually fatigued, Fredonia Williams, Ed.D., President and Newsletter Editor of Chapter 260 in Huntsville, Ala., underwent a cauterization for a leak in one of her heart valves. She was scheduled to have the valve surgically repaired in June. But on Mother’s Day, when the preacher asked all of the mothers to stand at church, Williams felt an unusual pain when she stood up.

“I thought I had pulled a muscle in my groin area,” she says. “It just didn’t feel right.”

She still felt a little “off” on Monday and stayed home from work. Her husband urged her to call the doctor. After examining Williams, the doctor immediately admitted her to the hospital, where she stayed for five days on blood thinners.

“They did a sonogram and saw the clot,” she says. “They wouldn’t even let me get off the table. They rolled me on a gurney to the hospital.”

The clot eventually dissipated and the surgery to repair the heart valve was done on schedule. Three days after surgery, while in ICU recovering, Fredonia noticed some unusual bleeding. The doctors discovered she had developed a clot on the lining of her heart.

Fredonia went into sudden cardiac arrest and was revived by a nurse. She spent 28 days in the hospital recovering — 21 of those days in ICU.

“I didn’t know what a blood clot felt like — I just knew that I didn’t feel right,” she says. “I was very lucky.”

When it comes to blood clots, listening to your body and being proactive is critically important.

“When you notice something different with your body — even it doesn’t seem related to a blood clot — don’t ignore it,” says Dusablon. “If something isn’t normal, don’t wait. Tell someone and get it checked out.”

For more information about deep vein thrombosis and pulmonary embolism, please go to www.thisisserious.org.
Let’s Keep in Touch

We love delivering Heartbeat to your mailbox, but you can catch up with us any time the year, 24/7, online.

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Social media sites and online campaigns offer CHD families vital lifelines to others in a tight-knit virtual community. By India Powell

For some people, social media sites like Facebook are simply a place to share funny videos and family vacation photos. But for those who have a child with a congenital heart defect, social media sites can serve as a vital lifeline to others who can empathize with their fears, worries, milestones and joys. It is within these online communities that scars are bared, connections are made, loved ones are remembered, awareness grows and money is raised.
Mended Little Hearts — both nationally and at the group level — has a strong presence on several social media sites, including Facebook, Twitter and Instagram. Using its public presence on these platforms allows MLH to reach hundreds of thousands, if not millions, of people internationally to spread the word about CHD and MLH. And within private, or “closed,” groups on Facebook, MLH members form strong bonds with other families who can sympathize with what they are going through. These groups also allow leaders to share information from group meetings — a welcome help for those who can’t attend every meeting.

Social Media Chair Shannan Pearsall, who took on this volunteer role in October of 2015, explains that one of the most active areas for MLH national is a closed Facebook CHD Chat Group where more than 1,580 members from all over the world interact with one another.

“Members, regardless of geographical location, can connect with other families to discuss upcoming surgeries, a new diagnosis, successes and sorrows,” Pearsall says of the chat group. (Read more about Pearsall, Heartbeat’s May/June Heart Hero, on page 5.)

Pictures Say 1,000 Words
Outside the members-only Facebook groups, MLH has a broad, international reach, which often grows during several specific campaigns that are aimed at increasing awareness about CHD among the public. One of these is the “Power of Pictures” campaign, which happens during the second week of every month. “This series has been very well branded so that it is instantly recognized as #PowerofPictures,” Pearsall says.

The concept is simple: pictures say a thousand words. Pearsall credits Lauren Gray, Awareness Chair for MLH as the brainchild of this campaign, which allows members of MLH to submit a photo of their heart warrior or angel. MLH leaders then write a message, “using either a quote from the family submitting the photo, a statistic about CHD, or from a song lyric or quote that helps tell the story,” Pearsall explains. The photos are then shared across social media sites. “When we designed this series, we wanted to help empower families to share their story — and to be able to do so in the support of our community.”

Roaring, Rocking, Remembering
For the past several years, MLH has taken to the Web full force in February with a trio of powerful

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2016 Roar ‘n Run: By the Numbers

- More than $40,000 was raised
- 700 participants signed up
- 219 teams registered
- Leading fundraising group, “Sweet Angel Ryan”, raised $3,420
- Change this bullet to:
  - Mended Little Hearts of Dallas led in MLH group fundraising with $2,000
- Highest number of participants was MLH of West Michigan, with 24 people raising funds on their behalf
- 90% of MLH groups registered a team
- Funds raised through this event will go directly to support families through the Bravery Bag Program, hospital visiting programs, expanding the Mended Little HeartGuide (a parent resource), and creating a new support program for tweens and teens.

More than 700 participants made a roar for CHD awareness by participating in the 2016 Roar ’n Run virtual race. The event raised more than $40,000 to help support MLH efforts such as Bravery Bags and the accredited visiting program.
2016 Rock Your Scar Winners
This year’s Rock Your Scar contest included 1,200 photo submissions — almost triple 2015’s number. And the winners (by age category) are...

0-1: Bridger Wingen
2-4: There was a tie for this age group. “Sherriff” Bryson Huff and AJ Greco, with his twin sister, Ella.

5-8: Four Heart Rockers, submitted by Tiffany Kopper
9-12: Avianna MacKeller
People’s Choice: Maxton Bucci

13-17: Maria Rodriguez
18-39: Mark Cummings
Over 40: Robert Kuechle
online events: the Roar ’n Run Virtual Charity Race and the Rock Your Scar photo contest, both in their third years, and the second-annual Candlelight Vigil in honor of heart angels, children who have lost their lives to CHD.

“All of these events are so important in creating community,” says Jodi Lemacks, National Program Director for MLH. “Families with children who have CHD and adults living with CHD often feel so isolated. We want them to know that we are here, and going on this hard journey together is much better than going it alone.”

The Roar ’n Run Race, which took place during CHD Awareness Week, Feb. 7-14, is aimed at raising money for MLH support programs that directly affect families. “This support is vital to our mission,” Lemacks says. “Raising money is not easy for nonprofits. Everyone has a good cause. Social media has allowed us to let others know about all of the great things we do so they can help us do them.”

The biggest fundraising team for Roar ’n Run was able to very effectively spread the word and raise $3,420 in honor of “Sweet Angel Ryan,” who passed away of CHD (read about Ryan in the March/April issue of Heartbeat). “What a huge way for the family to keep this baby alive,” she says. “Not only that, but his life will affect hundreds to thousands of others as they receive support from Mended Little Hearts when they are in crisis and need it the most.”

Lemacks’ son Joshua, who is almost 13 and has a congenital heart defect, is among those who have benefitted from connecting with others via the Rock Your Scar social media photo contest, which targets mainly teens and tweens and is the only national CHD awareness campaign. “I know for my son it means so much to see other teens and young adults, especially guys, with CHD.”

Raising awareness about the seriousness of CHD is another important goal of these virtual events. “People still are so unaware of congenital heart disease and its impact on families and on society,” Lemacks says. To that end, the Candlelight Vigil, held on Feb. 10 via social media and organized by Bereavement Chair Jen DeBouver, brought much-needed attention to the heartbreaking truth of CHD-related death among children.

“People forget that these families need support just as much, if not more, than other CHD families. The angel families often worry that their kids will be forgotten,” Lemacks says. Efforts like the Candlelight Vigil help ensure their memories live on.

‘Erase the Distance’

It is MLH’s presence on social media that allows the organization to reach across borders, oceans and time zones. “Some of the biggest followings we have online outside of the U.S. come from Africa, Australia and the U.K., just to name a few,” Pearsall says.

“A diagnosis, the time post-op after open heart surgery — these can be overwhelming,” Pearsall says. “And loved ones can lend an ear or perhaps a shoulder, but in the end, it is the comfort and the understanding of another heart parent that, for me, provides the most comfort. And social media allows us to erase the distance and support one another.”
Knocking on doors and strong relationships with cardiologists are key to chapters’ success.

While some Mended Hearts chapters are struggling, the Mid-Atlantic and Southern regions continue to grow.

What’s their secret to success?
“We knock on doors. We’re constantly talking to hospitals that don’t have chapters,” says Gerald Kemp, Mended Hearts Mid-Atlantic Regional Director. “We are very persistent.”

Kemp’s region includes Washington, D.C., Virginia, Delaware, Maryland, North Carolina and South Carolina. Each of his three assistant regional directors set up a chapter this past year including two in North Carolina and one in Florence, S.C.

The region also has a satellite chapter in Virginia and two in South Carolina on their way to becoming full-fledged chapters. A third in Spartanburg, South Carolina, is also in the works.

The best avenue into a hospital is often through the volunteer coordinator, the cardiac rehabilitation department, or through a cardiologist on staff who is familiar with Mended Hearts, says Kemp.

Kemp’s region has a booth at the American College of Cardiology’s annual convention in the Carolinas each year to connect with cardiologists and tell them about the organization. “If you can find a cardiologist who is interested in you coming to their hospital, that makes it a very easy path to get started,” Kemp says.

Mended Hearts’ southern region – which includes Alabama, Georgia, Tennessee, Mississippi, Florida, Louisiana and Arkansas — has opened two new chapters in the past year: one in Alabama and Florida, one satellite in Florida, reorganizing one in New Orleans and working on starting a second new one in Alabama.

Fredonia Williams, Ed.D., Mended Hearts Southern Regional Director, agrees that personal contact, networking and follow-up are key.

“I keep a log of all requests we receive through the national office, local hospitals, and patients visiting our website,” Williams says. “I connect hospitals to patients and then look to see if I have a contact in that city.” Williams likens this type of networking to when she was a principal seeking the best teachers for her school.
“I don’t do cold calls. I just work from references and stay on top of it,” she says. “I make contact with the hospital and the patient, then we hold a conference call with our field services director. Often, I will go to the hospital in person.”

Williams also helps new chapters get started by sharing information on the basics — like how to structure meetings. “I save everything and share it with new chapters so they don’t have to start from scratch,” she says.

“The chapters that closed last year had been struggling for some time. It doesn’t happen overnight,” says Millie Henn, Mended Hearts Executive Vice President. “As a chapter’s membership ages, they sometimes fail to engage new and younger members to fill their shoes. Also, we’re an organization of heart patients. Age alone compounds health issues, which can play a large part in a chapter’s struggle.”

In an effort to help new chapters form, the Mended Hearts board of directors created a task force to determine how to simplify new chapter development. As a result, the board approved new guidelines in February.

The guidelines allow new Mended Hearts chapters to form with a minimum of 10 members (down from 25) and three officers instead of four.

“We’re excited about the opportunity this presents to start new chapters. We want it to be easier so we can get more people involved across the country,” says Henn. “Mended Hearts is life changing. Having someone to talk to who understands what you are going through can make all the difference.”

For both Williams and Kemp, creating new Mended Hearts chapters and expanding the network is an act of passion. Williams, who had open-heart surgery in 2008, began as the newsletter editor of her local chapter.

Kemp, who had four bypass surgeries in 2003, was introduced to Mended Hearts while in rehab. Soon after, he became president of his local chapter.

Today, as regional director, Kemp is in touch with his assistant regional directors several times a week. The goal, he says, is to find the person in a hospital who is interested in Mended Hearts and can ultimately “green light” the program.

“Mended Hearts has made a huge impact on my life. I decided in rehab that I wanted to give back and this is what motivates me,” says Kemp. “Our motto is, ‘It’s great to be alive and help others!’ What we are doing is so great.”

— Scotty Fletcher

From left, Jill Everson, Manager, Cardiac Health and Rehab Center; Fredonia Williams, Mended Hearts Southern Regional Director; and Melita Willkie, Volunteer Services Director, hosted an informational booth at Thomas Hospital to recognize the launch of Chapter 396, in Fairhope, Ala.

Gerald Kemp (center) says that the best avenue into a hospital is often through the volunteer coordinator, the cardiac rehabilitation department, or through a cardiologist on staff who is familiar with Mended Hearts. Here, members of Chapter 289 Rock Hill, S.C. set up an informational booth at Piedmont Medical Center.
2 Leaders Filling Each Role Means Built-in Back-up for MLH of Milwaukee

Amy Randall was first introduced to Mended Little Hearts when her youngest son, Lucas, was diagnosed with a congenital heart defect in 2011. “I really wanted to connect with other parents going through this,” Randall says. “Our heart center gave us a card for the local Mended Little Hearts group. I went to a meeting, became a member, and I’ve been very involved ever since.”

When the coordinator of the Milwaukee MLH group stepped down in 2014, Randall took the reigns. Today, the group — which works closely with the Children’s Hospital of Wisconsin — has more than 50 members. Monthly meetings feature a wide variety of speakers and are promoted on the group’s closed Facebook page, which has almost 200 members. Notes from the monthly meetings are also shared on Facebook for members who are unable to attend.

“Communication is key,” Randall says. “We have a big metro area. Some people are an hour away and can’t make the monthly meetings. It’s important to keep them informed.”

Recent speakers include a heart center psychologist, who spoke to parents about helping kids make a seamless transition to school, and a heart center school interventionist who shared tips on how to handle special accommodations heart kids might need in the classroom.

“She provided materials to help parents create a letter for teachers to share with other parents, explaining that there is a child with a heart condition in the class and to keep their own kids home if they are sick,” Randall says. “It turned out to be a great resource for the parents, as well as the teachers.”

The group also hosts a summer social for all of its families and partners with the heart center for an annual picnic at the zoo.

Randall attributes the group’s success to the close relationship it has with the local hospital’s heart center. “Having a direct line to the hospital is very important,” Randall says. “When the chief surgeon recently left our hospital, for example, there was a lot of anxiety among the parents. We were able to set up a town hall meeting with the heart center to answer their questions and concerns.”

The group also has a unique approach to its leadership structure. Each role is filled with two people. Randall has a co-coordinator who helps her run the meetings. There are also two visit coordinators, two treasurers, and two secretaries.

“The team approach to leadership has been great because we are never filling a role completely from scratch,” Randall says. “It also provides us with built-in backup, which makes it easier for people to say ‘yes’ to a leadership role.” — Scotty Fletcher
Mended Hearts — Eight Regions

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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Historical Hearts

Chapter Anniversaries
May/June 2016

45 years
- Norfolk, VA – Chapter 63 – MA Region

35 years
- Honolulu, HI – Chapter 14 – WE Region
- Elgin/Fox Valley, IL – Chapter 53 – MW Region

25 years
- Cedar Rapids, IA – Chapter 184 – MW Region
- North Charleston, SC – Chapter 175 – MA Region

20 years
- Naples, FL – Chapter 232 – SO Region

15 years
- Aiken, SC – Chapter 294 – MA Region

10 years
- Omaha, NE – Chapter 340 – MW Region

5 years
- Charlotte, NC – Chapter 372 – MA Region

Mended Little Hearts Anniversaries
May/June 2016

5 years
- Mended Little Hearts of Long Island, NY – Northeast Region
- Mended Little Hearts of Lubbock, TX – Southwest Region

10 years
- Mended Little Hearts of Bakersfield, CA – Western Region
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Mended Hearts gratefully acknowledges the support of our conference sponsors: