PLUS:
- Advocacy update: Making sure all have access to the best heart treatments
- He can’t be stopped! Why Paul Smith keeps starting Mended Hearts chapters

A NEW CHAPTER
More patients now have access to minimally invasive heart valve procedures

Now that that election is over, see who’s running for national Mended Hearts officer positions
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We love delivering Heartbeat to your mailbox each quarter, but you can catch up with us any time the year, 24/7, online.

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More Valve Options Open New Chapters in Life
For years, only patients deemed “high risk” for open-heart surgery could get transaortic catheter valve replacement. Now, intermediate-risk patients may be eligible as well.

Meet the Candidates
If you didn’t like the results of this year’s presidential election, don’t lose hope — because you’ll soon have a chance to elect the national Mended Hearts officers for the 2017-2019 term.
Singing Praises for New Heart Valve Treatments

I’m always eager to see the patient census when I do my hospital visits so I can go down the list to find the TAVR patients. TAVR stands for Trans-Aortic Valve Replacement, and it allows doctors to replace a heart valve through a catheter as opposed to doing open chest surgery.

This topic is near and dear to my mended heart because I was born with a bicuspid aortic valve. I’ve had several surgeries to correct this, and all of them were open chest.

Though I’ve never had a TAVR myself, I have seen firsthand how the procedure works. Representatives for the hospital where I volunteer invited me to scrub in for a TAVR, just so I could better understand the procedure.

The patient’s circulatory system was projected live onto a TV screen. I watched it as the doctor threaded the replacement valve up through one of the patient’s arteries. When he reached the sick valve, he aligned the new one inside of it, expanded it, and then carefully removed the catheter. The patient’s heart was beating the whole time — and even better after the valve was placed. I felt like singing the *Hallelujah Chorus* when he was finished.

I got to meet with another patient and his wife, just one day after his TAVR procedure. Previously, he’d been practically wheelchair bound because his valve disease had left him so out of breath. He couldn’t even walk across the room, his wife told me.

But when his nurse came into the room to get him up for his first walk, the gentleman was out of bed and out of his room, walking down the hallway. “Wait for me!” the nurse told him. Advances like these make it such an amazing time to be a heart patient.

Donnette Smith
President
Mended Hearts

Advances like these make it such an amazing time to be a heart patient.
Consumers to Insurers: Keep It Simple

Insurance companies and start-ups have invested in numerous apps to help us better manage our health and maintain fitness goals. According to a recent survey, however, most consumers don’t want that advanced technology from health insurers. We just want the basics.

Strategy&, the consulting team at PricewaterhouseCoopers, surveyed more than 500 consumers to rank 15 technology-related features they wanted from their health plans. Simple out-of-pocket cost estimators, online appointment scheduling, online access to health records and mobile post-care instructions topped the list. Advanced features such as linked data from wearables and tools for self-diagnosis were some of the least important.

If health plans take this information into account, they will have to balance features that they believe may improve quality with the simplicity consumers want. Of the consumers surveyed, almost all of them — 94% — choose utility and transparency.
Owners of iPhones will soon be able to register as organ donors with the click of a button. Apple recently announced that with the fall release of iOS10, iPhone users can sign up as organ, eye or tissue donors using the Health app that comes with every iPhone. With a few taps, Apple sends information directly to the National Donate Life Registry managed by Donate Life America.

As heart transplant patients know, the demand for organs far exceeds the supply. More than 120,000 Americans are currently waiting for a transplant. One donor can save as many as eight lives.

Apple CEO Tim Cook and organ donor advocates hope the new feature will appeal to young adults, who are registering at a lower rate than in the past. The new feature offers hope that more people will receive life-saving transplants from qualified donors.

We all have them — those friends on Facebook and Instagram who post pictures of their healthy dinners or motivational sayings aimed at keeping themselves (and you) on track and eating right.

More and more, like-minded people are looking online to share ideas, encourage one another in weight loss and healthy eating, stay motivated and show off the results of their hard work.

Followers of the Whole30 diet post millions of health food photos on Instagram with the hashtag #Whole30, inspiring and encouraging others to follow the dairy-, sugar-, grain- and legume-free diet for 30 days. Millions more post before and after pictures using #WeightWatchers and countless other hashtags dedicated to fitness, Paleo lifestyles, family nutrition inspirations and health.

Why do so many look to online communities to find encouragement when it comes to nutrition and weight loss?

Recent studies show that some people are attracted to online communities because of the social support, while others like the privacy it provides. In an online community, members can share and interact with others as much — or as little — as they feel comfortable.

Whether you are the type to proudly post before and after photos of yourself and your diet results or just like to browse for healthy recipe ideas, social media can be a good place to get inspired to lead a healthier life!
HEART HERO

Paul Smith:
Starting New Chapters Is Easy With Good Support

Paul Smith would start Mended Hearts chapters all over the United States if he had time. The cardiac surgery physician’s assistant founded Chapter 382 in Bellingham, Washington, in 2012. As it grew from 30 to 120 members, Smith moved to Grand Junction, Colorado. Barely settled, he started another Mended Hearts chapter, this one in conjunction with his new employer, St. Mary’s Medical Center.

As a medical professional and former heart patient who had surgery in 2012 to correct a patent foramen ovale (hole in the heart), Smith brings both medical and personal experience to his practice. That dual perspective also motivates him to do more.

“I have seen Mended Hearts in action in multiple hospitals,” says Smith. “I know that the more information you have, the easier it is to accept that you have a heart condition. Patients also need to understand that they can live a full, productive life after heart surgery.”

To plant seeds for the Grand Junction chapter, Smith turned to Sister Barbara Aldrich, St. Mary’s Medical Center’s Vice President of Mission Integration, for support. With her help, Smith secured a $4,000 donation from the hospital for a new Mended Hearts chapter. He will use part of those funds to cover member dues for at least the first year.

Early signs indicate that Grand Junction has the potential to match Bellingham’s success. About 30 people attended the introductory meeting and many of them expressed interest in joining. After officer elections and some paperwork, “it’s up to the members to move it forward,” Smith says.

For go-getters who want to serve Mended Hearts in a big way, Smith says it’s not difficult to found a chapter with the right support. “You have to go to the right people and you have to have a buy-in,” Smith says. “In Colorado, I got the buy-in from Sister Barbara. My bosses and the volunteer department also support the idea.”

As Smith sees it, the more Mended Hearts chapters, the more potential to improve lives. “There’s no ownership manual for this,” Smith says. “People are really scared when they go into heart surgery. When a volunteer says, ‘I’ve had heart surgery too,’ it can change someone’s attitude in a split second.”

— Heather R. Johnson
Tomorrow, I want to step out with my favorite girl.
If you have Heart Failure, ENTRESTO can help make the gift of tomorrow possible.

ENTRESTO is a breakthrough Heart Failure (HF) medicine for people with the type of HF where the heart is enlarged and too weak to pump properly.

- ENTRESTO was proven to keep more people alive and out of the hospital compared to a leading HF medicine in the largest Heart Failure study ever
- ENTRESTO works two ways to help your heart pump more effectively

To help increase your chances of more tomorrows, ask your heart doctor about ENTRESTO today.

What is ENTRESTO?

ENTRESTO is a prescription medicine used to reduce the risk of death and hospitalization in people with certain types of long-lasting (chronic) heart failure. ENTRESTO is usually used with other heart failure therapies, in place of an ACE inhibitor or other ARB therapy.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about ENTRESTO?

ENTRESTO can harm or cause death to your unborn baby. Talk to your doctor about other ways to treat heart failure if you plan to become pregnant. If you get pregnant while taking ENTRESTO, tell your doctor right away.

Who should not take ENTRESTO?

Do not take ENTRESTO if you:
- are allergic to sacubitril or valsartan or any of the ingredients in ENTRESTO
- have had an allergic reaction including swelling of your face, lips, tongue, throat (angioedema) or trouble breathing while taking a type of medicine called an angiotensin-converting enzyme (ACE) inhibitor or angiotensin II receptor blocker (ARB)
- take an ACE inhibitor medicine. Do not take ENTRESTO for at least 36 hours before or after you take an ACE inhibitor medicine. Talk with your doctor or pharmacist before taking ENTRESTO if you are not sure if you take an ACE inhibitor medicine
- have diabetes and take a medicine that contains aliskiren

What should I tell my doctor before taking ENTRESTO?

Before you take ENTRESTO, tell your doctor about all of your medical conditions, including if you have kidney or liver problems; are pregnant or plan to become pregnant; are breastfeeding or plan to breastfeed. You should either take ENTRESTO or breastfeed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take potassium supplements or a salt substitute; nonsteroidal anti-inflammatory drugs (NSAIDs); lithium; or other medicines for high blood pressure or heart problems such as an ACE inhibitor, ARB, or aliskiren.

What are the possible side effects of ENTRESTO?

ENTRESTO may cause serious side effects including:
- angioedema that may cause trouble breathing and death. Get emergency medical help right away if you have symptoms of angioedema or trouble breathing. Do not take ENTRESTO again if you have had angioedema while taking ENTRESTO. People who are Black or who have had angioedema and take ENTRESTO may have a higher risk of having angioedema
- low blood pressure (hypotension). Call your doctor if you become dizzy or lightheaded, or you develop extreme fatigue
- kidney problems
- increased amount of potassium in your blood

The most common side effects were low blood pressure, high potassium, cough, dizziness, and kidney problems.

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

Please see Important Facts About ENTRESTO on next page.
IMPORTANT FACTS ABOUT ENTRESTO®

What is the most important information I should know about ENTRESTO?
ENTRESTO can harm or cause death to your unborn baby. Talk to your doctor about other ways to treat heart failure if you plan to become pregnant. If you get pregnant while taking ENTRESTO, tell your doctor right away.

WHAT IS ENTRESTO?
ENTRESTO is a prescription medicine used to reduce the risk of death and hospitalization in people with certain types of long-lasting (chronic) heart failure. ENTRESTO is usually used with other heart failure therapies, in place of an ACE inhibitor or other ARB therapy.

Heart failure occurs when the heart is weak and cannot pump enough blood to your lungs and the rest of your body. It is not known if ENTRESTO is safe and effective in children.

Who should not take ENTRESTO?
Do not take ENTRESTO if you:

- are allergic to sacubitril or valsartan or any of the ingredients in ENTRESTO. See the end of the Patient Information leaflet for a complete list of ingredients in ENTRESTO
- have had an allergic reaction including swelling of your face, lips, tongue or trouble breathing while taking a type of medicine called an angiotensin-converting enzyme (ACE) inhibitor or angiotensin II receptor blocker (ARB)
- take an ACE inhibitor medicine. Do not take ENTRESTO for at least 36 hours before or after you take an ACE inhibitor medicine. Talk with your doctor or pharmacist before taking ENTRESTO if you are not sure if you take an ACE inhibitor medicine
- have diabetes and take a medicine that contains aliskiren

What should I tell my doctor before taking ENTRESTO?
Before you take ENTRESTO, tell your doctor about all of your medical conditions, including if you:

- have kidney or liver problems; are pregnant or plan to become pregnant (See “What is the most important information I should know about ENTRESTO?”); are breastfeeding or plan to breastfeed. It is not known if ENTRESTO passes into your breast milk. You and your doctor should decide if you will take ENTRESTO or breastfeed. You should not do both.
- have had angioedema while taking ENTRESTO. People who have had angioedema before taking ENTRESTO may have a higher risk of having angioedema than people who are not Black and take ENTRESTO. People who have had angioedema before taking ENTRESTO may have a higher risk of having angioedema than people who have not had angioedema before taking ENTRESTO. See “Who should not take ENTRESTO?”
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- have diabetes and take a medicine that contains aliskiren

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Using ENTRESTO with certain other medicines may affect each other. Using ENTRESTO with other medicines can cause serious side effects. Especially tell your doctor if you take potassium supplements or a salt substitute; nonsteroidal anti-inflammatory drugs (NSAIDs); lithium; or other medicines for high blood pressure or heart problems such as an ACE inhibitor, ARB, or aliskiren. Keep a list of your medicines to show your doctor and pharmacist when you get a new medicine.

What are the possible side effects of ENTRESTO?
ENTRESTO may cause serious side effects including:

- See “What is the most important information I should know about ENTRESTO?”
- Serious allergic reactions causing swelling of your face, lips, tongue, and throat (angioedema) that may cause trouble breathing and death. Get emergency medical help right away if you have symptoms of angioedema or trouble breathing. Do not take ENTRESTO again if you have had angioedema while taking ENTRESTO. People who are Black and take ENTRESTO may have a higher risk of having angioedema than people who are not Black and take ENTRESTO. People who have had angioedema before taking ENTRESTO may have a higher risk of having angioedema than people who have not had angioedema before taking ENTRESTO. See “Who should not take ENTRESTO?”
- Low blood pressure (hypotension). Low blood pressure may be more common if you also take water pills. Call your doctor if you become dizzy or lightheaded, or you develop extreme fatigue.
- Kidney problems. Your doctor will check your kidney function during your treatment with ENTRESTO. If you have changes in your kidney function tests, you may need a lower dose of ENTRESTO or may need to stop taking ENTRESTO for a period of time.
- Increased amount of potassium in your blood. Your doctor will check your potassium blood level during your treatment with ENTRESTO.

These are not all the possible side effects of ENTRESTO. Call your doctor for medical advice about side effects.

The most common side effects were low blood pressure, high potassium, cough, dizziness, and kidney problems.

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

This information is not comprehensive. To learn more, talk to your health care provider or pharmacist, visit www.entresto.com to obtain the FDA-approved product labeling, or call 1-888-ENTRESTO.

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‘Angry Birds’ Help Keep Kids Fit

A ngry Birds Red, Chuck and Bomb are joining forces with Olympic swimmer Chloe Sutton to get kids all over the country excited about exercise!

The Angry Birds Movie and Sony Pictures Home Entertainment have teamed up with the American Heart Association (AHA) to launch the “Angry Birds, Happy Bodies” fitness initiative. The goal is to inspire kids to increase their physical activity and reduce the risk of developing cardiovascular diseases down the road.

Sutton, a two-time Olympian and five-time national champion, serves as the program’s ambassador.

The national campaign, which launched in August around the 2016 Summer Olympics in Brazil, encourages school-aged kids to participate in at least 60 minutes of physical activity each day. The focus is on making physical activity fun!

The campaign also supports the AHA’s #ProtectPE initiative, designed to increase students’ physical activity through daily physical education programs in the nation’s schools, as well as providing activity breaks throughout the day and supporting walking and bicycling to school.

Currently, only 4% of elementary, 8% of middle and 2% of high schools offer daily PE classes throughout the entire school year.

Programs like “Angry Birds, Happy Bodies” are in line with the AHA’s ongoing commitment to helping people all over the country — especially kids — lead heart-healthy lives. This includes encouraging kids to have at least 60 minutes of physical play time each day and ensuring the nation’s PE classes continue to be a part of school curricula.

Measuring Stress

Reducing stress is important for those with heart disease, and some “wearable” devices claim to measure stress levels, but do they really work? The truth is, these devices are external, and stress is largely internal — with a variety of physical and mental symptoms — so they’re unlikely to detect real-time stress in a very accurate way. Most focus on detecting fast or erratic breathing, just one indicator of stress, and have not met FDA requirements to prove their true health benefits.

Still, they can be useful in measuring physical activity, heart rate and other metrics, so if this info doesn’t stress you out, wear what feels good!
For years, only patients deemed “high risk” for open-heart surgery could get transaortic catheter valve replacement. Now, intermediate-risk patients may be eligible as well. By Paula Felps
Larry Haffner is a busy guy. The retired research sociologist and computer science teacher, along with his wife, often venture out to antiques stores in search of one-of-a-kind relics, especially old cameras and vintage telephones, to admire and display. Haffner, a Mended Hearts member-at-large in the St. Louis, Missouri, area, is also an avid reader, often driving to local bookstores to grab some coffee and read book jackets.

“I absolutely love to go to bookstores or newsstands to browse and overspend on magazines,” Haffner says. “I’ll read some there with a cup of coffee, or take a bunch home. And I even browse the racks of books and read jackets — just to see what I want to point and click and send to my Kindle.”

The diagnosis of ‘aging’ should only be made if every other possibility has been excluded.
— Dr. Roxana Mehran

But when simple trips to the bookstore became too tiring for Haffner, he knew something was wrong. In 2012, his doctor confirmed that Haffner had aortic stenosis and took a wait-and-see approach to see how the disease progressed. So, Haffner used that time to educate himself about the disease and treatment options. And thanks to good timing, Haffner discovered he was a candidate for a trial that allowed younger patients like him to avoid open-heart surgery and instead have a valve-replacement procedure through a less invasive method.
Valve Disease by the Numbers

Every year, about 5 million people in the U.S. are diagnosed with heart valve disease. It may occur in a single valve or in a combination of the heart’s four valves, but the most common areas affected are the aortic and mitral valves.

According to the U.S. Census Bureau, about 2.5 million Americans over the age of 75 suffer from aortic stenosis, most commonly as the result of calcium deposits building up on the aortic heart valve. The build-up causes it to narrow and reduce blood flow to the rest of the body.

“Valvular heart disease is a pretty important disease, particularly for the older population,” explains Roxana Mehran, M.D., Director of Interventional Cardiovascular Research and Clinical Trials at Mount Sinai Hospital. “It affects both men and women, and the prevalence is actually greater than the number of diagnoses we’re seeing.”

Without treatment, aortic stenosis can become severe aortic stenosis, or SAS, which is life-threatening. Patients diagnosed with SAS have a survival rate as low as 50% two years after diagnosis, and 20% at five years after diagnosis unless they have aortic valve replacement. (To compare, that is a lower survival rate than breast, lung, colorectal or ovarian cancer.)

Getting the Right Diagnosis

One of the biggest problems with aortic stenosis is that many of the disease’s symptoms — which can include shortness of breath, angina, fatigue, heart palpitations and other complications — are often overlooked or misunderstood. According to a 2005 study published in European Heart Journal, many of the symptoms of aortic stenosis are often passed off as “normal aging.” That’s a mindset that Dr. Mehran says needs to change. Patients must become more educated about heart valve disease — and more proactive in making sure they’re receiving the care they need.

“The diagnosis of ‘aging’ should only be made if every other possibility has been excluded,” she says.

However, according to a 2009 study published in the Journal of Heart Valve Disease, as many as 50% of patients whose echocardiogram shows evidence of heart valve disease are not referred to a surgeon for further exploration.

“When I went back to the doctor and he said we had to replace the valve, we both said ‘TAVR’ at about the same time.”

— Larry Haffner, Mended Hearts member-at-large

After his TAVR procedure, Larry Haffner was out of the hospital and able to resume his life in just three days — with the added bonus of good health.
Less-Invasive Valve Procedures Are Helping Kids, Too

While the majority of heart disease occurs in older adults, a small segment of the population — about one in every 110 babies — is born with congenital heart disease. Of those patients, heart valve disease comprises “a fair bit of that,” says Evan Zahn, M.D., Co-Director of the Congenital Heart Program and Director of the Division of Pediatric Cardiology at Cedars-Sinai Medical Center.

“The difference in children and adults is mainly that they have far more years of life ahead of them,” he says. “There’s not a valve that exists today that will last 90 years, so it’s going to require multiple valve-replacement procedures throughout their lifetime.”

The transcatheter option means that young patients can have fewer invasive surgeries over their lifetimes. And that can be a priceless gift for both the patient and their family.

“To be able to have the procedure done in such a short time and be able to go back to school, back to cheerleading, made it so much easier,” says Shari Bethel, whose daughter, Kaitlyn, was born with congenital heart disease. Kaitlyn had her first open-heart surgery when she was just 11 days old and her second one at the age of five. When she was 13, her cardiologist presented the option of inserting the Melody transcatheter pulmonary valve instead of going through another open-heart surgery.

“I’m so grateful for this option,” says Bethel, who lives in Michigan. “To have to take a child out of school for a month to recover — that affects everything. It affects her physically, educationally, emotionally. But with this, she had the surgery on a Thursday and was home the next day.”

Kaitlyn is now 15, and her family and their doctor anticipate the Melody valve will last at least another four years.

“What a gift that is for my daughter,” Bethel says. “And when that one needs to be replaced, they can put another [valve] inside it instead of doing open-heart surgery. And by then, who knows what technology will be available?”

Dr. Zahn says that the older the child, the greater the number of options for procedures. The option of transcatheter valve replacement has minimized risk and lowered morbidity rates.

“Any time you can increase the amount of time between surgeries, you’re improving the patient’s quality of life,” he says.

And Dr. Dennis Kim, Director of the Cardiac Catheterization Labs at Children’s Healthcare of Atlanta Sibley Heart Center Cardiology and Associate Professor at Emory University, says extending time between surgeries is vital.

“Transcatheter procedures for children aren’t meant to replace surgery, they’re meant to extend times between operations. Children and infants grow up, and their valves grow with them. So a valve that is surgically placed in someone who is two or three years old won’t be suitable down the road when they’re much bigger.”

While one of the greatest barriers to receiving the procedure right now is that not all doctors are qualified to perform it, or don’t understand its benefits, Dr. Kim says that is changing.

“More and more doctors are becoming educated, and advocacy groups like Mended Hearts are playing a big part in that. These days, it’s rare for a doctor not to be aware of the procedure, even if they don’t know how to perform it.”

As technology progresses and the implantation process becomes simpler, Dr. Kim predicts the procedure will become even safer, while at the same time valve durability will improve.
need, get a second opinion. Have a cardiologist listen to your heart and have some sort of imaging technology done so you can rule out heart disease,” Dr. Mehran advises. “The earlier the treatment begins, the better the results will be.”

A Game-Changer: Transaortic Valve Replacement

“In the past, we thought that the answer to valvular heart disease was medication to deal with the symptoms, then to wait until it got bad enough to have surgery,” Dr. Mehran says. For years, this meant open-heart surgery to replace the faulty valve. But patients who weren’t good candidates for open-heart surgery — such as those who were too frail to endure having their chest opened up and having the valves replaced — faced a grim outlook.

“With the introduction of less invasive measures, and the various imaging technologies available, doctors are more aware of [the disease],” Dr. Mehran says. “They’re examining the patient more closely and looking for symptoms that they wouldn’t have been able to see before.”

Not only has technology improved the ability to diagnose heart valve disease, but it has also revolutionized how it can be treated. The introduction of the transcatheter aortic valve replacement, or TAVR, proved to be a game-changer. This procedure is less invasive than open-heart surgery and uses a catheter to put a new valve inside the diseased one.

The catheter is typically inserted into a small incision in the leg to deliver the valve. It usually takes two hours or less, and patients go home in as little as three days — much faster than the recovery time required for open-heart surgery.

When it was first introduced, TAVR was reserved for only the sickest of patients; in fact, patients had to prove they were too sick for open-heart surgery to qualify for the procedure. In October 2012, the FDA approved the device for use in high-risk patients, and in August 2016, the FDA expanded that approval to include intermediate-risk patients.

The SAPIEN Valve, made by Edwards Lifesciences, is presently the only FDA-approved therapy for TAVR in the U.S.

“The technology is complex, but the process for the patient is much simpler,” says Dr. Mehran. “I’ve seen patients go home the next day. This is a tremendous, important breakthrough that we never could have imagined in the past.”

Researching His Options

Haffner, who had already undergone two bypass surgeries by the time his aortic stenosis was diagnosed, wanted to avoid yet another open-heart surgery.

“I started reading about TAVR, and by 2014, my aortic stenosis started getting severe,” says Haffner, who lives in the St. Louis area. “When I went back to the doctor and he said we had to replace the
valve, we both said ‘TAVR’ at about the same time.”

The problem was that Haffner didn’t qualify for the procedure; he was 63 years old, and at that time, the average age of patients receiving the valves was around 85.

“Fortunately, Edwards Lifesciences was doing its Partner II study, which looked at intermediate-risk patients like me, and I was able to get it done.” Not only was he out of the hospital in just three days, but he immediately resumed his life — with the added bonus of good health.

His experience with Mended Hearts when he was a patient led him to become active in advocacy efforts. He has become increasingly involved with the organization and frequently talks to other patients about his experiences.

“I felt great,” he says. “The change is literally overnight. It’s remarkable. I immediately went back to exercising and I still do. Since then, my valve has functioned great, and I’ve met a lot of other people who have had the same experience. It amazes me.”

Adding to TAVR’s appeal for younger patients like Haffner is the fact that the procedure can be repeated and a second valve can be inserted if the first replacement valve begins to fail again after several years.

“These days, the things they can do are so vastly improved,” he says. “Something like aortic stenosis doesn’t go away, and there’s nothing they can do pharmacologically to treat it — so it’s important to know there’s a solution like this out there.”

**Doing His Part**

These solutions didn’t exist when Bill Voerster had open-heart surgery in 2006. Voerster, who is now the Assistant Regional Director for Mended Hearts’ Mid-Atlantic Region, suffered a heart attack on the day he was scheduled to take a stress test to check his heart function. In addition to discovering he had three blocked arteries, tests revealed he had aortic stenosis. Within just a few days, he had bypass surgery for the blocked arteries, and the surgeon also replaced the valve.

The surgery made a “150% difference in my life,” says Voerster, now 84, but he also credits the support of Mended Hearts, and following his doctor’s orders, with his new and improved life.

Today, in his work with Mended Hearts, he talks to many patients who are facing valve replacement and helps them address their fears.

“What they are doing with TAVR is amazing,” Voerster says. “The recovery is three times faster, and they are doing it in younger and younger people. The procedures they have today are fantastic, and people just need to know the new ways they’re treating valve replacement are nothing like it used to be.”

Dr. Mehran of Mount Sinai Hospital agrees. “For those patients who are lucky enough to be alive and have seen the advancements being made, this is an exciting time,” she says. “We’ll continue testing the waters and refining the technology. This will only improve.”

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**Learn More About Aortic Stenosis and Other Valve Disease**

Included with this issue of *Heartbeat* is the GoToGuide on Valve Disease. Be sure to check it out. And go to www.MendedHearts.org to download and share an electronic version of this guide that has videos, interactive quizzes and other handy tools to help you manage valve disease.
If you didn’t like the results of this year’s presidential election, don’t lose hope. There’s another election you can weigh in on: the election for Mended Hearts officers. Though many candidates are running unopposed, we’ve asked them to share their vision for Mended Hearts over the next five years in terms of where and how to best reach the heart patient and caregiver community. Here’s what they said.

**Candidate for President (Incumbent)**

Donnette Smith

My vision for Mended Hearts and Mended Little Hearts is still growth. We have made great strides in the past year, but I think we have miles to go in order to see significant growth in our membership.

I want to stabilize our chapters and focus on outreach to all heart patients. With current technology providing innovative treatments, visiting patients at the bedside is becoming more of a challenge than ever before. I hope to see stronger chapters, more accredited visitors and support for every heart patient who needs us.

**Candidate for Executive Vice President (Incumbent)**

Millie Henn

(Currently National Executive Vice President, National Chapter Development Committee Co-chair, National Patient Advocacy Committee)

My vision for Mended Hearts and Mended Little Hearts is growth and national recognition of MH and MLH as the first-choice support and resource organizations for the heart patient community.

Mended Hearts is the oldest and largest peer-to-peer support group for cardiovascular patients in our nation,
yet thousands of patients and caregivers across this country do not know about us. We can help those patients and caregivers as they face the challenges of diagnosis, treatment, recovery and managing daily cardiovascular health challenges when they know we are here.

We must increase public awareness of MH and what we offer in order to reach those patients, and also to attract new members and sponsors who support our mission. We must be innovative in the when, where and how we attract, serve and benefit our current and future members while providing creative ways to be involved and easy access to our many resources.

**Candidate for Executive Vice President**

**Dale Briggs**

(CURRENTLY CHAPTER PRESIDENT, CHAPTER 92, OF FRESNO, CALIFORNIA)

If a chapter doesn’t have a close relationship with their hospital(s), we need to strive to make sure that hospital employees know us and know what we do. I think a lot of hospitals think that all we do is visit. We need to let them know about our support meetings and speakers, etc. I realize that with the turnover in many hospitals, this is a continuing process.

I am also a fan of getting involved in the cardiac rehab in your area. This may produce more new members than we get from visiting! If your rehab will let you, present Mended Hearts to every “new batch” of rehab patients (preferably) in a meeting setting. Most rehabs have classes for all of their “newbies.” Maybe your chapter can be one of those classes.

**Candidate for Vice President (Incumbent)**

**Patrick Farrant**

(CURRENTLY NATIONAL VICE PRESIDENT)

Our traditional model of bedside patient visits has served us well in the past. As treatment options and hospital stays have changed dramatically, solely relying on hospital relationships to reach patients is, by itself, no longer effective. Other outreach methods involving social media, patient databases and other technology advances need to be developed to bring us in contact with heart patients and caregivers. Creative options of connecting and staying connected with heart patients is a top priority for me.

As hospitals are embracing the concept of “community health,” we are the perfect organization to offer partnering programs to help these hospitals reduce readmissions and to provide preventative heart health information to the communities they serve. Mended Hearts will become the “go to” organization for patient heart health.

**Candidate for Treasurer**

**Gordon “Gus” Littlefield**

(CURRENTLY CHAPTER PRESIDENT)

I would like to see us continue to make more hospitals and health care providers aware of Mended Hearts, to show that MH is an asset in the recovery and education of heart patients — as well as continue to expand Mended Little Hearts and improve and increase fundraising for them.
CANDIDATES FOR REGIONAL DIRECTORS

Central Region Director
G. Bruce Norris
(Currently Central Assistant Regional Director)
I would like to see more Mended Hearts chapters in the central region, especially in Michigan, Kentucky, West Virginia and western Pennsylvania. We need to develop chapters in smaller towns and cities to reach more heart patients in areas that have hospitals with rehab programs, but do not perform heart procedures. I also feel that having regional conferences in those years when national officers are not installed is a good idea.

Midwest Region Director
Larry Mantle
(Currently Chapter President and Midwest Assistant Region Director)
Over the past several years, the number of Mended Hearts chapters has decreased while Mended Little Hearts has grown. The one thing I have noticed in the five conventions I have attended is the enthusiasm and positive attitude the MLH members have. As a visitor, I am sure we have all noticed how much younger the patients we visit are. These patients are the future of Mended Hearts.

Mid-Atlantic Region Director
Bill Carter
(Currently Mid-Atlantic Assistant Regional Director)
I believe the growth of Mended Hearts lies in the development of a better relationship with the African-American and Hispanic populations of the country. As I visit our local hospital, I see that at least 50% of the patients visited are minorities, but few, if any, respond positively to the opportunity to attend a chapter meeting. It is important that we do a better job in attracting membership from these communities.

Northeast Region Director
Frank Cecco
(My goals have remained the same. We need more stability on the executive board, and we need to communicate with chapters and members. Both are improving. Heartbeat magazine is currently the only communication with members who don't attend meetings or whose chapter doesn't have a newsletter. We need to increase membership, increase our visits to patients, and we need to be more visible in the caregiver community.)
Rocky Mountain Region Director (Incumbent)  
Bob Oberfield  
I plan to work to increase membership in Mended Hearts and Mended Little Hearts through implementing and following a strategic plan, strengthening current chapters, continuing to increase revenue and sponsors, and through continued improvement of our visiting program.

Southern Region Director  
Marvin Keyser  
(Currently Assistant Region Director, Southern Region, Chapter 161 President)  
My vision for Mended Hearts and Mended Little Hearts is to properly train regional directors and assistant regional directors to assist chapters in growing their memberships; to help visitors serve their patients; and to strengthen marketing strategies for the organization. Training should be a top priority.

Southwest Region Director (Incumbent)  
Lynn Berringer  
I hope to increase the number of chapters and members in the southwest region. By reducing to 10 the number needed to form a chapter, it makes it easier to contact hospitals and rehabilitation facilities. Over the next five years, we should be able to increase our sponsors for our national objectives.

Western Region Director (Incumbent)  
Ron Manriquez  
I plan to develop and organize Mended Hearts into a widely recognized non-profit organization that has a large outreach to a variety of hospitals and Mended Little Hearts groups so that MH is no longer the best kept secret, but recognized as a world-class peer-to-peer patient support group using hospitals, groups, communities and chapters to accomplish the vision.

YOUR VOTE COUNTS  
In early December, the Mended Hearts national team will distribute ballots electronically to chapter presidents and group leaders, as well as members at large. Chapters will be allowed to vote in January and February 2017, with the results to be announced in the spring. Happy voting!
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

Speak from the heart about your angina

Watch Donnette’s video

Your cardiologist is listening

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ADVOCACY UPDATE

Fighting for Equal Access to Care

Earlier this year, Mended Hearts and Mended Little Hearts formed the Patient Advocacy Network (PAN), which pushes for health-care policies that positively affect heart families. To keep you updated, we’re launching a new section in Heartbeat called Advocacy Update. To learn more about PAN, visit www.mendedhearts.org, click on “Get Involved” and then on “Advocacy.”

Step Therapy
MH supports legislation that provides step-therapy protections for cardiovascular patients. Step therapy is when insurance policies require a patient to try a different (cheaper) drug before they’ll approve the use of another (usually pricier) medication. In 2005, only 27% of insurance plans had these policies; by 2013 more than 67% had them.

Step therapy takes your doctor out
VITALS

of the treatment decision and requires patients to follow a one-size-fits-all approach. Many patients fight these roadblocks while dealing with serious illnesses. Plus, studies have shown that delaying effective treatment can lead to disease progression, worse patient outcomes, higher hospital costs and patients deciding to forgo treatment altogether after encountering these obstacles.

Several states have enacted legislation that allows some patients to be granted a step-therapy exception. They also require these step-therapy protocols to be based on clinical evidence, not just cost. This legislation has reduced the time it takes to be granted an exception from over month to just three days — and in the case of emergencies, just 24 hours.

Prior Authorization

Another policy area we’re focusing on is prior authorization. This is when an insurance company covers a medication only if certain criteria for coverage have been met. These measures exist to standardize care and contain costs. But they lead to an access problem for many patients. The process is also labor intensive and expensive for doctors and other medical providers.

The Food and Drug Administration (FDA) has an expedited review process and provides priority review for products that offer an effective treatment for life-threatening conditions for which there are no alternative treatments. On average, only three technologies a year qualify as breakthroughs.

And even if a new technology meets the “breakthrough” criteria, it can still take up to three years for the provider to get a reimbursement from Centers for Medicare and Medicaid (CMS).

In April 2016, Representatives Cárdenas and Boustany and Senator Coats introduced the Ensuring Patient Access to Critical Breakthrough Products Act (H.R. 5009/S. 2298). This develops a streamlined Medicare coverage and payment approach for medical devices approved through the FDA Expedited Review Process. If a product qualifies for the FDA expedited review, it would be automatically eligible for CMS reimbursement for three years.

We support H.R. 5009/S. 2298, as it ensures that efficient regulatory processes at the FDA are matched with timely payments at CMS. This measure encourages pharmaceutical and medical device research and development, and protects patients’ access to these life-saving and life-sustaining treatments.

Research estimates that prior authorization requests consumed about 20 hours a week per medical practice: one hour of the doctor’s time, nearly six hours of clerical time, plus 13 hours of nurses’ time. This translates to a financial burden on physicians. These complex procedures and policies also cause some patients not to fill their prescriptions.

Nearly 40% of prior-authorization requests are abandoned because of complex procedures and policies, and nearly 70% of patients encountering paper-based prior authorization requests do not receive the original prescription.

Mended Hearts supports legislation that would standardize prior authorization protocols and streamline patient access to innovative medications and treatments. These measures would establish a single standardized form for providers to submit for prior authorization. They would also require payers to make a prior-authorization decision within 48 hours of submission or grant automatic approval.
Taking the National Education and Training Conference on the road in 2016 has been a huge success. By bringing the conferences closer to members, we were able to triple the attendance of the single national conference in 2015 and reach more than 700 heart patients, caregivers and families in six locations across the country.

Because each conference lasted only two days — compared to the four days of the national conference — travel costs were also reduced. The variety of locations allowed the majority of attendees to drive a short distance to meet other members, share knowledge and take advantage of all that the conferences had to offer.

Mid-Atlantic Regional Director Gerald Kemp was with Gastonia chapter members as they received an Award of Excellence in Raleigh.
First-Time Attendees

Events were held in Austin, Texas; Mission Viejo, California; Huntsville, Alabama; Chicago, Illinois; Raleigh, North Carolina; and Scottsdale, Arizona. Thanks to the easy travel and shortened time frame, many members were able to attend for the first time. On average, 70% were first-time attendees to a national Mended Hearts conference.

One attendee at the Western Region conference said, “Having never been able to attend a big national conference, I can only say, regional and smaller conferences give more members the opportunity to attend, interact and thus learn from others.”

Educational Opportunities

Among the many educational presentations were sessions focusing on heart failure symptoms, the latest treatments, AFib arrhythmias, valve disease, CHD treatment and second heart attack prevention.
Attendees were also able to learn about the future of Mended Hearts and how the organization works on a national level as they met and interacted with national staff members such as Board President Donnette Smith and Director of Field Services Marcia Baker. An attendee from the Midwest Region conference said, “I have a little better understanding of what national does, and wow, I am impressed.”

**Your Ideas Matter**

But the ideas and information didn’t just flow one direction. We also collected fantastic ideas from you. At the Rocky Mountain Region conference, Randy Gay noted, “Members are never left to feel that their ideas and contributions are unimportant, quite the opposite in fact. The current leadership is obviously excited and motivated to push Mended Hearts to higher levels of success as the world’s largest peer-to-peer support group for heart patients, their families and caretakers.”

VITALS

We have already started putting some of your ideas into place. For example, back issues of our award-winning magazine, *Heartbeat*, are now available in the Market Place. Members can distribute them to cardiology offices, cardiac surgeons’ waiting areas, YMCAs, churches and other facilities to help raise awareness and share knowledge. As we implement more and more of your suggestions, we’ll keep you updated on Facebook and in future issues of *Heartbeat*.

**Recognizing Excellence**

Also keep an eye on Facebook to learn about the members who were recognized by their regional directors for outstanding service, including Regional Mended Heart of the Year, Accredited Visitor of the Year and Regional Hospital of the Year. These winners will be recognized online.

Other honorees included the recipients of the Mary M. Amato Education scholarships: Josiah Parsons — son of Tiet Parsons and member of Arlington, Texas, Chapter 152 — and Aubrey Lovell — niece of National President Donnette Smith. At the July MLH CHD Symposium, MLH of West Michigan was awarded the Group Excellence Award and MLH of Philadelphia was recognized as runner-up. Finally, Jill Melia, RN, BSN, of Central Virginia Chapter 28 and April White, RN, BSN, of Fairhope, Alabama, Chapter 396, were honored with Sydney & Helen Shuman Nurse Recognition Awards.

Thank you to everyone who made our “On the Road” road trip such a success in 2016!
Gifts From the Heart

Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from August 2, 2016 through September 30, 2016.

IN MEMORY OF:
Bill Alarid
Joann Kamada for C & J
Revel Dankner
James and Rita Sullivan
Thomas Edward De Vries
Mended Hearts Chapter #214
Joy Hannon
Mended Hearts Chapter #51
William “Bill” Kreps
Mended Hearts Chapter #38
Dale “Craig” Lichty
Thad and Vicki Bechtelheimer
Glen McCay
Ben and Sara Arndt
Lynn and Patricia Boedwine
Daryl and Susan Eichacker
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Lauren Beskow
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Fredonia Williams
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W. Kenneth Harrell
Sean Hickson
Jerry and Pam Koudelka
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Jeanette Oliver
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Connie Youngers
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Toby, Mandy and Carter Concienne
Neal and Beverly Owens
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Johnny and Elly
Debby Bohanon
Cristie and Bibie
Saveria Henzi
Charles and Barbara Loy
Rosalie Martens
Joshua James LaFave
Judy LaFave
Norman E. Rowan
The Larson Family
Local 3276
Diane, Kenny, Deb, Tony, Carmen and Andrew McJunkin
Thomas A. Rowan
### VITALS

- **Milo Sisaithong**
  - Alyssa Ossenkop
- **Jase Reid Smiley**
  - Len and Sherry Reid
  - Rebecca Sadler
  - Stan and Sharon Wolfenbarger

In Honor/Recognition/Celebration Of:

- **Virginia Davis’ First Birthday**
  - Rebecca Petty for Mommy and Daddy
- **Christi Farrow**
  - Tom Cowlishaw
- **Leila Halawani**
  - Brittany Halawani
- **Becky Harris**
  - Kline May Realty
- **Christopher Michaelides**
  - Kara Neviackas
- **Rosemary “Rosie” Miller**
  - The Appelt Family
  - Tom Candelaria
  - Lorraine Rossettie
  - Shena Rossettie
- **Samantha Mortimer**
  - Aunt Lisa
  - Great Grandmom, Maria Larmanis

- **Sydney Pearce**
  - The “IT Ladies”
- **Rob Petersen**
  - Jonathan Ball
- **Grace Smith’s Birthday**
  - Heather Pearson
- **Uncle Patrick’s Birthday**
  - Anthony and Margaret Marren
- **UVA’s Pediatric Heart Team**
  - Cindy Foster

In Lieu Of Expense Reimbursement:

- Andrea Baer
- Andrea Himmelberger
- Jodi Lemacks
- Megan Setzer

Bravery Bags:

- LLR, Inc.
- Brandi Mizell

General Donations:

- Tennise Allen
- Chris Byers
- Melissa Chapman
- Kathryn Compa
- Tim Daniel
  - Harlequin - on behalf of the Harlequin More Than Words award recipient, Jodi Lemacks

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**Open Your Heart: Donate Today**

Ways to Give to Mended Hearts and Mended Little 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.

- **Honored 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/get-involved/donate](http://www.mendedhearts.org/get-involved/donate).

Thank you for your support!
Historical Hearts

Chapter Anniversaries: November/December 2016

55 Years
- Mended Hearts of Houston, Texas — Chapter 38 — Southwestern Region

45 Years
- Mended Hearts of Suffolk County, Stony Brook, New York — Chapter 67 — Northeastern Region

40 Years
- Mended Hearts of Atlanta, Georgia — Chapter 81 — Southern Region

35 Years
- Mended Hearts of Circle City, Indianapolis, Indiana — Chapter 78 — Central Region
- Mended Hearts of Ohio Valley, Steubenville, Ohio — Chapter 87 — Central Region

30 Years
- Mended Hearts of Knoxville, Tennessee — Chapter 24 — Southern Region
- Winchester Mended Hearts, Winchester, Virginia — Chapter 173 — Mid-Atlantic Region
- Mended Hearts of Rhode Island (dba, Little Rhody Hot Hearts), Pawtucket, Rhode Island — Chapter 185 — Northeastern Region

25 Years
- Blue Ridge Mended Hearts, Lynchburg, Virginia — Chapter 16 — Mid-Atlantic Region
- Phi Monfil/Marge McAndrews, Columbia, South Carolina — Chapter 71 — Mid-Atlantic Region
- Mended Hearts of Palm Beach County, Palm Beach, Florida — Chapter 206 — Southern Region
- Mended Hearts of North Iowa, Mason, Iowa — Chapter 222 — Midwest Region

20 Years
- Banks/Jackson/Commerce, Commerce, Georgia — Chapter 171 — Southern Region
- Mended Hearts of Wabash Valley, Terre Haute, Indiana — Chapter 236 — Central Region
- Twin Tiers Mended Hearts, Johnson City, New York — Chapter 262 — Northeastern Region
- Scranton Area, Scranton, Pennsylvania — Chapter 276 — Northeastern Region

15 Years
- North Central Ohio, Mansfield, Ohio — Chapter 109 — Central Region
- Mended Hearts of Tucson, Tucson, Arizona — Chapter 116 — Rocky Mountain Region
- Mended Hearts of Scottsdale, Scottsdale, Arizona — Chapter 126 — Rocky Mountain Region
- Central Florida Hearts, Leesburg, Florida — Chapter 298 — Southern Region
- Mended Hearts of Oak Ridge, Oak Ridge, Tennessee — Chapter 299 — Southern Region
- Raleigh Mended Hearts, Raleigh, North Carolina — Chapter 300 — Mid-Atlantic Region
- Kings County-Hanford Mended Hearts, Hanford, California — Chapter 301—Western Region
- Northeast Georgia Mended Hearts, Gainesville, Georgia — Chapter 302 — Southern Region

5 Years
- Mended Hearts of Central Maine, Lewiston, Maine — Chapter 358 — Northeast Region
- Mended Hearts of Maimonides, Brooklyn, New York — Chapter 359 — Northeast Region
- Portsmouth Mended Hearts, Portsmouth, New Hampshire — Chapter 360 — Northeast Region
- Mended Hearts Waukesha County, Oconomowoc, Wisconsin — Chapter 384 — Midwest Region
- Little Rock Mended Hearts, Little Rock, Arkansas—Chapter 385—Southern Region

Mended Little Hearts Anniversaries: November/December 2016

10 Years
- Heart-To-Heart-Mended Little Hearts of Des Moines, Iowa — Midwestern Region

5 Years
- Mended Little Hearts of Central Virginia (Richmond, Virginia) — Mid-Atlantic Region
- Mended Little Hearts of Cincinnati, Ohio — Central Region
- Mended Little Hearts of Dayton, Ohio — Central Region
- Mended Little Hearts of Greater Baltimore, Maryland — Mid-Atlantic Region
- Mended Little Hearts of St. Louis, Missouri — Midwestern Region
- Mended Little Hearts of St. Petersburg — Southern Region
- Mended Little Hearts of Tulsa, Oklahoma — Southwestern Region
- Mended Little Hearts of Western Michigan (Grand Rapids, Michigan) — Central Region
- Mended Little Hearts of Winchester, Virginia — Mid-Atlantic Region
Mended Hearts is proudly expanding our presence in early 2017 with a redesigned, interactive website and online community. This new community, called Connections in a Heartbeat, will allow patients and families to connect, get support, build relationships and navigate through their heart journey together. The moderated community will provide a safe place to connect with new and exciting resources for the heart community. Look for these updates coming soon at www.MendedHearts.org.