Independence!

A bold new direction for Mended Hearts and Mended Little Hearts!
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“Tell your cardiologist exactly how you're feeling. Don't hold anything back.”

Donnette, angina patient

www.SpeakFromTheHeart.com

Tips, information, and more from real angina patients Donnette, Ralph, and Claudia.
**Mission:** Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support

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**Et cetera...**

We'd love to hear from you ... about **Heartbeat** or anything else having to do with Mended Hearts or Mended Little Hearts. Send your thoughts to **editor@mendedhearts.org** and we'll consider them for the magazine.

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**Visit us online:**

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“**It’s great to be alive … and to help others!**”

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Mended Hearts is the oldest cardiac peer-to-peer support organization in the United States. We have 300 chapters and satellite offices 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 Regional Directors listed below:

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Change is sometimes not easy, but managing change effectively is always rewarding. For the first time in many years, Mended Hearts is a completely independent organization. This is actually good news. We can now act independently — we don’t have to rely on others to perform certain tasks in exchange for support.

But on the other hand, it’s also a big responsibility — we really have to ensure every program and project we undertake has a detailed cost-benefit ratio which benefits our organization and our members. We need to continually ask the question, “How will this improve our efforts?” So we’re going to have to be even more careful with our funds and more innovative in raising funds for our organization.

One way we’re changing is in our vision and focus. Where we once approached individual hospitals in order to establish visiting programs, we will now approach entire hospital corporations for that purpose. There are challenges in doing this because some hospitals are still independently operated and don’t have to comply with regulations of hospitals that are part of larger organizations. But, the benefits far outweigh the challenges. We will create a demand from hospitals to request a Mended Hearts or Mended Little Hearts chapter or group. New demands on hospital administrations will require them to ensure readmittance rates are held to a nationwide standard, and we will prove that having Mended Hearts in their hospital can help them do that. I’m certain you’ll agree the opportunity of reaching an entire group of hospitals with our visiting and other programs is too great to pass up.

We’re also endeavoring to strengthen the lines of communication and collaboration between National and Regional offices and local chapters more than ever before. Closer relations with the chapters are desired and necessary to ensure that nationwide, Mended Hearts is a recognized leader as the oldest and largest cardiac peer-to-peer support organization. I encourage you to work with your Regional Directors and our National office to develop communication channels between us to ensure that we understand how we all fit together both nationally and locally.

It’s true, we’re taking some chances. But this is the best way to update and continue Mended Hearts’ volunteer work and support of patients with cardiovascular disease. I’m confident our membership will support the changes, and developing new pathways will ensure our future will be a bright one.
As I write this column, we are deep in preparations for our annual Training and Education Conference. The sound of packing tape and boxes being moved around has become a soundtrack in our offices, as we pack up shirts, promotional items and Joy Jars for distribution to our attendees in Indianapolis.

While I have been to hundreds of conferences all over North America, this will be my very first Mended Hearts/Mended Little Hearts gathering. Based on my experiences at three Regional Connections meetings in Plano, Texas (Southwest Region), Hackensack, N.J. (Northeast Region), and Inverness, Fla. (Southern Region), I have some very high expectations!

The people at the three Regional Connections meetings were welcoming, open to new ideas, interested in what’s going on at the National Center (or home office, as I like to think of it) and very, very kind to me. I got hugged and kissed and treated to delicious meals (interestingly, chicken Marsala was on the menu at most of the meetings … I think that means it’s a delicious, heart-healthy entree). I was given presents(!) and was generally spoiled rotten by some of the nicest, most outgoing people I have ever met. I even got to attend the 50th anniversary celebration of Chapter 45 with my new friends Margaret Elbert, Bobbi Cecco and Frank Cecco. It was a lovely afternoon in historic Roslyn, N.Y., and I was honored to be part of the festivities.

Mended Hearts is an organization very much run by its members whose mission is delivered through the hard work of dedicated and passionate individuals in our 300 MHI Chapters and satellites and nearly 90 MLH Groups. This wonderful strength of our organization is one thing that hasn’t changed in our 63-year history.

During that same 63 years, however, a lot of other things have changed. The medical environment, for starters, has changed drastically, and probably will continue to do so. A good change, recently, was the addition of rehab to services covered by insurance for chronic heart failure patients. There are fewer surgeries these days, and many more cardiac interventions that are done in other ways.

This calls on us to broaden our perspective a bit, to take in the full scope of cardiovascular diseases, and to adapt our offerings and methods to a growing population of heart patients and people at risk of heart disease and stroke … which is pretty much everyone.

There’s no shortage of patients, unfortunately, as the Baby Boomers age and acquire heart disease. So why is our membership shrinking? I’m looking to hear your theories about this when I meet you in Indianapolis. Or, if you’re not able to join us at Conference, could you send me your thoughts on this crucial question? My email address is michelle.packardmilam@mendedhearts.org and my phone number is 888-HEART-99.

I have some theories about why our member numbers are declining, but I think I’ll keep my opinions to myself until I’ve had the chance to experience the Conference. Look for more on this topic in our next issue. In the meantime — tell me what you think. I’m all ears! 😊
It was in June 1988 that Donnette Smith was first introduced to Mended Hearts. “I was visited by a Mended Hearts [volunteer] before I had the first of three surgeries to replace my aortic valve,” she said. “That visit gave me the courage and hope I so desperately needed.”

Prior to that point, the only heart surgery patient she had ever known had died during surgery. “To see and talk to someone who was healthy and back to his normal life just meant everything to me,” she said.

Since becoming a part of Mended Hearts, Smith has served in numerous capacities including, on the national level, Assistant Regional Director, Regional Director, National Treasurer and, currently, Executive Vice President. She also recently served as Fundraising Chair, which she describes as being “fun, exciting and challenging.”

“This was the first time I have ever been involved with actually starting a fundraising campaign from brainstorming with my fantastic committee members to actually seeing it bloom and grow!” Smith said. “It has been exciting to see our chapters embrace this National Day of Giving event and come up with successful — and FUN — ideas to support it. I am so proud of our chapters and their members.”

Over the years, Smith said, she’s had many opportunities to spread the word about heart health. She’s worked with Dr. Clyde Yancy on the cross-country “I Heart Flu Shots” media campaign; and with Dr. Bob Arnot, former chief medical correspondent for MSNBC and NBC News, on the “Hearts in Harmony” campaign. Smith has also served with the American College of Cardiology, including their CardioSmart Patient Advisory Council, to help get out the word about heart health.

“I’ll have to say, though, that the most exciting experience for me was as spokesperson for Gilead Sciences’ ‘Speak from the Heart’ campaign,” Smith said. “This campaign was focused on chronic angina and the importance of talking to your doctor. A video was done about me and my struggles as an angina patient, and featured my husband, my daughter and my grandchildren.” Donnette’s story and video are viewable on SpeakFromtheHeart.com.

Most recently, Smith has filled in for the President of Mended Hearts, who had been hospitalized. “Fortunately, he is on the mend and able to resume his role as our leader,” she says. “It did give me a unique perspective on how hard the President works and the responsibilities he has to this organization, so I’m extremely happy to have him back!”

Of her greatest experience while serving with Mended Hearts, Smith said there has been so many she doesn’t know where to begin. “I think the greatest experience is to visit a heart patient in the hospital and be able to give them the same hope I was given,” she said. “To have someone say, ‘Thank you for what you do!’ really humbles me and makes me grateful to be able to give back to others.”
Mended Little Hearts of West Michigan got its start out of a shared sense of need. “We started in June 2012 when a group of heart moms got together and discussed that there was a need for support in our area,” said Jenna Wood, lead coordinator of the group. “We got busy working and researching different support groups. We became official in November 2012.”

Not surprisingly, the group has since found many more mothers who share that need. The group currently has a care bag program with which they reach out to heart families at Helen DeVos Children’s Hospital in Grand Rapids, Mich. “We have prenatal bags for families who find out their unborn child has a heart defect. We’re partnering with Hearts of Hope, a support group that serves the east side of Michigan to provide prenatal bags to all Michigan families,” said Wood.

The bags are stuffed with helpful items that arrive at a time of need for heart families. “The bags have useful information, sleepers, notebooks and handmade hats,” said Wood. “Our care bags include lip balm, toiletries, care notebooks, snacks, puzzle books and more.” The group also makes “regular” care bags for patients who are having surgery at the hospital.

But that’s not all the group is doing in terms of outreach. The group’s website (www.mlhmi.org) is also home to their quarterly newsletters (available as PDFs at the site), and they maintain a Facebook page, as well. “We also do TV and radio interviews, especially in February around CHD Awareness Week. For CHD Awareness Week, we host a free celebration party for the heart community to celebrate and raise awareness,” Wood said. “This gives an opportunity for the doctors, surgeons, nurses and other medical staff to see their patients in a normal setting.”

The group also hosts a fall picnic that will be held at a local campground overlooking Lake Michigan this year. Picnic events include a potluck dinner, lawn games and lots of fellowship.
Looking ahead, MLH of West Michigan plans to touch as many hearts as the group possibly can. “We want to let them know they’re not alone, that we’re on this journey with them,” said Wood. “We want to make support available as soon as possible. Our long-term goal is to find new and better ways to support our families.”

Part of that process will be the establishment of a visiting program at the group’s local hospital. Another goal is to continue building on the group’s fundraising efforts. One of the group’s biggest sources of fundraising is through the support of a group of runners who solicit donations through their races. “With those folks we raised $11K in sponsorships, which funds our care bag program,” Wood explained. “The runners wear specially designed running T-shirts that show our name and logo at their races, which also raises awareness.”

Given the powerful impact that MLH of West Michigan is already having on their community, the future looks very bright indeed.
Mended Hearts and Mended Little Hearts both have a long history of service and accomplishments to be proud of. It’s a strong foundation to build a promising future upon. And now there is even more reason to be excited about the future of both Mended Hearts and Mended Little Hearts.

Heartbeat magazine spoke with Mended Hearts Executive Director Michele Packard-Milam, CAE, about the bold new steps the organization is taking to serve even more heart patients and families than ever before, and to expand our impact on the communities we serve.

**Heartbeat:** Explain how the theme of “independence” impacts Mended Hearts and the new direction the organization is taking.

**Michele Packard-Milam:** We have been affiliated with either the American Heart Association (AHA) or the American College of Cardiology (ACC) for the past 19 years. While these were terrific relationships that helped us immensely in their day, we weren’t able to stretch our wings as much as we would have liked.

Being tucked up under other associations’ wings also kept our brand from becoming as well-known as it should be, given that fact that we’re 63 years old...
and have visited literally millions of patients and families! We need the Mended Hearts and Mended Little Hearts brands to be ubiquitous — meaning that people need to recognize them as readily as they recognize the American Heart Association, with whom we are often confused.

Because of this confusion, we are creating new logos and slogans for both Mended Hearts and Mended Little Hearts. These new logos will give us a springboard to express our broader mission, of helping patients who are dealing with all types of cardiovascular disease.

**HB: What are some concrete examples of how that might play out in the coming months?**

**MPM:** We will launch the new logos in August 2014. We will redesign our websites in the fall, not only to include the new logos, but also to make visits to our sites more interactive and productive. We will also be designing the new HeartPack, which will debut in January 2015. The next-generation HeartPack will be interactive and will serve as an organizational tool for patients and caregivers. It will help them organize their paperwork, plan their conversations with healthcare providers, and assist with medication management. The new HeartPack will also be interactive on the website, and for the first time, we’ll be developing an app for both smartphones and tablets that will mirror this useful interactivity.

Being independent also means that we’re free to participate in any kind of coalition that we choose, including opportunities with AHA and ACC, simultaneously. We are no longer constrained from working with any coalition we want for advocacy or public health. We can choose what suits our needs for advocacy, funding, research, insurance coverage, patients’ rights and any other issues that help us deliver on our mission of saving lives and improving patient outcomes.

**HB: What will need to change to fully embrace this new independence?**

**MPM:** Throughout our history, the chapters have functioned independently from National, and vice versa. In this new, self-determining environment, it’s obvious that we have to pull hard, and we have to pull together. The National Office and the chapters need to agree on a course of action and pursue it with laser focus. I am hoping that the chapters will want to participate more fully in the direction the National Office is pursuing.

To express what this could mean to the whole organization, I’m rolling out a concept called “From 2 to 10 in 5.” I plan to take us from a $2 million organization to a $10 million organization in 5 years. To reach this aggressive goal, we must coordinate our energy on all fronts.

We have a wonderful system in place that touches more than two million patient lives every year. It’s a very personal, high-impact model of outreach. While personal contact sets us apart from all other organizations and it...
needs to continue, we need MORE. More types of patients — beyond surgical, including all cardiovascular diseases. More age groups and more diverse populations need to become part of what we’re doing. And we need to go top-to-top, at the business level, into more hospital systems. We’re going to talk to the CEOs of hospital corporations instead of individual hospitals. It’s going to change the scale and scope of what we do. And that will attract more and different sponsors and advertisers to our publications and events, which will help fund these new strategies.

**HB:** What will this mean for Mended Little Hearts?

**MPM:** Mended Little Hearts just celebrated its 10th anniversary, which is a wonderful milestone for our fastest-growing program. Like Mended Hearts, however, Mended Little Hearts is not as recognizable as it should be. MLH needs to standardize its infrastructure and help its new groups launch with guidelines and best practices already in place. Further, MLH needs to realize its funding potential, which is significant. With every one out of 110 births resulting in a congenital heart defect, there’s no doubt that the need is there, and we can address that need by getting MLH “on the map” as a strong, self-funded brand.

I believe — strongly — that we can go from 2 to 10 in 5 by pulling hard and pulling together. Let’s celebrate independence by doing more and being more.

**From 2 to 10 in 5 … Let’s Go!**

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**New Patient Advocacy Training Videos Available**

**Watch Today!**

Would you like to share your story about heart disease to create greater awareness locally or nationally? Mended Hearts has created a new video series to help you tell your story effectively and with inspiration. The video series shares the steps needed to speak to the media and to legislators. The step-by-step guide will give you the skills and confidence to share your story in a way that can make a difference in heart disease care and research.

To view the video series, go to the Mended Hearts website at [www.mendedhearts.org](http://www.mendedhearts.org). Your voice is important and we hope you’ll take a few minutes to join your fellow heart heroes as we work together to improve the lives of people living with cardiovascular disease. 🌟
Cholesterol and FH: Getting Control

Having high levels of “bad” (LDL) cholesterol can lead to serious cardiovascular health problems, which is why it’s so important to keep cholesterol under control. For people with familial hypercholesterolemia (FH), that can prove to be a life-or-death matter.

She was with friends at a restaurant when the sweats suddenly hit her. That’s all it was, just sweating. A hot flash, perhaps? “We were joking that ‘40 is the new 60’ and this was the world’s biggest hot flash! For about 25 minutes, I was uncomfortable but not enough to go home,” said Wenter Blair, describing those odd sensations just a few years ago. “I got back to the house later, and I was still thinking it was just a hot flash … the next morning I got up and called my OB/GYN, and she said she wanted me in the office right now. So I went in — she met me at the front door and immediately hooked me up to an EKG machine. When it was done, she said, ‘Honey, you had a heart attack last night.’”

It took three more heart attacks, several heart procedures and the insight of a leading cardiologist to get to the bottom of what was really wrong with Wenter Blair. She has familial hypercholesterolemia, better known as FH. Blair, the co-founder and a member of the Founding Board of Directors of The FH Foundation, has taken her frightening experiences and turned them into a major cause: educating all who need to know about the very real threat FH poses to their lives.
Understanding Cholesterol

Let’s start with cholesterol. Cholesterol is absolutely necessary to life. Your cells use this fat-like, waxy substance to repair and make more cells, among other essential purposes. Your body makes cholesterol naturally, and you may get more cholesterol from the food you eat—in particular, animal products, such as meats, dairy, eggs and other types.

According to the U.S. Centers for Disease Control and Prevention (CDC), some 71 million American adults have high LDL-cholesterol, and only about one-third have it under control. But what does it mean to have “high cholesterol”? There are three main types of cholesterol:

- **LDL or Low-Density Lipoprotein cholesterol** (sometimes referred to as the “bad” kind), which can build up inside the arteries and form substances called plaques. Plaques can choke off the blood flow inside the arteries, which in time can cause blockages in the arteries serving the heart or brain—possibly leading in time to a heart attack or stroke. It’s wise to keep LDL-cholesterol levels at low levels.

- **HDL or High-Density Lipoprotein cholesterol** (sometimes referred to as the “good” kind), which can help remove LDL-cholesterol from the bloodstream. A higher level of HDL-cholesterol is desirable.

- **Triglycerides**, another type of fat that can accumulate inside the artery walls. As with LDL-cholesterol, it’s good to keep triglyceride levels low.

When people say “I have high cholesterol,” they’re usually talking about their LDL-cholesterol level. Although different guidelines disagree about what a healthy level of LDL-cholesterol is, the National Cholesterol Education Program (NCEP) recommends that a level below 100 mg/dL is considered ideal for people who are not at high risk for cardiovascular disease, while less than 70 mg/dL is better for people who are. Your doctor will determine your cholesterol level with a test called a fasting lipoprotein profile. For this simple blood test, you’ll need to fast for a period of time before having your blood drawn—usually 8 hours.

Treating High Cholesterol

The first line of treatment for high LDL-cholesterol is usually making diet and lifestyle changes. This means eating a heart-healthy diet:

- Low in saturated fat, trans fats and cholesterol—try to keep your dietary cholesterol to less than 300 mg per day (200 if you have coronary heart disease or your LDL-cholesterol is 100 mg/dL or above).

- High in deeply colored fruits and vegetables (4 to 5 servings per day)

- Limited in dairy products (2 to 3 servings per day of fat-free, 1 percent and low-fat milk products)

- With 2 servings of fatty fish per week

- With some lean meats and poultry (up to 5 to 6 total ounces per day)

- With some nuts, seeds and legumes (dried beans or peas, 4 to 5 servings per week)

- With some unsaturated vegetable oils (canola, corn, olive, safflower or soybean) and limited tub or liquid unsalted margarines (or spreads made from them)

Physical activity is also part of a cholesterol-lowering program.
lifestyle change plan. You should try to get at least 30 minutes of moderate-intensity aerobic activity 5 days per week, or at least 25 minutes of vigorous aerobic activity 3 days per week. Talk with your doctor before starting or changing your exercise pattern.

For people whose cholesterol can’t be adequately controlled with diet and exercise, medication may be necessary. The first line of medication therapy is usually statins — a type of medication that helps the liver process and remove LDL-cholesterol from the bloodstream.

**FH: The Extreme**

If you think of the many Americans who have high levels of LDL-cholesterol, think of those with FH as the extreme of that population. Not much was known about FH until around 40 years ago, when two Dallas cardiologists, Dr. Michael S. Brown and Dr. Joseph L. Goldstein, identified the genetic cause of FH.

People with FH have very high total and LDL-cholesterol levels — typically greater than 300 mg/dL (total) or 220 mg/dL (LDL). About 1 in 500 people have FH (the National Lipid Association believes that number may be as high as 1 in 250), but according to the FH Foundation, only around 10 percent get diagnosed and treated.

For people with FH, the usual high-cholesterol treatment program starting with changes to diet and exercise patterns usually doesn’t work. The reason is that the liver of a person with FH isn’t functioning properly, failing to remove LDL-cholesterol from the bloodstream at an adequate rate—or at all.

This is a huge concern. People with FH are at very high risk of getting cardiovascular disease at very early ages — as young as in their 40s. For people with two particular faulty genes (known as homozygous FH), it can be even more devastating. They can experience cardiac events as young as in their late teens or early 20s. That’s why it’s critical that people with FH get diagnosed as young as possible and started on therapy immediately upon diagnosis.

**Wenter’s Tale**

For Wenter Blair, finding out she had FH was an arduous process. After her OB/GYN diagnosed her heart attack, she was referred to a cardiologist. “She literally called me a cardiologist right then and they waited for me to arrive. That doctor looked at me and said, ‘No way you’re a heart patient. You’re in great shape,’” Blair said. “I learned that that’s how a lot of women present with a heart attack — it’s not the typical ‘heart attack’ scenario. My media education was that high cholesterol people were slovenly and obese, and that just wasn’t me. I’d run a 10k two weeks before my heart attack.”

But Blair did indeed have FH, as she later learned — and that took time. Finally, she wound up getting a heart procedure done. “I ended up with 5 stents and still had no diagnosis, just knew I had crazy high cholesterol and was on a high dose of statin, with all the problems that brought with it. It was just crazy,” said Blair. “People were convinced I was going to die, and the children were so worried — calling me all throughout the day to check in on me, that sort of thing. It went from ‘Mom can do anything’ to ‘Mom is totally fragile.’”

Enter Dr. Helen Hobbs, the renowned geneticist at the University of Texas Southwestern Medical Center in Dallas. “So it’s just before Christmas, and a friend of mine told me that Dr. Helen Hobbs was working on a Dallas Heart Study. We called her and she had me come in, and told me immediately that I have FH.
Blair has one major message for everyone: “FH is not curable, but it is 100 percent treatable if caught at the pediatric stage.”

‘What’s that?’ I asked. She wanted to bring me into the heart study, and needed all my blood relatives — who just happened to be in town for Christmas. It was God at work again!

“So I was tested, and she told me the results were in — I have FH and my son Christian has FH. My daughter did not. So I said, ‘God, let me save my son.’” Blair took her son to see Dr. Sarah Blumenschein, who had Christian get a lipid profile. The result? “My son Christian is a very competitive ice hockey player, and his LDL was 253 — this was a kid who lived in my heart-healthy home and was in great physical condition,” said Blair.

Christian was immediately started on a pediatric dose of statin therapy. “Christian’s LDL is now 112 and we have 100 percent eliminated his heart and stroke threat from his future,” said Blair. “It cost me $4 a month to get his prescription, to save my child’s life.”

When Christian converted to ice hockey after a skiing trip to Banff in Canada, it led to another “God moment” for Blair. It turned out that the wife of Christian’s ice hockey coach was a pharmaceutical company recruiter. “Within days I was talking with a Genzyme patient advocate and that’s how everything got started … all because my son insisted on playing ice hockey.

“Now there was a head of steam around the issue. One thing led to another, and Kynamro is the name of the new drug, which is approved for homozygous FH,” said Blair. “We also have PCKS9 protein inhibitors in FDA drug trials, too, where we had nothing before.”

But there was still a problem, at that point, in Blair’s eyes: a lack of information on FH. That stirred her and several others to co-found the FH Foundation, the first-of-its-kind advocacy group and information clearinghouse on FH. It’s mission: to educate the public about the dangers of FH and emerging hope for new treatments.

“Many doctors don’t know about FH, but that’s changing. The American College of Cardiology a couple of years ago did a presentation on FH — ‘Familial Hypercholesterolemia, and You Thought There Was Nothing New,’” said Blair. “If someone is diagnosed with FH, everyone needs to be tested in the family — everyone is under threat, even if they’re apparently perfectly healthy. Everyone needs to have a lipid panel done, they need their lipid numbers.”

Blair has one major message for everyone: “FH is not curable, but it is 100 percent treatable if caught at the pediatric stage,” she said. “High cholesterol is not benign. It’s a fit-as-a-fiddle person’s issue. It’s a child’s issue. It is absolutely necessary to save these children’s lives.”

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New Mended Hearts Cholesterol and FH Go-to-Guide

Later this summer, Mended Hearts will launch a new electronic guide to cholesterol and FH, titled Why Cholesterol Matters: Why You Should Be Tested for High Cholesterol and FH. This Go-to-Guide provides up-to-date guidance on managing cholesterol and FH, as well as tips on living healthy and keeping possible complications at bay. The guide will be posted to the Mended Hearts website, www.mendedhearts.org.
Kentuckiana Chapter 11 was already planning a fundraiser at Uptown Art in Louisville, Ky., when they learned about Mended Hearts’ National Day of Giving. “Our Chapter Special Projects Coordinator, Jessica Pasbrig, reserved the date and organized the event,” said Chapter President Sandy Larimore. “She is a very talented asset to our chapter.”

Uptown Art offers art classes to organizations for fundraisers, birthday parties, etc. “A picture is selected before the class begins, and everyone knows what they will be painting when they arrive,” said Larimore. “It basically is an art class where an instructor directs your painting as a group.

“You do not have to have ANY artistic ability to participate,” she said. “Before you know it, you’ve painted a picture all by yourself!”

The fundraiser, held on Tuesday, May 20, 2014, was a success. Several chapter members, along with 55 to 60 other members of the community, attended. “We were able to promote Mended Hearts and explain our mission before the class began,” Larimore said.

A portion of the registration fee and 10 percent of all beverage sales went to the fundraiser. “Everyone goes home with a beautiful painting,” said Larimore. “It’s a lot of fun having fellowship with the other attendees.”

Another highlight for Chapter 11 this year is that 12 of their members, including Past President’s Council member Charles Christmas, attended the 2014 Education and Training Conference in Indianapolis, Ind., June 19–22. “When we learned the conference would be in Indianapolis, just two and a half hours from Louisville, we knew this was an excellent time for our members to attend at a lower expense,” Larimore said.
We started advertising after last year’s conference that we would try to pay the registration fee for anyone attending the 2014 conference, and we had several people take advantage of the opportunity,” she added. “We normally have four to five members attend the national conference, so we’re happy to have this group going. We would like to offer this opportunity every year as long as funds are available.”

Kentuckiana Chapter 11 celebrated its 40th anniversary on March 17, 2014.

Citrus County Chapter 367
A Gathering of Hearts in Florida

On May 17, 2014, Citrus County Chapter 367 held its first Regional Connections meeting. Titled “A Gathering of Hearts,” it was held on the campus of Citrus Memorial Hospital in Inverness, Fla., in association with Citrus Memorial Health System Heart and Vascular Center.

“We had the pleasure of having Michele Packard-Milam, CAE, Executive Director of Mended Hearts, as guest speaker,” said Millie King, President of Chapter 367. “She spoke about the vision for Mended Hearts.”

The event began at 8 a.m. with a continental breakfast. Chapters from the Southern District attended, including Assistant Regional Directors Mike Weber and Lee Meneses. Scott Sinigalliano, Director of Cardiovascular Services, Citrus Memorial Health System, made introductions and served as moderator.

Several guest speakers provided information about health issues throughout the day. Eileen Handberg, PhD, ARNP, BC, FNA, FACC, Associate Professor of Medicine at the University of Florida, spoke about stem cell research and its therapeutic regenerative application in heart disease; Donna O’Hara, ARNP, gave a presentation on chronic angina, Speak From the Heart; and Suman Pasupuleti, MD, CCDS, FACC, spoke about cardiovascular disease and cardiac rhythm device therapy.

In the afternoon, a roundtable discussion on the impact of cardiovascular disease on the patient and caregiver was held.

“Events like this don’t just happen,” said King. “It takes a lot of hard work and people coming together, sharing ideas, making a plan and then implementing that plan.

“Although the task looked daunting at first, Mended Hearts of Citrus County Chapter 367 members eagerly stepped up to the challenge and formed a committee to produce a fun and informative ‘Gathering of Hearts.’”

King adds that not only did Mended Hearts members step up, so did many business and community members. “To all the people who made this Regional Connections meeting a success, we give you thanks,” she said. “Especially to Citrus Memorial Health System and Citrus Memorial Heart and Vascular Center, and Peter Kim, MD, Inverness-Ocala Heart Institute, for their overwhelming support.”

Mike Weber, Assistant Regional Director, said that Chapter 367 is a “strong, vibrant chapter with great leadership.”

He says some of the chapter’s past events have included exhibiting at numerous health fairs and helping celebrate Citrus Memorial Hospital’s 10-year anniversary of treating heart patients.

What contributes to the chapter’s success? “Having good speakers at chapter meetings, strong publicity of chapter events and having a successful visiting program,” said Weber.

Mended Hearts Chapter 367 of Citrus County, Florida, was formed in September 2010.
Change for the Better

With greater independence, the future is bright for Mended Little Hearts.

MLH Goals and Objectives

Communication: Convey the right information to the right people at the right time using the right channels, in an orchestrated manner.

Leadership and Ownership: Equip leaders and change champions with the information and tools to lead, own and sustain the program outcomes.

Capability Readiness: Prepare the organization and employees with the relevant tools necessary.

Journey Management: Provides the “glue” to integrate Change Management, Program governance with a holistic understanding of expected outcomes, key interdependencies and risks.
If there is one thing we want our children to learn, it’s to be independent. Following that example, Mended Little Hearts (MLH) is undergoing changes to become more independent. Since its inception in 2004, MLH has followed the tried and true, 60-plus-year model of Mended Hearts as its parent organization. Today, the program has expanded so much that it’s time for MLH to grow up and become its own entity — one that best serves the needs of a special subset of the heart disease population, families with children who have congenital heart disease.

From September 2013 to May 2014, MLH worked with Accenture Federal Services, a global management consulting, technology services and outsourcing company, to define a new mission and create ways to better serve families touched by congenital heart defects (CHDs) and heart disease.

“I believe that Mended Little Hearts is preparing for a wonderful future,” said Andrea Baer, Vice President of Mended Little Hearts, and Mended Little Hearts National Committee Chair. “MLH is growing rapidly, which is a good problem to have. We are currently working to maintain and improve the quality of the program as we grow.

“We are restructuring internally with staff and volunteers in order to address the growing needs of the organization now and in the future,” she added. “We are preparing our new strategic plan and are currently working to diversify our partnerships with organizations and corporations in order to work toward our strategic goals.”

Baer says that working with Accenture was a wonderful experience. “I am grateful that MLH had the ability to work with such an amazing company to help us design a structure that would support the needs of our local groups now and in the future,” she says. “Their volunteers were engaged and worked well at trying to understand our organization to help us grow.”

Baer became involved with Mended Little Hearts after the birth of her third son, who was born with a CHD. A friend, who was an MLH member, reached out and supported her during the family’s crisis. “We were alone and afraid and I wanted to make sure that other families in our area did not have to walk this journey alone,” she says. “My husband and I founded our local group [in southwestern Pennsylvania] in 2009 with this mission in mind.” She was elected Vice President of Mended Little Hearts in June 2013.

A New Mission

With the many changes already under way at MLH, including the new look and feel and the services provided, MLH is now reaching more families. Baer said she is looking forward to a promising future for Mended Little Hearts. “This is an exciting time for our organization. We have amazing volunteers across the country in our local groups, and we will be focusing on procedures to assure our standard of excellence as we grow,” she said. “Mended Hearts’ new independence will allow for the freedom of growth, but all growth comes with obstacles. Our goal is to plan for those obstacles and be prepared to establish new relationships and programs that support our mission without boundaries.”

Megan Setzer, National Director for Mended Little Hearts, agreed. “Over the last couple years, MLH has experienced rapid growth while continuing to function with limited resources,” she said. “Moving forward, I see MLH as self-sustaining with a structure that may look different than the traditional Mended Hearts structure, but that best supports the children and families we serve.”

Part of that, she added, will include more consistent branding; a clearer organizational structure; training, support, guidelines and oversight for group leaders; and
quality support and resources for families affected by CHD. “My hope is that as MLH continues to grow, our organization will be a leading resource for families receiving a CHD diagnosis.”

Setzer’s youngest son was diagnosed prenatally with hypoplastic left heart syndrome (HLHS) in fall 2008. “When our son was born at a children’s hospital a few hours from our home, we had a care bag from MLH of Central Virginia waiting for us at the nurses’ station,” she said. “This gesture helped us feel less alone.”

With MLH’s restructuring, they’ll be better equipped to provide that same support for other families. “For 10 years, MLH has followed Mended Hearts’ wonderful example, but some of those don’t work as well for our different population of members and leaders,” said Setzer. “As MLH becomes more independent, the organization will be able to seek different types of funding sources that may align more closely with our organizational goals. For example, there is increasing evidence that suggests children with CHDs would benefit from neurodevelopmental consultations at various life stages. In that sense, Mended Little Hearts could seek collaborative partnerships that could benefit both researchers and CHD families.”

As Mended Little Hearts and Mended Hearts move forward into their new era of independence, Baer’s wish list for MLH would include funding to enable MLH to reach all CHD families with its Bravery Bag and Little Heart Guide programs. “I believe those programs are essential to our mission of supporting families,” she said. “A diverse funding portfolio is needed to build a strong infrastructure to staff and support these programs as we continue to grow.”

Setzer said she would like to see MLH become a nationally recognized name as a leading CHD organization. “I’d like to grow and strengthen our partnerships with children’s hospitals and CHD and other healthcare organizations,” she said, “so that we can continue to stay up-to-date with information that will allow us to empower families to make decisions for their loved ones.”

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**Q&A with Dwain Young, Manager, at Accenture Federal Services**

Dwain Young, PHR, Manager at Accenture Federal Services, worked with Mended Little Hearts over the last few months to help the organization find ways to better achieve its goals of helping families affected by coronary heart defects and heart disease.

**Heartbeat:** In what capacity did you help Mended Little Hearts (MLH)? Have you done similar work with other organizations in the past?

**Dwain Young:** We recently worked with MLH through Accenture’s Skills Based Volunteer Program, where we offer consulting service free of charge to non-profits. This project was an Organizational Transformation Project where we analyzed their current organizational design, areas of improvement and suggested a new organizational model for becoming their own 501(c)(3). It helped them define a new vision and mission and key performance indicators (KPIs) for the organization’s success.

Additionally, this project was coupled with a Change Approach on how to implement the new changes from the Executive Leadership level to their local groups across the country. The Change Management approach included communications and training to be conducted and suggested timelines that coincide with the Organizational Design Implementation along with a branding campaign for the new change.

We have done similar work with many Fortune 100 and Fortune 500 companies and federal clients through our Management Consulting/Talent and Organization Practice at Accenture. Accenture’s Talent and Organization Practice offers a comprehensive, analytics-based approach to identifying workforce needs in light
of business goals, collaborating with clients to dramatically improve performance through integrated talent, HR and organization change services.

**HB**: What was the timeframe for working with MLH?

**DY**: We worked with MLH from September 2013 to May 2014.

**HB**: How will MLH be a more independent organization going forward?

**DY**: MLH can become a more independent organization by seeking additional partnerships with sponsors in order to be able to raise enough funds to support their mission and vision for their organization and causes.

They should also continue to be a closely tied partner with their parent organization, Mended Hearts, as they can provide brand recognition, financial support and guidance for expanding the MLH organization so they can better serve the community and families affected by a congenital heart defect.

They can also implement portions of the suggested To-Be Organization Design, suggested by Accenture, such as the governance and reporting structure, new mission and vision statement, branding materials and certain key roles such as a focus on fundraising and local group management.

**HB**: What do you see for the future of MLH?

**DY**: The future of MLH is very bright and promising. I foresee MLH serving more in the community with congenital heart defects by extending their reach to the local community through their local groups. I also see them extending their support through additional channels such as the medical community. If they can integrate their services with additional children’s hospitals, Mended Little Hearts can easily be the top non-profit for families to contact when they are faced with a congenital heart defect in their family.

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**About Accenture’s Skills to Succeed/Skills Based Volunteer Program:**

Accenture’s **Skills to Succeed** Corporate Citizenship initiative helps address the global need for skills that open doors to employment and economic opportunity. By 2015, Accenture plans to equip 700,000 people globally with the skills to get a job or build a business.

**About Accenture:**

Accenture is a global management consulting, technology services and outsourcing company, with approximately 289,000 people serving clients in more than 120 countries. Combining unparalleled experience, comprehensive capabilities across all industries and business functions, and extensive research on the world’s most successful companies, Accenture collaborates with clients to help them become high-performance businesses and governments. The company generated net revenues of US$28.6 billion for the fiscal year ended Aug. 31, 2013. Its home page is [www.accenture.com](http://www.accenture.com).
Dr. Harken would be so pleased to have seen chapters nationwide host fundraising events in support of Mended Hearts. As this was our first-ever national fundraising event, we are extremely proud of those chapters that donated directly or hosted local fundraising events in June, including on Dr. Harken’s birthday, June 5.

Every chapter that contributed received recognition at the National Education and Training Conference in Indianapolis, Ind., June 22, during the Awards Ceremony. Below are a few photos from local events. In our fall issue we will recognize all the contributions received to date.

Thank You for Making our National Day of Giving a Huge Success
**MAPLE-BOURBON PORK MEDALLIONS**

Serve with pasta, couscous, rice or potatoes.

- 1 pound pork tenderloin, all visible fat removed
- ½ cup maple syrup
- ½ cup bourbon
- 2 Tbsp whole-grain or Dijon mustard
- 2 Tbsp ketchup
- Pam cooking spray

1. Cut pork into 12 slices and flatten each with the palm of your hand to about ¾-inch thickness. Set aside.

2. In a small bowl, stir together remaining ingredients except Pam. Set aside.

3. Spray a large skillet with Pam. Place over medium-high heat. Add 6 pork slices to hot skillet and cook for 3 minutes on each side or until slightly pink. Remove from skillet and keep warm. Repeat with remaining pork slices.


**VENDANGE SALAD WITH DIJON VINAIGRETTE**

A delicious side dish for the pork medallions.

**Salad**
- ½ avocado per person, peeled and seeded
- 12 crispy red grapes per person, washed and dried
- Red onion (sweet, if possible) sliced in thin, small rings

**Dijon Vinaigrette**
- 2 Tbsp good wine or balsamic vinegar
- ¼ tsp salt
- ¼ tsp dry mustard or 1 tbsp Dijon mustard (more if you wish)
- 6 Tbsp salad oil or light olive oil
- Big pinch of pepper
- 2 Tbsp honey or 1 Tbsp sugar (may need to adjust this based on vinegar and mustard tartness)

1. Either beat vinegar in a bowl with salt, honey and mustard until salt is dissolved, then beat in the oil by droplets and season with pepper, OR place all ingredients in a screw-top jar and shake vigorously for 30 seconds to blend thoroughly.

2. Place grapes and onion rings into vinaigrette to marinate for 1-4 hours before serving. Spoon grapes and onion rings over avocado halves on lettuce leaf, spooning extra vinaigrette as needed.
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 real angina patients—including Claudia—visit www.SpeakFromTheHeart.com.
Historical Hearts

Mended Hearts Chapter Anniversaries
September – November 2014

35 years
Evansville, IN • Chapter 107 • Central Region

25 years
Columbia, SC • Chapter 71 • Mid-Atlantic Region
Lynchburg, VA • Chapter 16 • Mid-Atlantic Region

20 years
Greenville, NC • Chapter 23 • Mid-Atlantic Region
Huntsville, AL • Chapter 260 • Southern Region
Johnson City/Binghamton, NY • Chapter 262 • Northeast Region
Johnson City, TN • Chapter 259 • Southern Region

5 years
Brooklyn, NY • Chapter 359 • Northeast Region
Lewiston, ME • Chapter 358 • Northeast Region

Mended Little Hearts Anniversaries
September – November 2014

5 years
Mended Little Hearts of Bowling Green, KY • Central Region
Mended Little Hearts of Rhode Island • Northeast Region
Mended Little Hearts of the Shenandoah Valley, VA • Mid-Atlantic Region
Mended Little Hearts of Southwestern PA • Central Region

MENDED HEARTS INTERNET VISITING PROGRAM
Heart patients, their family and friends

Internet visitors offer support, encouragement and understanding by sharing their experiences.
If you need support from people who have experienced your particular type of heart event, contact the Mended Hearts Internet Visiting Program by emailing Gerry Harrelson, Chairperson, at support@mendedhearts.org.

Meet others who know what you’re going through
Join the Mended Hearts Support Community

www.mendedhearts.org/inspire

We’ve created an online support community at Inspire where you can:

• Meet others dealing with heart disease
• Learn what to expect, from diagnosis to treatment
• Write about your experiences
• Start a guestbook for family and friends
• Maintain complete control of your privacy

“It’s free and takes just a minute to join.

“In just one day, I’ve felt surrounded by hope, love, and the exquisite feeling that I was not alone.”

Mended Hearts

Summer 2014 Heartbeat 27
### in Memory of...

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<tr>
<th>Name</th>
<th>Chapter/Location abbreviated</th>
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<tbody>
<tr>
<td>Keith Beard</td>
<td>Mended Hearts Chapter 245</td>
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<td>Dale Dille</td>
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<td>Seymour Miller</td>
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<td>Raul and Dot Fernandes</td>
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<td>Norman Polman</td>
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<td>Julius H. Schwartz</td>
<td>Howard S. Heyman and Barbara Simpson</td>
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<td>Naomi Freeman</td>
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<td>Larry and Judy Yolken</td>
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<td>Margie Worthington</td>
<td>Mended Hearts Chapter 240</td>
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### in Honor/Recognition of...

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<td>Dr. Paul Massimiano</td>
<td>Joel Wind</td>
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<tr>
<td>James Mucha</td>
<td>for his many years of service heading up the chapter visitation program</td>
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<td>Randy Gay</td>
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### general Donations...

- AmazonSmile Foundation
- Clarence and Polly Clodfelter
- Suzanne Galvanek via the AT&T United Way/Employee Giving Campaign
- Del Hardesty
- Ken and Carolyn Hayes
- Dona Joseph via the Network for Good Giving System
- Loren C. Lyall
- Mended Hearts Chapter 235
- Vero Beach, FL
- Microsoft Matching Gifts Program
- Lew and Laura Moorman
- Joseph and Sheila Nadler
- G. Bruce and Louise Norris
- Bill Schramer via YourCause, LLC Trustee for Pacific Gas and Electric Company/Employee Giving
- Donald and Twila Weber
- Samuel Weinstein Family Foundation
- Victor and Deon Williams

### National Day of Giving...

Donations received on the National Day of Giving will be featured in the Fall 2014 issue of Heartbeat.
IN MEMORY OF:

Angela Ascone
  Chris Kazimir and Nikki Kilgour
  Elizabeth Monroig
  Bonnie Zeolla

Mariana Ceschini Moyses
  Eisenmann Corporation

Godfrey “Fritz” Hoffman
  The Family of Phillip Schurrer

Clinton J. Romig
  Robert C. Case

Gracelyn Nicole Taylor
  Stephen Cannady and Parents, John and Rebecca Cannady

IN HONOR/CELEBRATION OF:

Brian and Jennifer’s Wedding
  Michael Spiecker

Aidan James Crowley
  Interact Club

Avery Garrett
  Jason and Janelle Gilbert — in honor of Avery’s 4th birthday!

Alexa Jackson
  Robert Hostetter

Jackson Charles Lewis
  Charles Romberg

Price Llewellyn
  Ashley Dean

Kolton Pennell
  Keisha Moorefield

Ozzy Reyher
  Securitas Security Services USA, Inc.

Planned Giving:
Consider a Gift to Mended Hearts or Mended Little Hearts in Your Will

To make a tax-deductible gift to Mended Hearts or Mended Little Hearts, send a check or money order to:

The Mended Hearts, Inc.
8150 N. Central Expwy.,
M2248, Dallas, TX 75206

Mended Little Hearts
8150 N. Central Expwy.,
M2248, Dallas, TX 75206

Or contribute online using your credit card at
www.mendedhearts.org

Some members have found that leaving a gift to Mended Hearts or Mended Little Hearts in their will is a meaningful and personal way to support the objectives of Mended Hearts or Mended Little Hearts. The process can be as simple and easy as discussing the matter with your estate planner or attorney. Here’s some suggested language:

“I give, devise and bequeath the sum of $XX dollars to The Mended Hearts, Inc. or Mended Little Hearts, to be used for the support of heart patients in accordance with its charitable purposes.”
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 real angina patients—including Teddy—visit www.SpeakFromTheHeart.com.

"With my new treatment plan, I feel like the old me is back."

Teddy, angina patient
TO ORDER:
Call toll-free at 888-432-7899
or send an email to
tierney.wright@mendedhearts.org.

Or, send your order with a
check or money order to:
The Mended Hearts, Inc.
National Office
8150 N. Central Expressway,
M2248, Dallas, TX 75206

SHIPPING AND HANDLING
SCHEDULE (USA ONLY)

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Expedited
Next Day Delivery
(via UPS Next Day Air)
Call the National Office for quote at 888-432-7899

2nd Day Delivery
(via UPS 2nd Day Air)
Call the National Office for quote at 888-432-7899

ALL ITEMS ARE NOW 50% OFF!
Order anything you see below or check out our website at mendedhearts.org and mendedlittlehearts.org! Limited quantities available.

MHI WRISTBAND
$2.00

MHI VISITOR VESTS (S-3XL)
$25.00

MHI PILL BOX
$2.50

MLH BEACH TOWEL
$20.00

MLH TODDLER SUNHAT
$20.00

MLH POLO SHIRT
$20 (ADULTS S-XL) $22 (ADULTS 2XL)
A Bold New Direction for Mended Hearts

Mended Hearts has built a strong national reputation for being a “friend in need” to thousands of heart patients nationwide for more than 60 years. We’re now building on that reputation to take Mended Hearts farther than it has ever gone before.

Starting now, Mended Hearts will broaden the organization’s outreach as we seek to expand the impact of everything we do. We will be reaching out to hospitals at the corporate level; operating independently but in collaboration with national healthcare associations; and strengthening the bonds between the national organization, our regional leadership and our individual chapters and our Mended Little Hearts groups.

These are ambitious goals, and they will be the focus of everything we do as we take our first steps into this bright new future. We strive to make Mended Hearts more vital than ever to the heart patients we serve nationwide!

To find out more about our program and how our organization could benefit you or your family, please call 1.888.HEART99 (1.888.432.7899), or go to www.mendedhearts.org