PLUS:

- Has American Heart Month moved the needle on heart health?
- Candlelight vigil for heart angels
- Getting paid to take your meds

6 Tips for Great Hospital Relationships
MH and MLH chapter leaders share tips for getting along with hospital personnel

TWO OF A KIND

Rare heart defect unites two Mended Hearts women
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10 Kindred Hearts
Late last year, Mended Hearts stepped in to help a teenage girl in dire need of heart surgery. The act of support created a friendship that only two heart patients can fully appreciate.

14 6 Ways to Nurture a Better Relationship With Your Hospital
Mended Hearts and Mended Little Hearts leaders share their best chapter-hospital relationship secrets.

20 52 Years of American Heart Month
We’ve made great strides in heart health since 1964. But there’s still plenty of room for improvement.

On the Cover: Through several phone calls, Donnette Smith helped Hannah Long through a difficult diagnosis. They met in person for the first time during our cover shoot at Huntsville Hospital in Alabama, a long-time supporter of Mended Hearts. Cover photo: J. Hanshaw Photography, Inc.
Heartfelt Connections

Fear is not a fun emotion to live with. Yet as heart patients and caregivers of heart patients, fear sometimes comes with the territory. We may fear a surgery that lies ahead, or may be afraid that we won’t be able to make all the lifestyle changes that the cardiologist has asked of us.

It’s in this darkness of fear that we as Mended Hearts members can offer a bit of light. While I’ve been blessed with many opportunities to help bring some light to heart patients, I recently had an especially poignant experience with a young woman in my hometown of Huntsville.

Hannah Long is a beautiful 16-year-old girl who for months was worried about her heart. She had several fainting spells and had episodes where her heart would race. She quit cheerleading because she feared she’d pass out. Friends thought she was being lazy, and even some doctors dismissed her experience as a panic attack. She was finally diagnosed with SVT (supraventricular tachycardia), a condition I also have, and was told she’d need an ablation.

Her family members knew of Mended Hearts and contacted us to see if anyone could talk to Hannah’s mother and Hannah. I was able to do that and explained that not only had I survived the condition, but so had my own daughter. I reassured Hannah’s family that there is life after a scary diagnosis. I hope you’ll read Hannah’s story, “Kindred Hearts,” later in this issue.

This is what Mended Hearts and Mended Little Hearts are all about — pushing back the darkness that comes with fear and shedding light on what life can be like after diagnosis.

Donnette Smith
President
Mended Hearts
Speak from the heart about your angina

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

Donnette, angina patient

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

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

Watch Donnette’s video

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Our 3-Year Strategic Plan

With a new year laid out before us, what will each of these precious days bring to us, as patients, parents, caregivers or spouses?

For the Board of Directors and staff, the answer to some of these questions became much clearer when the Board adopted a new, three-year Strategic Plan. This plan, which was developed by the Board of Directors, will help us stay focused on the big-picture goals that will help us grow. It also gives us a crucible by which to gauge the relevance and potential impact of the many we make every week. Here are the main goals of our ambitious new plan:

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<td>Goal 1</td>
<td>Programs</td>
<td>Mended Hearts has high-impact educational programs that meet the needs of individuals, hospitals, patients, communities and caregivers.</td>
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<td>Goal 2</td>
<td>Corporate Development</td>
<td>Mended Hearts has predictable and robust revenue flow from diverse sources, individuals, sponsors, foundations, donors, advertisers and partners.</td>
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<td>Goal 3</td>
<td>Publications</td>
<td>Mended Hearts produces relevant, interesting publications that engage and enlighten audiences.</td>
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<td>Goal 4</td>
<td>Membership/Visiting</td>
<td>Mended Hearts has an engaged, growing member population, comprised of diverse audiences, including age, race, disease, language and gender.</td>
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<tr>
<td>Goal 5</td>
<td>Chapter Development</td>
<td>By December 2018, we will double the number of Mended Hearts chapters that are engaged and that offer impactful, virtual and physical support groups.</td>
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<tr>
<td>Goal 6</td>
<td>Conferences</td>
<td>By December 2018, we will reach a total of 2,000 people in face-to-face conferences with a purpose of chapter development and member training.</td>
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The idea of a strategic plan is to organize every single activity to help achieve these major goals. If you see an opportunity to change or improve our processes to accomplish this, please speak up. And remember to turn in your visiting numbers and complete your annual reports quickly so we can see how we’re reaching our goals. Your work is what really counts — help us understand how we can help you!

Michele Packard-Milam, CAE
Executive Director
Mended Hearts
Getting Paid to Take Your Statins

Nearly half of all patients who are prescribed statins to lower cholesterol stop taking them. But what if patients and their physicians were paid to take them? A recent study by Penn State showed that when patients and their physicians were given an incentive — as much as $1,024 split between the two — patients lowered their cholesterol more than study participants who were not paid. That amount may seem high, but not compared to the costs of heart attack treatment, which can run into the tens of thousands of dollars. “We shouldn’t have to,” says Bobbi Cecco, president of the Hackensack, N.J., chapter of Mended Hearts. “But if that’s what it comes down to . . . .”

The Roar ’n Run 2016 Virtual Charity Race will take place during CHD Awareness Week, February 7-14. Registration is $25 per adult and $15 per child under 16. To learn more and to register, visit www.crowdrise.com/roarnrunvirtualrace.
Bob McLean:
Calm Reassurance for Heart Patients

When he first joined Mended Hearts, Bob McLean — a visitor with Chapter 339 of Portland, Maine — used to get nervous before every visit. “I wasn’t one of those people who could walk into a room all by myself and just start talking to people,” he says. “It wasn’t my style.”

What a difference six years makes. During his weekly Thursday visits, Bob has touched the lives of countless families and is now so comfortable talking with fellow heart patients that one of them reached out to the Cardiovascular Institute at Maine Medical Center to nominate him as a Health Care Hero. He was recently honored with the award at the hospital, which also received a significant donation from the patient.

Chapter 339 President Betsi Dupont trained with Bob as a visitor and understands why he received the award: “Bob is a kind, friendly fellow who is always willing to help our chapter and other visitor volunteers. His demeanor when visiting with patients, both pre- and post-op, is calm and reassuring.”

Bob, who had two stents in 2001 and five bypasses in 2005, offers both hope and good advice to patients. “I tell people, ‘If they tell you to do something, do it.’ I didn’t the first time. I let them know that things will get better if they do that. I’m proof.” He says listening was the key to eventually calming his nerves. “You’ve got to listen to them first and talk second. I learned to do that. They’ll let you know if they want to hear about the operation or how you got through it or if they have other questions.”

Gail Crocker, cardiac rehab manager at Maine Medical Center, says, “Bob and all of the Mended Hearts visitors have a priceless impact on the outlook of patients who have come for treatment from far away and lack family and friends to visit.” She notes that the visitors bring something unique to patients. “We health professionals can recommend and guide, but motivation to start appreciating life daily and choosing to live heart healthy comes from seeing that active volunteer visitor who is not just surviving, but thriving.”  
— Kimberly Turner
MLH FUNDRAISING

Family Raises More Than $3K for MLH

Kalyn and Trevor Bertholf lost their newborn son less than 24 hours after bringing him into the world. Now, little Ryan’s legacy is the driving force behind one of the most successful Roar ‘n Run campaigns to date.

“No one expects a baby not to live,” says Kalyn Bertholf. Though her son was only 22 hours old when he passed away, he had already endeared himself to so many. In the months leading up to his birth, family members had thrown a beautiful, generous shower to ensure he’d have a good start in life.

Doctors knew the unborn boy had an abnormal aortic valve that might restrict blood flow, but specialists were optimistic that he would have a positive outcome. Ryan Matthew, the “spitting image” of his father, Trevor, was born on August 26, 2015, with a rare heart defect known as Shone’s Syndrome. He was whisked away to the NICU and, five hours later, transferred to the children’s hospital for a cath lab procedure.

The procedure went well, but the hopeful prognosis didn’t last. Doctors worked on Ryan through the night. He had to have a pacemaker put in — his second surgery in 12 hours. Trevor watched as grey-haired doctors stepped in to intercede after the younger ones had been unsuccessful. By 8:30 a.m., it was evident that Ryan wasn’t going to make it. Kalyn had just enough time to be discharged and get to her husband’s side. Ryan passed away at 11:18 a.m. on August 27, 2015.

“Less than 24 hours after we said hello, we had to say goodbye,” Kalyn wrote in a message to friends and family. She began looking online for other parents who had lost a child to CHD. She found Mended Little Hearts. “It felt like the family I should have been a part of,” says Kalyn. “I had the urge to spread awareness about CHD because [before my pregnancy] I had no idea how common it was, and I consider myself an educated person.”

At press time, the Bertholfs had raised more than $3,200 through their Roar ‘n Run campaign — the leading team by at least a couple thousand dollars. Friends and family have responded with an outpouring of donations in honor of “sweet angel Ryan.” It’s a gesture Kalyn never expected: “When you lose a baby, no one knows what to say. This is their way of showing their love for us.” — Maria Carter

Ryan Bertholf lived only 22 hours because of a rare heart defect. His parents are raising money for the MLH Roar ‘n Run race to raise awareness of CHD.

Candlelight Vigil for Heart Angels

On Wednesday, Feb. 10, light a candle in remembrance of loved ones who have passed away because of a congenital heart defect. Why February 10? It’s the middle day of Congenital Heart Defect Awareness Week: February 7 – 14. Mended Little Hearts national will highlight the occasion on its social media sites, including Facebook, Twitter and Instagram. You’re invited to join in the conversation by using the hashtag #rememberourhearts.
As a 14-time NBA All-Star, Olympic gold medalist, and one of the “50 Greatest Players in National Basketball Association History,” Jerry West, 77, is not a man who lets much slow him down, including AFib. Here, he discusses his condition and what he does to stay heart healthy. — Kimberly Turner

On his diagnosis:
When I was a player, doctors told me I had an extra heartbeat. Sometimes I felt like my heart was coming through my chest, but it wasn’t until age 55 when they put me in a hospital for exhaustion that I was diagnosed with AFib.

On eating well: I try to eat healthy. I eat a lot of fruits, a lot of salads. I don’t eat a lot of meat at all. Things that I think would make me weigh 400 pounds, I’m not gonna do that.

On physical fitness: I get on the treadmill. I lift weights. I stretch. I do all the things that I’ve sort of been trained to do, to be honest. I see other people who are 77 who walk with a cane. They have no balance. I work on balance. I’ll stand on one leg and hold weights. I make myself do it. Some people don’t make themselves do anything. They give up and that’s no fun … no fun at all.

On motivation: Have a reason to get up every morning so at least you feel like you’re contributing something other than just fighting to live out the remaining years of your life. Be active. Keep your mind active. Read. Walk. Do something besides sit in a chair.

On spreading awareness: Most athletes don’t like to talk about their health, but to me, it’s just natural to be associated with Janssen and MyAFibRisk.com. If this will help make someone more educated about the risk of a stroke or if I can get anyone to pay attention to their health and heart-related issues, I’m going to do it.
DIGITAL TOOLS

No Age Limit for Health Apps

Think health-related smartphone apps are just for younger generations? Think again. The Rock Health Digital Health Consumer Survey showed that, among smartphone owners age 55 or older, 30 percent have downloaded and used a health-related app. That’s only 4 percent less than the (presumably most tech-savvy) demographic of adults age 35 and younger.

Try these two Mended Hearts apps: The HeartGuide app provides users with descriptions of common heart conditions, procedures and tests, plus cardiac rehab reminders and healthy lifestyle tips. The Heartbeat Now app places the latest issue of Heartbeat magazine at your fingertips. Both are available on the Apple Store and Android Market. — Maria Carter

HEARTBEAT: BEHIND THE SCENES

MH, MLH Members Weigh In

Every story in Heartbeat magazine is written to help you live healthier, feel connected, or inform you about medical news. To that end, Mended Hearts begins each issue with a story-planning meeting where we decide which articles will go in a particular issue.

New for 2016, Mended Hearts and Mended Little Hearts members are joining in the editorial planning sessions. Our inaugural team of members includes:

- Alexandria Calhoun, a member and former president of the Mended Hearts Sacramento, Calif., chapter
- Tiffany Horn, co-coordinator of MLH of Evansville, Ind.
- Willa Welter, group secretary for the Cape Girardeau, Mo., chapter

“Serving on the editorial board of Heartbeat offers an excellent opportunity for me to expand my efforts to serve those impacted by CHD,” says Horn, whose 3-year-old son, Kendon, was born with CHD. “The message the publication brings to its readers, that of education and encouragement, is beneficial to all families who have been affected by heart disease.”

This is your magazine, and we want to make it as inspiring as possible. Please feel free to share your story ideas with us at info@mendedhearts.org. — Melanie Medina

#RockYourScar, MLH’s photo contest to raise awareness for CHD, is currently accepting submissions. Be sure to check out facebook.com/MendedLittleHeartsNationalOrganization and tag your photos with #RockYourScar on social media.

Approximately 30 percent of smartphone users age 55 or older have downloaded and used a health-related app.
Late last year, Mended Hearts stepped in to help a teenage girl in dire need of a heart procedure. The act of support created a friendship that only two heart patients can fully appreciate. By Maria Carter
When 16-year-old Hannah Long woke up in the back of an ambulance, she had no idea how she'd gotten there. Her heart had stopped, paramedics said. They were headed for the hospital. This has to be a dream, she thought.

Minutes earlier, the Priceville High junior from Decatur, Ala., had been sitting in the living room at her boyfriend’s house, talking with his parents, when she lost consciousness. “Brandon was trying to wake me up,” Long recalls. “I came to for a second. All I remember is looking at him and falling back over.”

Brandon’s dad checked for a pulse; when he couldn’t find one, Brandon’s mother dialed 9-1-1. The operator talked them through checking for a pulse on Long’s wrists and feet. Still nothing. Without a pulse, they’d need to perform CPR. By the time the ambulance arrived, it could be too late.

Both men were CPR certified. It took eight chest compressions to bring Long’s heart rate back. When paramedics arrived, she was still unconscious.

Fearing that Long might go into cardiac arrest — her heart was racing at more than 200 beats per minute (bpm) — paramedics were preparing to shock her when she opened her eyes. “I didn’t know what was going on or where I was,” Long says. “I was distraught. I didn’t know what had happened to me.… I’ve had a panic attack before,” she says. “Anxiety doesn’t make your heart stop beating.” Long knew it was something much more serious.

**Vague Symptoms**

Six months earlier, Long had begun experiencing occasional shortness of breath. She told her mother something wasn’t right with her heart; it felt as if it were speeding up, going so fast Long felt like she couldn’t breathe.

Long’s mother, Melanie Ennis, made an appointment with Huntsville pediatric cardiologist Paul Israel, M.D. After asking about Long’s family history of heart disease — she was born with a slight heart murmur, and her maternal grandfather died during his third heart attack, at age 55 — Dr. Israel decided further testing was needed.

He performed an echocardiogram and placed Long on a 30-day heart monitor. He suspected that her fainting spells were caused by an abnormally fast heartbeat known as supraventricular tachycardia (SVT), but nothing out of the ordinary happened during the monitoring period. They would have to wait, watch and see what happens. She might outgrow the condition, whatever it was.

Four months passed without incident. Still wary, Long took a break from the activities she loved, like cheerleading. “I didn’t want to go anywhere because I was worried I might fall out,” she says. Slowly, she regained some normalcy.

On one of her better days, she felt well enough to attend a friend’s baseball game. Returning home from the game, she began feeling short of breath. As she climbed a flight of stairs to get into her house, she fell to the ground and lost consciousness. She
woke up in the hospital, where she learned that her heart rate had reached 180 bpm. She wore another heart monitor, this time for 20 days, but doctors still didn’t have a clear answer. “All I knew is that I was short of breath, and there could be 70 different causes for that,” Long says.

Long’s mother made an appointment with Yung Lau, M.D., a pediatric cardiologist at Children’s of Birmingham, to get a second opinion. His next availability was weeks away. Long would have another trip to the emergency room before Dr. Lau could see her.

**A Diagnosis and Some Reassurance**

After Long’s heart stopped at her boyfriend’s house, she knew she was lucky to be alive — *what if Brandon and his dad hadn’t known CPR?* The upside of the frightening event was that Dr. Israel, the cardiologist in Huntsville, finally had the information he needed: data from the ambulance’s cardiac monitor showed that Long was indeed suffering from SVT. The time for taking chances was over. Long needed to get to Birmingham for surgery as quickly as possible.

Though Long’s family was relieved to finally have a diagnosis, they were worried about her recovery and her future. One of Long’s relatives — an aunt named Patricia Alred, who works for Janssen Pharmaceuticals, a sponsor of Mended Hearts — was talking about Long’s condition at the American Heart Association’s Scientific Sessions this past November. Alred shared her niece’s story with several Mended Hearts national staff and board members, including Donnette Smith, President of Mended Hearts. Smith and her daughter also have SVT and have had a procedure to repair it.

When Smith returned home from the conference, she called Long’s mother. “My daughter and I have both had the same type of procedure that Hannah is going to have,” Smith told Long’s mother, Melanie Ennis, who recently passed away.
Smith knew that Ennis was worried about Hannah’s quality of life after the heart procedure. “I told her that my daughter had gone through the procedure at 19, and now she’s married and has kids. Her pregnancies were healthy, and she is living a normal life. Melanie said that made her feel so much better,” Smith says.

The Road to Recovery
Dr. Lau, the Birmingham pediatric cardiologist, diagnosed Long with atrioventricular nodal reentry tachycardia (AVNRT) — a form of SVT common in young adults because symptoms often do not show up until one’s heart is fully developed, usually in the late teens or early 20s — and began cardiac ablation. He had to induce SVT multiple times to find out where Long’s heart was “firing” incorrectly. The risky procedure could have resulted in Long needing a pacemaker. Thankfully, Dr. Lau’s team found and deadened the extra nerves on Long’s heart that were mimicking an extra heartbeat and causing her heart to stop. The procedure was successful.

While Long was recovering, she received a phone call from Smith. They talked about the physical healing and found they also shared common ground emotionally. Some of Long’s classmates didn’t believe anything was really wrong with her and accused her of faking a condition. Smith could relate.

“I was so upset as a young adult because I couldn’t get anyone to believe that I was really sick,” Smith says. “Hannah went through some tough times at school, and I can remember going through some of the same things. This went on for years, and I got really depressed. Doctors finally were able to find it and treat it.”

Long says the encouragement she’s received from Smith and other Mended Hearts members has given her hope. She adds that Mended Hearts is “a great group of survivors sharing their hope and love for others... It has affected me in realizing I’m not alone.” Long started her own charity, Hannah’s Helping Hearts, to give back to children with congenital heart defects, and plans to get more involved in the Mended Little Hearts chapter in her community. She’s focused on her academic future, making straight As as a National Honor Society member, and her budding career as a model — she’s walked the runway for emerging designers at New York Fashion Week twice now.

So far, Long hasn’t had any other health issues. “It’s been a tough, challenging journey,” she says. “It’s a miracle I’m here.”

Editor’s note: Shortly before publication, Melanie Ennis, Hannah Long’s mother, passed away unexpectedly. Our thoughts and prayers are with the family.

Long’s boyfriend, Brandon, and his father performed CPR on Long when a heart arrhythmia caused her to pass out. Brandon later gave Long this puppy, who she named “Mel” in honor of her mother.

Long says her little brother, Cameron Blake Ennis, has stayed close by her side throughout her diagnosis and the loss of their mother.
WAYS TO NURTURE A RELATIONSHIP WITH YOUR HOSPITAL

If your chapter or group hasn’t made a love connection yet with your local hospital, try these tips from other groups who’ve achieved relationship bliss. By Kimberly Turner
OME HOSPITALS ARE WAR Y about allowing peer-to-peer organizations such as Mended Hearts and Mended Little Hearts to interact with patients in any way. Others accept the delivery of educational brochures or Bravery Bags but don’t allow visiting programs. Many fully support MH/MLH programs but do not go the extra mile to maximize the benefit of having a chapter or group at their facility.

Then there are the love stories.

There are chapters and hospitals that work together so seamlessly, they are able to do things like raise money to place life-saving automated external defibrillators (AEDs) in their communities, which is happening with Chapter 127 in Cookeville, Tenn., and Chapter 28 of Central Virginia. Others, like Chapter 161 in Hollywood, Fla., collaborate with their hospital to create comprehensive cardiac surgery discharge classes. Still others, including the hospital that works with Mended Little Hearts of Greater Rochester, have hosted annual celebrations for 500 families and staff members.

They’re the kind of hospital relationships that make Mended Hearts and Mended Little Hearts leaders say things like: “Is there such a thing as a perfect world? Of course not, but the relationship between our hospital and our chapter is the closest you’ll find.” That’s what Marvin Keyser, President of Chapter 161 and Assistant Regional Director of MH Southern Region said about Memorial Regional Hospital in South Florida. And Blanche Smithers, President of Chapter 127, has this to say about Cookeville Regional Medical Center: “I just cannot say enough good things about our hospital. We continuously talk about how good they are to us.”

We talked to these leaders about how chapters and groups around the country can reach that level of bliss with their local hospitals. Here are their best tips.

Find a Champion on the Staff

If you do not yet have a relationship with your local hospital or are trying to start a visiting program, find a hospital staff member who can act as your advocate. Jodi Lemacks, Mended Little Hearts National Program Director, says, “Figure out who you need to talk to and just go sit down with them, maybe bring them some food. You have to have a contact who will be your champion at the hospital. Let them know what we can and can’t provide and reassure them that we don’t compare facilities, and we don’t give medical advice. We’re only there to be a positive presence to the families.”

Christine Delaughter, Director of Volunteer Services at Bon Secours St. Mary’s Hospital in Richmond, Va., suggests approaching the hospital’s volunteer services department to learn more about the requirements of Mended Hearts Chapter 28 of Richmond, Va., enjoys a strong relationship with the hospital it serves, Bon Secours St. Mary’s Hospital. Here, several hospital employees and Mended Hearts members show off an AED. On the left-hand side of the photo are (back row, from left) Leonard Amendola, accredited visitor and captain of the St. Mary’s Mended Hearts visitors; Peter McCourt, the St. Mary’s Vice President of Mission; (front row, from left) Christine Delaughter, Director of Volunteer Services for St. Mary’s Hospital; Barbara Ferguson, director of Clinical Management; Nellie League, Chief Nurse Executive; and Chris Snidow, Mended Hearts accredited visitor. On the right-hand side are, from left, Joe Shocket, President of MH Chapter 28; Tommy Broughton, First Vice President; and John Hagadorn and Jeff Miller, both accredited visitors for St. Mary’s hospital.
volunteering at that specific hospital. She agrees with Lemacks and says, “It’s critical that Mended Hearts identifies who in their hospital will be their champion, whether it’s the volunteer services department, the cardiac surgeons, or the cardiac care staff.”

**Play Nice**

Sometimes, you may have to wait a while for the right champion to come along. When Chapter 380 in Boise, Idaho, was forming, its leaders hoped to serve two hospital systems in the area: St. Luke’s and St. Alphonsus. St. Luke’s welcomed Chapter 380, but a cardiologist at St. Alphonsus wasn’t so accepting. He preferred to have a chapter that exclusively served that hospital. When the cardiologist left St. Alphonsus, another leader there — the Vice President of Heart & Vascular Services — asked Chapter 380 members if they would be willing to serve St. Alphonsus patients.

“Of course we said ‘of course,’” says Elaine Grossaint, Visiting Chair for the chapter. “We want to be inclusive of all hospitals if we can.” In October 2015, Chapter 380 members began visiting patients twice a week at St. Alphonsus.

Grossaint says that even before Mended Hearts started visiting at St. Alphonsus, her chapter tried to include leaders from that hospital in various events and educational sessions. For instance, earlier in 2015, the chapter hosted a community-wide lecture about congestive heart failure and invited medical professionals from both St. Luke’s and St. Alphonsus to speak. “It was a feather in our cap to bring together the two hospitals because that doesn’t often happen,” Grossaint says. “It was a big statement for us to say we’re not affiliated with either hospital, we’re affiliated with Mended Hearts, and we think both of you have great professionals.”

Between October 2015 and December 2015, visitors touched the lives of 211 heart patients at St. Alphonsus, by either visiting with them or leaving behind Mended Hearts materials.

The relationship has been going so well that Chapter 380, along with the burgeoning Mended Little Hearts group in Boise,
participated in a holiday fundraiser for St. Alphonsus. The two groups decorated a Christmas tree for the hospital’s Festival of Trees event, with the trees being auctioned off and proceeds going to St. Alphonsus. The Vice President of Heart & Vascular Services won the Mended Hearts tree and displayed it throughout the holidays on one of the cardiology floors at the hospital.

**Take Your Time**

It can be difficult to be patient when you know that there are patients and families who could benefit from MH and MLH, but setting up a visiting program or expanding your chapter’s services in a hospital can take time. Don’t get discouraged.

Scott Eitman, President of Chapter 138 in Cleveland, says after a nurse at the Cleveland Clinic began advocating for a MH chapter, it took her eight to 10 years to get a trial run approved. That was 1986. They have been working with the hospital ever since.

It took MLH of Rochester two years to get brochures placed in all of the hospital’s patient rooms. “It’s baby steps,” says chapter founder Jennifer Kowal. “You can’t just go in thinking you’re going to have a full program and an office in the hospital. You have to ease into it.”

MLH of Cincinnati has faced similar delays. Leslie Sams, who is both Co-coordinator for MLH of Cincinnati and Assistant Regional Director of MLH’s Central Region, says, “We’ve been working with our hospital for five years, and we’ve just now gotten our foot in the door to have an official visiting program. A huge key is to be patient and persistent. It takes time, especially with children’s hospitals. There are a lot of restrictions — for good reason.”

Flexibility is as important as patience. “Even if they just let you provide coffee to families and they’ll promote it, that’s a start,” Lemacks says. “If you help one family, that’s a big deal to that family.”

**Build Relationships**

Behind every successful chapter-hospital collaboration are strong personal relationships. Marvin Keyser, Assistant Regional Director of the Mended Hearts Southern Region and President of Chapter 161 in Hollywood, Fla., says, “Relationships really matter. Become a friend. This is really not a business.” The relationships he has helped to build at Memorial Regional Hospital in South Florida led to the creation of a cardiac surgery discharge class.

Members of Chapter 161 and nurses teach the class together.

Get staff members involved when you can. According to Al Malick, Visiting Chair of Chapter 309 in Concord, Calif., at least three hospital staff nurses serve as MH officers and participate in meetings. That kind of involvement isn’t unusual among successful chapters and hospital staff.

Sams has found that inviting key staff members to come speak at meetings helps. “It gives them a chance to see our group, to talk to us more, and understand what we’re all about. One of our heart surgeons who is also on the executive committee came to speak to our group, and now he’s 100 percent supportive. It gives them a chance to get to know us better. Using educational programs for that really works.”
Everyone loves to feel appreciated, and your hospital’s staff is no different. Show them how much your chapter values their work with gestures such as cookies on holidays or flowers when they’ve gone above and beyond. Chapter 184 in Cedar Rapids, Iowa, for example, provides nurses with flashlight pens that feature the chapter’s name and contact information. Even more effective are the more than 5,000 heart-shaped pillows they have created and delivered to bypass patients during the last 18 years.

Another way to show your appreciation is to, as Sams says, “find a way that you, as individuals and as a group, can be an asset to the hospital. We want to be a program that benefits not only the families we serve but also the staff.” To that end, members of her chapter serve on the Family Advisory Council for their heart institute and volunteer their time for quality-improvement projects at the hospital. “It shows them that we’re there for them too and has really built those relationships,” she says.

When I see a red Mended Hearts vest, I see a heart angel walking among us.
— Christine Delaughter, Director of Volunteer Services at Bon Secours St. Mary’s Hospital

Put Their Minds at Ease
There are a number of reasons hospitals may be hesitant to allow peer-to-peer groups into their facilities: concerns about privacy, worries over the accuracy of information and bad experiences with unreliable groups.

“The truth is, there are some parent-to-parent support groups out there that do things that justifiably cause hospitals concern,” Lemacks says. “I think one of the biggest benefits of Mended Little Hearts is we do have policies and procedures in place. If we hear of a problem, we address it right away. People can have confidence in our brand. There are hospitals that have definitely gotten burned by a lack of professionalism, and it hurts everyone when this happens.”

Helping hospitals better understand the accreditation process may diminish some concerns, suggests Malick: “Help not just the administrators but even the staff understand how MH actually works and what the visiting accreditation process is to give the whole thing a sense of professionalism and legitimacy that they may not be aware of.”

Harry Bowers, president of Chapter 309 in Walnut Creek, Calif., encourages a proactive approach to address privacy concerns. “We do our re-accreditation for visitors every year,” he says. “I specify that they are now HIPAA trained, and then I make sure our hospital’s chief administrative officer has a copy of that list on his desk, so he knows we’re following HIPAA rules.”

Play by the Rules
Leonard Amendola, who heads up the visiting program at St. Mary’s Hospital in Virginia, says, “The key to success in any
hospital is to understand that Mended Hearts is there as a visitor and as a guest of the hospital. It’s their hospital; they call the shots.” Whether it’s getting annual flu shots, undergoing additional hospital-specific training, or wearing a badge, he says respecting the facilities’ regulations is vital.

Delaughter, a staff member at the same hospital, advises MH representatives to “understand that policies and procedures are in place to ensure the highest level of safe and competent care for every patient. They deserve our best at every encounter, including the encounter they have with a MH visitor. Be willing to follow policy and procedures, and understand that if they change, it’s important to adapt to those changes. Be proactive in keeping chapter members current on any changes or updates that may affect them. Keep an open, positive line of communication.”

Reap the Rewards
Working well with your local hospital has all sorts of advantages. Blanche Smithers, President of Chapter 127 in Cookeville, Tenn., can read off an extensive list of things that Hospital of the Year winner Cookeville Regional Medical Center does to support her chapter, but she is most proud of the bake sale and silent auction it hosts to raise money for the chapter’s AED program. “We have given away more than 135 AEDs, which cost us $1,300 each. It’s quite an achievement,” she says. (This past December, an AED from a similar program in Central Virginia saved a life at Bon Secours St. Mary’s Hospital.)

In the end, it is the heart patients themselves who benefit most when MH/MLH and hospitals cooperate. “The visiting volunteers are role models to our patients and families,” says Delaughter, of St. Mary’s Hospital. “They can be the hope that patients and families need in the midst of what may be a life-threatening crisis. They are the only people who really understand what a patient or caregiver is experiencing. When I see a red Mended Hearts vest, I see a heart angel walking among us.”
February marks the 52nd anniversary of American Heart Month. When President Lyndon B. Johnson announced the creation of the national awareness month in 1964, cardiology was very different than it is today. Statins were not yet being prescribed to lower cholesterol. Physicians were just beginning to identify the link between heart disease and factors such as smoking and a sedentary lifestyle. The automatic implantable cardiac defibrillator and echocardiography had not yet been developed, and the first successful coronary artery bypass surgery on a human was still more than a decade away. It’s no wonder annual deaths from cardiovascular diseases have fallen by nearly 1 million per year since the 1960s.

American Heart Association President Mark Creager, M.D., says in addition to the prescription of life-saving drugs such as statins, blood pressure-lowering medications, and antiplatelet medications, the way we care for heart patients has also substantially improved survival rates. “Probably the best example of that is how we approach patients who have had heart attacks,” says Dr. Creager. “That has changed dramatically in the past 50 years. We used to treat heart attacks as an untreatable condition in which a patient would be put on bed rest for up to six weeks and allowed to ‘recover.’ Now we identify heart attacks promptly and get patients to facilities where the heart attack can be not only diagnosed, but treated immediately, particularly with catheters to open up the blockers and insert stents. That has made a huge difference in reducing fatalities from heart disease.”

Let’s take a look at how far we have come in the fight against the nation’s No. 1 killer since American Heart Month began — and what we need to do to continue making strides in decades to come.

We’ve made great strides in heart health since 1964. But there’s still room for improvement. By Kimberly Turner
**PROGRESS: THEN AND NOW**

- **1964**
  - U.S. population of **192 million**
  - **924,000** Americans died each year from cardiovascular disease

- **2010**
  - U.S. population of **309 million**
  - **784,000** Americans died from cardiovascular disease

The rate of coronary heart disease rose steadily during the first half of the 20th century until it reached its peak in 1968. If it had continued to rise at the same rate, by 2015, more than 1.7 million Americans would have died from heart disease each year.

- **1964**
  - The average American’s life expectancy was **70.2 years**

- **2015**
  - Life expectancy has risen to **78.8 years**. According to the CDC, as much as **70%** of that increase may be attributable to a reduction in cardiovascular disease.

- **1979 to 1993**
  - **67%** of infants with critical CHDs survived to 18 years of age

- **1994 to 2005**
  - **83%** of infants survive to age 18

Dr. Creager explains: “Congenital heart diseases are being detected much earlier, often in utero, which enables parents to be aware of potential problems and physicians to identify strategies that can be implemented early, thereby avoiding more complicated issues downstream. The catheter-based techniques and surgical techniques have improved dramatically, so that many children with congenital heart disease are growing up to become adults. This is an incredibly important area. We are making good strides but there’s much more to do.”
AWARENESS & EDUCATION

American Heart Month aims to educate the public about risk factors for heart disease, the signs of a heart attack, healthy blood pressure numbers and stroke prevention.

80% ❤️
Percentage of heart disease and stroke events that are preventable, according to the American Heart Association

1 million 🚨
Number of heart attacks and strokes the national Million Hearts Initiative hopes to prevent by 2017.

Dr. Creager says, “I think the key word is awareness. Although smoking has diminished considerably, there are still too many people smoking. Even though treatment of high blood pressure has improved, many people are not aware that they have high blood pressure or are not being treated effectively. We want people to consult their physicians to see if they’re at risk for a heart attack and make sure that other things are being taken care of.”

29% 🕒
Percentage of Americans with high blood pressure

48% 🕒
Percentage of those Americans whose blood pressure is not being appropriately managed

7 out of 10 people who have their first heart attack have high blood pressure.

8 out of 10 people who have their first stroke have high blood pressure.

Dr. Creager continues, “We have a long way to go to ensure that the public at large is adhering to healthy lifestyles, including a proper diet and exercise, and that healthy foods are accessible to everybody. We’re making strides, but the battle is not yet won. We haven’t really reversed the trend with Americans being overweight and obese, which leads to diabetes as well as high blood pressure. We need to be much more vigilant in our efforts regarding that.”

32% 🕒
Percentage of Americans with high LDL (“bad”) cholesterol. Of these, only 29.5% have the condition “under control,” according to the CDC. People with high LDL are twice as likely to have a heart attack as those with lower LDL.

47% 🕒
Percentage of Americans who has one of the three key risk factors (smoking, high blood pressure, high cholesterol) of heart disease. Diabetes, obesity, poor diet, physical activity and excessive alcohol use also play a role.

27% 🕒
Percentage of Americans who are aware of all the major heart attack symptoms: chest pain or discomfort, shortness of breath, nausea, light-headedness, cold sweats, pain in the upper body, or discomfort in the arms, back, neck, jaw or upper stomach.

1964: 42% of Americans were cigarette smokers

2014: 17% of Americans were smokers

The New HeartGuide Is Here!
The new HeartGuide is made possible by our sponsors: Amgen Cardiovascular, AstraZeneca, Bristol-Myers Squibb, Pfizer, Daiichi-Sankyo Lilly, Gilead, Janssen and Novartis Pharmaceuticals.
The HeartGuide app is now available for free in the app store.
For new heart patients, life can quickly become overwhelming. They hear unfamiliar medical terms, undergo complicated procedures, take new medications and begin making major lifestyle changes.

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

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

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

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

The new HeartGuide is made possible by our sponsors: Amgen Cardiovascular, AstraZeneca, Bristol-Myers Squibb, Pfizer, Daiichi-Sankyo Lilly, Gilead, Janssen and Novartis Pharmaceuticals.
Why I Visit

“My wife was tired of me sitting around the house.”

Having survived three heart attacks, quintuple bypass surgery and eight stent procedures, Fayetteville, N.C., retiree Bill Farr had never been visited by a Mended Hearts visitor, much less heard of the organization. The closest chapter to Farr was an hour away in Goldsboro, N.C., Chapter 194.

That all changed when Farr retired in 2012 after a 22-year career as a Geospatial Intelligence Officer for the U.S. Army Special Operations Command in the civil service (prior to that, he served in the U.S. Army as a Corps of Engineer Topographic Officer).

Here’s his story about why he became a Mended Hearts visitor and how he’s serving heart patients at the Cape Fear Valley hospital in Fayetteville. — As told to Melanie Medina

Well, I retired from working for the Army. That freed up a lot of time. My wife was tired of me sitting around the house. So now I’m at Cape Fear Valley Hospital visiting patients five days a week. I don’t know how I found out about Mended Hearts. That’s a blank. I’ve got post-perfusion syndrome from the heart-lung bypass machine. They call us “pump heads.”

After I found out about Mended Hearts, I became a member and then an accredited visitor with the Goldsboro Chapter 194. Four of us from Fayetteville became visitors and started operating as a satellite chapter of Chapter 194. Since we started our satellite in 2012, we’ve visited more than 1,000 patients. A lot of them end up coming to meetings. As of January 2016, we have officially chartered our chapter, Mended Hearts of Fayetteville Chapter 400 with more than 40 members.

Before my last heart surgery, my fifth, I was pushing 250 pounds. I’m male and I’m stupid, and I finally realized I had to lose weight. I lost 45 pounds. My wife and I are eating better. Where we live, everyone likes good ol’ Southern cooking. I tell patients’ families, “Southern food will kill you.” They look at me like I’m insane. It’s sad. I’ll probably visit one of them sometime.

I’ve learned that you have to be careful when you’re visiting a patient who’s about to get discharged. If you’re standing in the way of the door, you better move, because you’re about to get run over.

I visited another patient getting ready for a cath procedure, and she was just quivering in that hospital bed. When I left she was considerably calmed down. We have a saying that we tell patients: “As you are I was. As I am, you will be.”
MENDED LITTLE HEARTS GROUP SPOTLIGHT

Despite Hurdles, MLH of Mexico Helps Families Battling CHD

In December, Mended Little Hearts of Mexico delivered their first Bravery Bags and held their second meeting to plan educational programs and social activities, opening a world of support for CHD-affected families in the country. The path to success hasn’t been easy though. Getting to this point has taken two years of work and dedication from founder Marina Ruiz Díaz.

Marina’s daughter, Renata, was born in 2011 with multiple congenital heart defects. Heart surgery was delayed because, Marina explains, “we cannot have open-heart surgery before the age of one in Mexico because we have doctors who can do it, but we don’t have the instruments and equipment.” After Renata’s successful operation, Marina and her husband traveled to the 2013 Mended Hearts national conference in San Diego, where they learned how to start a group of their own.

For legal reasons, MLH of Mexico has not been able to formally incorporate, but Marina and her husband attend the U.S. conference each year, and their group of about 10 families operates in the spirit and model of American MLH groups.

In addition to the legal hurdles, the Mexican group does have some unique challenges. Marina says they cannot, for example, leave Bravery Bags with social workers the way that American groups do. “It’s very different here,” she says. “There are a lot of needs, not only CHD, so the social workers would just say, ‘Okay, we can deliver these bags to kids with cancer or kids with other conditions.’ It’s seen as some kind of discrimination to only give them to kids with CHD, so we need to be aware of that.” She says the whole process is “very, very difficult, but I have a good feeling.”

During the last conference, they navigated through customs with tools and supplies for assembling their own Bravery Bags. The first delivery was made after Marina got a phone call at 10 p.m. from a distraught family who had seen a MLH flyer with Marina’s phone number on it. She and her husband rushed to the hospital to share the bag and some hope. “We took the bag with food, tissues and other things. They were a very poor family. The grandmother was crying and crying, so we told our story. I showed her my daughter’s pictures, and she was relieved and filled with hope. I saw her face and I knew I was really doing what I want to do with Mended Little Hearts.” — Kimberly Turner

Members of Mended Little Hearts of Mexico gather for a group photo.
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- Norfolk, VA · Chapter 63 · Mid-Atlantic Region

**35 years**
- Elgin/Fox Valley, IL · Chapter 53 · Midwest Region
- Honolulu, HI · Chapter 14 · Western Region

**25 years**
- North Charleston, SC · Chapter 175 · Mid-Atlantic Region

**15 years**
- Aiken, SC · Chapter 294 · Mid-Atlantic Region
- Orlando, FL · Chapter 296 · Southern Region
- Valdosta, GA · Chapter 295 · Southern Region

**10 years**
- Omaha, NE · Chapter 340 · Midwest Region

**5 years**
- Charlotte, NC · Chapter 372 · Mid-Atlantic Region
- Tavares, FL · Chapter 376 · Southern Region
- Tucson, AZ · Chapter 374 · Rocky Mountain Region

**Mended Little Hearts Anniversaries June - July 2016**

**5 years**
- Mended Little Hearts of Lubbock, TX · Southwest Region
- Mended Little Hearts of Volusia County, FL · Southern Region
Mended Hearts — Eight Regions

Mended Hearts is the largest cardiovascular peer-to-peer support network in the world. We have 300 chapters and satellites in nearly every state. Our community-based organization is built upon the principles of service, charity and partnership.

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

Mended Little Hearts ARDs

- **Northeast**: Julia Rowbotham
  mhlphiladelphia@gmail.com • (601) 306-4061
- **Mid-Atlantic**: Laura Tamberrino
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- **Southern**: Dana Magee
  chdheartmom@gmail.com • (501) 454-6667
  Tina Hoover • tinahoover13@gmail.com • (336) 689-8822
- **Southwestern**: Candida Schendel
  lenandcandida@aol.com • (210) 213-6140
- **Central**: Leslie Sams
  lsams612@gmail.com • (859) 559-5580
- **Rocky Mountains**:
  Angie Wickersham
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- **Western**: Nicole Sanchez
  nicole.mitre@gmail.com • (925) 362-1489
- **Midwest**: Jenna Kidd
  jenna@grampaint.net • (618) 246-7876

*(including Colorado)*

Mended Hearts Regional Directors 2015-2017

- **Western**
  Ronald Manriquez
  (562) 531-0701
  rmanriquez2@gmail.com

- **Rocky Mountain**
  Robert Oberfield
  (480) 860-1247
  Rxplus@cox.net

- **Midwest**
  Cathy Byington
  (605) 339-2431
  tass114@att.com

- **Southwest**
  Lynn T. Berringer
  (936) 597-4019
  lynn@berringer.com
In 2016, the Mended Hearts National Education and Training Conference will be “on the road” in six locations across the United States. With multiple locations, the conference will reach more heart patients, caregivers and families than ever. We hope you’ll save the date and join us in this exciting journey as we gather across the U.S. Check our website, www.mendedhearts.org, for details.