CHD Survivors Rock Their Scars on Instagram
See entries from MLH’s 2nd annual photo contest

GROWING UP WITH CHD

CHD survivors are living longer than ever, but medical care isn’t always picture-perfect

PLUS:
- Gearing up for the Orlando conference
- Keeping your LDL in check
Your cardiologist is listening

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

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

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

Donnette, angina patient

Watch Donnette’s video

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It’s great to be alive… and to help others!”
Mended Hearts — Eight Regions

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

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

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*(including Colorado)
Letting the Light In

I t has occurred to me recently, and quite powerfully, that a lot of what happens in the world — good and bad — is generated by feelings.

I have heard some of you tell stories about feeling hopeless, lying terrified in a cath lab bed or standing beside a hospital crib, finding unexpected hope when a visitor opened your door and changed the course of your life.

I have felt that terror and the unimaginable isolation. For me, it was when my 13-year-old was diagnosed with cancer in 2011 on an otherwise unremarkable Tuesday afternoon.

No one opened her hospital door to say, “I have been where you are.” In that awful week, I caught a glimpse of why marriages sometimes break up when a child becomes seriously ill. Over the next few months, I came to appreciate the friends who showed up to help, unasked, sometimes with (non-institutional) food or a small gift for Kate, sometimes with just a little time and the patience to help me process what was happening and to give me a safe space to rage and cry over how unfair this horrible situation was.

We were so lucky. My husband and I were able to reach across the chasm of shock and grief and find each other again. My daughter was cured by surgeries and chemotherapy, and is now a normal, smart-mouthed 17-year-old. Sometimes, I look at her as she rolls her eyes at me and think “I can’t believe you just said that,” and at the same time, a part of me (my inside voice) is saying “Yay! She’s normal!”

Whatever the feeling is that drives you to visit other CHD families or heart patients and spend hours and hours scheduling visits, planning meetings, stuffing Bravery Bags, fundraising and writing newsletters, I am deeply grateful that you feel it. Sometimes I think I should be trying to do the same for other pediatric oncology families, but there’s no Mended Hearts on that side of the hospital. There is no Mended Hearts for cancer patients.

What we have created is powerful and profound. I am honored to be part of it, and believe me when I say that I will do everything in my power to help reach more CHD families and patients, so there aren’t so many left in those hospital rooms without anyone to let the light — and the hope — in. 

“The best and most beautiful things in the world cannot be seen or even touched — they must be felt with the heart.”
— Helen Keller
Widening Our Reach

Doctors may have saved my heart, but Mended Hearts has saved my life. Thanks to the incredible vision of Dr. Harken and others, this organization has had such transformative power in my life, and in so many other lives. That’s why I’m so delighted at the opportunity to serve as the president of Mended Hearts.

I never thought I’d be the organization’s president, though I’ve long been an active member. My journey with Mended Hearts began in June, 1988. I’d known that eventually I’d need surgery to replace a valve in my heart, and that time had finally arrived. I was absolutely terrified; I didn’t know anyone who had been through anything like that, and I was convinced my life was over.

Then a man knocked on my door. He held a bud vase with a single rose. The nurse introduced him, but I didn’t even pay attention to his name. He said, “I had heart surgery two years ago.” This man was fit, healthy and happy. He talked about how he played golf and traveled. Heart surgery had been a bump in the road for him, nothing more. Hearing his story gave me such hope, such encouragement. I asked him questions that I hadn’t dared ask the nurses. When he left, I felt a new sense of peace, and I was determined that when I got well, I’d become part of this organization. Of course, after my surgery, I went back to my career and my family.

Five years later, in 1993, I suffered an aneurysm and was desperate to talk to someone who had pushed through the same condition. By then, our local chapter had disbanded. I resolved to start it again after I recovered. Starting a new chapter took about a year, but we’ve been around since 1994. I’ve been honored to serve at the local and regional level in multiple capacities. Mended Hearts is truly the greatest organization I’ve ever been a part of.

And this organization is changing! Though my presidency has only recently begun, we’re already making tremendous progress. We’ve made impressive inroads on a project for medication adherence, forging new partnerships with pharmaceutical and medical device companies. They’re helping us to educate patients on the importance of taking their prescribed medications—and asking the doctor questions.

The new board members and I are also excited to expand the organization’s reach. Our first step: engage a younger generation, who will soon be the lifeblood of the organization. We’ve begun to offer virtual training and webinars for our more computer-savvy volunteers, who may need to squeeze in their training on a lunch break or between their kids’ extracurricular activities. Meanwhile, we’re also focused on improving name recognition not only in patient care settings, but also in the broader community. We want people to know Mended Hearts, to trust us as a vital, reliable resource.

I also hope to enhance our resources for caregivers. The most romantic moment of my life was after one of my heart surgeries. I was still in the ICU, but I couldn’t sleep. The nurse suggested that I take a walk and told me that my husband was in the waiting room. I found him there, asleep on the floor, underneath a makeshift tent he’d made by draping a sheet over a table. He’s been so absolutely devoted, and he’s certainly not alone. Mended Hearts can support our caregivers, the way they’ve supported us.

I look forward to building on Dr. Harken’s extraordinary vision alongside our members and our newly elected board members. It’s my pleasure to introduce the Mended Hearts national board members of 2015-2017.
Board of Directors 2015-2017

Millie Henn, Executive Vice President
Patrick Farrant, Vice President
Randy Gay, Treasurer
Andrea Baer, Mended Little Hearts National Vice President
Jana Stewart, Central Region Director

Gerald Kemp, Mid-Atlantic Region Director
Cathy Byington, Midwest Region Director
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Lynn Berringer, Southwest Region Director
Ron Manriquez, Western Region Director
Megan Setzer, Mended Little Hearts National Director
The Myth of ‘Fixed’

Living with a CHD requires lifelong care and close observation. Here’s a look at how physicians, support groups and advocates for heart health are working to make life easier for adults with CHDs.

By Kimberly Turner

Annaleci Lamantia’s parents were told several times that their daughter wouldn’t make it. But after three open heart surgeries and numerous other procedures, Annaleci has thrived. She is 16 and will soon have her driver’s license. Her mother, Cassandra, took this photo of her for the RockYourScar contest, which you can read about in this issue.
“Mom, I don’t want to die young.”

Those heartbreaking words were uttered by 11-year-old Joshua Lemacks after he and his mother, Jodi (national program director of Mended Little Hearts), returned from this year’s Congenital Heart Lobby Day in Washington, D.C. Fortunately, thanks to recent advances in surgery, technology, and diagnostic procedures, Lemacks was able to honestly tell him, “You could outlive all of us.” There was a time, not so long ago, when that was not the case. Kids born with Joshua’s condition, hypoplastic left heart syndrome, would simply not survive — the oldest person living with his defect is in their early 30s — but times are changing.

Today, about 85% of the roughly 40,000 babies born each year with congenital heart defects in the U.S. will live to see their 18th birthdays. According to the Journal of the American Heart Association, deaths from congenital heart disease decreased by 24.1% between 1999 and 2006. Those rates continue to improve, and for the first time in history, there are now more adults than children living with CHDs in the United States.

It’s not all good news for adult survivors though. On top of the multiple surgeries, heart rhythm problems, developmental and psychological issues, strokes, and other medical issues that many endure, they also contend with lapses in care, insurance issues, doctors who are unqualified to handle CHDs, and a variety of other unique concerns.

**Lifelong Care for Adults with CHDs**

CHD is more than a birth defect; it’s a chronic disease state that requires lifelong care and vigilant observation. Yet a recent study found that about 40% of adult CHD (ACHD) patients have had a gap in care of more than three years. There are several reasons these individuals fall out of care, but the most common is the misconception that their hearts have been repaired and require no further attention.

Shannon Tucker, who helped start the first ACHD support group for Mended Little Hearts, was born 50 years ago with Tetralogy of Fallot. “Back then,” she says, “they didn’t know as much about CHD as they do today, so they told my parents, ‘She’s cured.’” During her teenage years, she began to experience chest pains and shortness of breath during gym class, symptoms that her mother — having been assured by doctors — shrugged off as “growing pains.” By age 28, the chest pains had become more frequent and intense. When Tucker finally saw a cardiologist, she was told, “You need to have open-heart surgery right away. Your pulmonary valve never grew.” Even after the valve replacement, the importance of lifelong care and monitoring was not stressed to Tucker, who fell out of care again until 2005 when her replacement valve began to fail. Her story is, unfortunately, not uncommon.

Danielle Stephens, director of programs at the Adult Congenital Heart Association (ACHA), says that one of the orga-
Summer 2015

It’s important for non-cardiology providers — internal medicine docs, family practice, OB/GYNs — to know that if they’re seeing a patient who has a scar on their chest or who says, ‘I had a heart problem as a kid, but it’s better now,’ they should tell that patient, ‘It’s important that you check in with a congenital cardiologist.’”

Although CHDs are the most common type of birth defect, many patients lack information and support because they grow into adulthood without ever having met anyone with their condition. Understanding the size of the ACHD community can make survivors feel less alone, particularly as they go through the potentially tough transition from pediatric to adult care and begin navigating the healthcare system and dealing with adult health concerns.

ACHA’s Heart to Heart Ambassador Program helps members connect one-on-one with patients who have a similar diagnosis, and several M.L.H groups have created support groups for adult survivors. (Read more about the Chicago ACHD group in this issue.)

Education and Support

The key to eliminating the “fixed” mentality is education that starts with parents and continues throughout the survivor’s life. Mended Little Hearts works toward educating families with the upcoming new digital Mended Little HeartGuide which will contain a section on lifelong care, and its involvement with the Congenital Heart Public Health Consortium, which has a committee dedicated to lifelong care education.

Ideally, adult support groups and any physicians the ACHD patient comes into contact with should help reinforce the importance of maintaining care. Dr. Michelle Gurvitz, cardiologist at Boston Children’s Hospital, instructor of pediatrics at Harvard Medical School, and a member of the medical advisory boards of both Mended Hearts and ACHA, explains how doctors can work together to educate patients: “Most people touch the medical system somewhere and it’s important for non-cardiology providers — internal medicine docs, family practice, OB/GYNs — to know that if they’re seeing a patient who has a scar on their chest or who says, ‘I had a heart problem as a kid, but it’s better now,’ they should tell that patient, ‘It’s important that you check in with a congenital cardiologist.’”

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Working With Specialists

General cardiologists receive just six hours of congenital 

“The word ‘fixed’ should be taken out of the CHD world.”

— Danielle Stephens, director of programs at the Adult Congenital Heart Association

Several members of Mended Hearts and Mended Little Hearts visited with Senator Mark R. Warner on Congenital Heart Lobby Day in Washington, D.C., this past February.
After completing 13 grueling hours of surgery, the physician informed Raimondi’s family that he would “never touch her again.” Following that surgery, she suffered multiple complications, endocarditis, and an infection that spread to the bone of her sternum. “I was really lucky to have made it through that,” she says. “I had my next surgery at Mayo with a surgeon who exclusively sees adult congenital heart patients, and he did the revision of the conduit, plus two valve replacements and a valve repair in six hours. That’s the difference between a doctor who is used to seeing CHDs versus one who isn’t.”

Transitioning from a pediatric cardiologist to a care team that includes ACHD specialists becomes particularly vital once patients

heart disease training, and that lack of experience can have serious consequences. When Carol Raimondi had her third open-heart surgery, a revision of her pulmonary conduit, she saw a cardiologist who had limited CHD experience. After completing 13 grueling hours of surgery, the physician informed Raimondi’s family that he would “never touch her again.” Following that surgery, she suffered multiple complications, endocarditis, and an infection that spread to the bone of her sternum. “I was really lucky to have made it through that,” she says. “I

## This October, a board certification for adult congenital heart disease will become available for the first time.


Dr. Jamil Aboulhosn, director of the Ahman-son/UCLA Adult Congenital Heart Disease Center, says women with a congenital heart defect can have healthy pregnancies but should undergo comprehensive testing from an adult congenital heart defect specialist before becoming pregnant.

Adult Congenital Heart Association offers a passport-sized booklet where patients can note their medications, surgeries and emergency contact information.

Joshua Lemacks, 11, stands in front of Senator Mark R. Warner’s office on Congenital Heart Lobby Day in Washington, D.C. Lemacks has hypoplastic left heart syndrome and is the son of Jodi Lemacks, national program director of Mended Little Hearts.

Shannon Tucker, who helped start the first ACHD support group for Mended Little Hearts, was born with Tetralogy of Fallot. She also started a Congenital Heart Walk in Sacramento, Calif.
reach the age when they begin facing other adult diseases or start the process of family planning. Dr. Jamil Aboulhosn, director of the Ahmanson/UCLA Adult Congenital Heart Disease Center and vice chair of ACHA's medical advisory board, explains, “Pregnancy, in decades past, was thought to be extremely dangerous and was recommended against in patients with more complicated forms of congenital heart disease, but what we have found over the past 15 or 20 years is that a large number of these women can become pregnant and safely deliver a child, but it certainly requires the input of an adult congenital specialist and some really comprehensive testing needs to be carried out before we will give the green light to proceed with pregnancy.”

Yet despite the importance of checking in regularly with an ACHD specialist, fewer than 10% of ACHD patients receive care from a physician who specializes in their condition. Some of that, again, comes down to education about the need for specialized care, but there’s another factor at play as well: the numbers. Dr. Gurvitz says, “If every single congenital heart patient in the country tried to go [exclusively] to a specialized congenital heart doctor, the numbers would never work out. There are more than a million adults in the U.S. with congenital heart disease and maybe 100 self-identified centers across the country. There would be no way they could ever take care of that many patients.”

That is why Dr. Aboulhosn stresses the importance of co-managing patients: “We have patients coming to us from hundreds of miles away. It’s unrealistic to think that every time one of these patients has a problem, they’re going to be able to come all the way to L.A., so I have to cooperate with local adult and pediatric cardiologists to deliver the best care possible. They can’t work alone on these patients, so it’s important to set up these sort of regional care models. That way, even if somebody lives in a rural part of the state, at least then they are referred on an intermittent basis to see specialists in the major metropolitan area.”

This October, a board certification for adult congenital heart disease will become available for the first time. MLH supported this certification effort. “We hope it will stimulate more people to actually specialize in this field and get the appropriate training,” says Dr. Aboulhosn. Dr. Gurvitz also expects a certification process for congenital heart programs and centers to happen within the next few years. In the meantime, ACHA offers an online directory of centers and physicians with self-reported experience in ACHD.

Understanding the size of the ACHD community can make survivors feel less alone, as Jennie, Frank, Danielle and Maggie would attest. Danielle formed a Surviving CHD group as part of MLH of Cincinnati.
General cardiologists receive just six hours of congenital heart disease training, and that lack of experience can have serious consequences.

“What Are We Looking At Here?”
In an age where our refrigerators can stream video from the internet, the inefficiency of electronic health records is surprising. In an ideal world, ACHD patients would be seen by a care team familiar with their heart issues, but in reality, trips away from home and unexpected ER visits can put patients in scenarios where the physicians may not have access to their health records or background.

Take, for example, 32-year-old Nicole Sanchez (assistant regional director of Mended Little Hearts Western Region), born with tricuspid atresia and hypoplastic right heart, who visited an ER for pericarditis: “They saw my heart [with the echocardiogram], looked kind of confused and said, ‘Ummm, so what are we looking at here?’ They had no idea because it looks so different. They called everyone in to look, and even the cardiologist didn’t really know much about it. They ended up calling my pediatric cardiologist, but that was my first experience where I was like, ‘Okay, not everyone knows what this is. I need to know exactly what is going on. I need to be able to explain it to people. I knew what it was called and I knew the operations I had had, but I didn’t really know what they had done or what my heart looked like.’

To help patients communicate their vital history to new care providers, ACHA offers a passport-sized booklet (put it with your real passport when you travel!) where patients can note their medications, surgeries, emergency contact information, along with the name and a drawing of their defect, and other information.

The Big Picture
Educating about the importance of lifelong care, of seeing a cardiologist with ACHD experience, and of being able to share your medical history could not be more important for individual patients and families. But legislation, research funding, and awareness campaigns can work in tandem with these individual efforts to ensure better care for all ACHD patients.

Each year, congenital heart advocates from a variety of organizations, including Mended Little Hearts, visit Washington, D.C. for Congenital Heart Lobby Day, hosted by the Pediatric Congenital Heart Association, to talk to legislators, advocate for research funding and raise awareness of CHD-related issues. Goals for this year’s event included ensuring that congenital heart defects remained on the Department of Defense’s list of research priorities and that the Congenital Heart Futures Act, passed in 2010 to promote awareness and surveillance of CHD as a lifelong chronic disease, was funded again this year. Senator Richard Durban of Illinois, whose daughter passed away at age 40 from congenital heart disease, is one of the legislators who continues to be a strong ally for CHD research and awareness.

Danielle Stephens says ACHA is also concerned about insurance reform to prevent network issues that can prevent ACHD patients from being able to see the specialists they need. Medical costs for ACHD patients in the U.S. are 10 to 20 times greater than those of their peers, and many struggle to get coverage for specialized care. “We’re trying to be the voice for our membership,” she says.

ACHA is also pushing for better surveillance studies and research programs. Dr. Gurvitz agrees with that need, saying, “We don’t really have an equivalent to the Framingham heart study (a long-term, ongoing cardiovascular study on residents of the town of Framingham) for ACHD or a long-term registry like cancer patients do. They can follow survival and complications over time because all their patients are enrolled in registries or chemotherapy protocols, things like that. If we want to truly understand the long-term effects of anything about congenital heart disease, we need to have something like that. Our real payoff won’t be for 10 or 20 years, but it will be there eventually.”

Growing up with a rare heart defect means it’s sometimes hard to find friends who can relate. But ACHD survivors find camaraderie in peer-to-peer support groups like Mended Little Hearts. Danielle Fritsch and Hannaford Klaassen show how friends can rock their pacemakers together.

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
Speaking of Peer-to-Peer Support

Mended Hearts shares importance of peer-to-peer support at national conference.

By Dean Calbreath

Mended Hearts members and staff were among the 20,000 representatives who attended the American College of Cardiology conference this past March. The event allowed Mended Hearts to show how empowering patients can improve the outcome of cardiovascular treatments.
A
S NEARLY 20,000 HEART SPECIALISTS and industry representatives converged on San Diego this spring for the Scientific Sessions of the American College of Cardiology (ACC), the cavernous exhibit hall at the Convention Center was transformed into the world’s largest showcase of heart treatments, with more than 275 companies and organizations touting new products and services in a space big enough to hold nine football fields.

The exhibit hall included a Sim Center, where doctors could practice their skills on “virtual patients,” as well as Industry-Expert Theaters, highlighting the latest developments in cardiovascular treatment. And for the first time ever, there was a Patient Engagement Pavilion, where organizations like Mended Hearts could show how empowering patients can improve the outcome of cardiovascular treatments, cutting hospital time and costs.

**Patient-centered Care**
Mended Hearts has been exhibiting at the ACC conference for several years, “bringing the voice of the patient into our proceedings and, in so doing, adding a crucial and very human grounding to our deliberations,” says Kevin Fitzpatrick, the ACC’s newly appointed chief innovation officer. “This year we made a special effort to bring together a number of patient advocacy groups, anchored by Mended Hearts and Mended Little Hearts, and created a special physical community for them within our meeting.”

The pavilion, hosted by the ACC’s CardioSmart, featured displays from groups ranging from StopAFib.org to the Association of Black Cardiologists. It also highlighted the ACC’s own patient-centered programs, such as SMARTCare, the Patient Navigator Program and Shared Decision Making Tools.

“Health care overall is shifting to a more patient-centered approach as patients are becoming more engaged in their own care,” said an ACC press release announcing the pavilion, adding that the ACC “recognizes that physicians need the right tools to better communicate and work with their patients in making treatment and care decisions.”

**Spreading the Word**
For Mended Hearts, the pavilion offered a forum where it could unveil its first detailed analysis of the effectiveness of its programs with its recently released study, “The Power of Peer Support in Patient Outcomes.” The report noted that readmission rates for heart failure patients at the 164 hospitals with organized Mended Hearts visiting programs is significantly lower than the average at other hospitals across the country.

In the study Mended Hearts patients indicated that only 19 percent were readmitted to a hospital within 30 days of their discharge, compared to the national average of 25 percent. One reason: patients in the Mended Hearts program tend to do a better job of taking care of themselves. Nearly 90 percent said they were diligent about taking their medications — roughly the same percentage as those who rated their Mended Hearts volunteers as being very or extremely helpful in the recovery process.

During a presentation at the Patient Engagement Pavilion, Michele Packard-Milam, CAE, executive director of Mended Hearts, outlined the results of the survey, stressing the importance of lowering readmission rates at a time when the government is using the rates as a way of evaluating hospital efficiency.

Donnette Smith, executive vice president of Mended Hearts, then gave her own story, telling of how she was just 40-years old when she had the first of three heart surgeries to replace a bicuspid aortic valve. “I was just sobbing,” she told the audience. “I thought my life was over.” And then she was visited by a Mended Hearts member who assured her she would survive and put her on the path to recovery. Over the past 27 years, she has been increasingly involved in Mended Hearts: “I’ve been able to lead a normal life and I just wanted to give back.”

**Issues Affecting Heart Patients**
Behind the scenes, the ACC conference gave a chance for Mended Hearts leaders to meet with the organization’s Corporate Advisory Council to discuss upcoming plans, as well as general issues and trends that could have an impact on heart patients. Mended Hearts meets with the corporate advisors at the ACC annual conference each March and at the scientific sessions of the American Heart Association each November.

“We always learn about new drugs that are in the process of being approved, and find out about new ideas for patient
Heart Valve Patients, Makers Meet Face-to-Face

Not everyone gets to meet somebody who has handcrafted a piece of their heart.

But that’s what happened in March when dozens of heart valve recipients journeyed to Edwards Lifesciences Inc., in Irvine, Calif., where they met the people responsible for the valves that keep their blood flowing.

“We brought them there to connect with one another and to meet the dedicated team of employees who hand-sew every heart valve, stitch by careful stitch,” says Michael Mussallem, Edwards’ chief executive. “Needless to say, it was a very emotional day.”

More than 100 patients and caregivers came to Edwards’ first Patients Day —timed in conjunction with the ACC conference — to tour the manufacturing plant, hear from Mussallem and other executives, talk with patient advocates about how to make their voices heard, and meet the workers who created their specific valves, matched by serial numbers.

The most impressive stories came from the visitors themselves.

A Marine Corps veteran from Michigan, who had received an Edwards valve just two months earlier, proudly noted how he was on his feet 48 hours after the transcatheter aortic valve replacement (TAVR) procedure, which uses an expandable catheter to insert an artificial valve through an artery into the beating heart.

A Colorado teacher spoke of how she survived Hodgkins lymphoma only to find that her aortic valve needed replacement. With her chest weakened from radiation, the doctors ruled out open-heart surgery and instead inserted an Edwards valve using the TAVR procedure. It wasn’t long before she could once again brave a classroom full of middle-schoolers.

Long-distance runner Tom Price told how he had run seven marathons before a faulty aortic valve left him so weak he could barely run a mile. In January 2007, he went to St. Joseph’s Hospital in Syracuse, N.Y., to get a new valve from Edwards. Within eight weeks he was running again, joined by other heart patients he met through his website “Cardiac Athletes.” In November 2008, he ran his eighth marathon.

Price says that as a member of Mended Hearts, he often returns to St. Joseph’s to visit other patients and give them “a spark of encouragement on their road to recovery.”

“Patients like these remind us of the importance of our daily work, and the chance to bring our ideas out of the lab, into the clinic and to the patients and physicians that need them most,” Mussallem says. “Each heart valve represents a patient and their family, who otherwise would miss out on both the extraordinary and precious ordinary experiences of their daily lives.”
“This year we made a special effort to bring together a number of patient advocacy groups, anchored by Mended Hearts and Mended Little Hearts.”
— Kevin Fitzpatrick, chief innovation officer, ACC

Support and how to generate better outcomes,” Packard-Milam says. “For Mended Hearts members particularly, it’s an exhilarating look at what’s coming down the pike in the form of new therapies, treatments, drugs and opportunities to heal — and prevent — heart disease.”

Packard-Milam says two pharmaceutical companies she met with at the ACC are both working on “promising new approaches to heart failure” that could come to fruition sometime later this year, constituting “the first breakthrough for heart failure in decades.” Other companies are developing new “super-statin” drugs that could help people do a better job of lowering their LDL or ‘bad’ cholesterol.

She adds that the Patient Engagement Pavilion gave Mended Hearts a chance to interact with other patient-focused organizations. “We always learn something when we get to see them,” she says. “Everyone is focused on the mission of improving outcomes, and most of our work is synergistic with other organizations, since Mended Hearts has such a distinctive, peer-to-peer, in-person model.”

Dean Calbreath has been a business journalist for the past three decades, including a significant amount of coverage of the health care industry. He currently works at The San Diego Daily Transcript, where health care is one of his beats.

ACC’s New Chief Innovation Officer Calls Mended Hearts ‘Integral’

An epidemic of heart disease, obesity and diabetes is threatening to overwhelm health care providers around the world, says Kevin Fitzpatrick, chief innovation officer at the American College of Cardiology (ACC).

But Fitzpatrick predicts that within the next five years the crisis will spark unprecedented collaboration between governments, health systems, nonprofits, insurers, consumers and medical professionals, leading to new models of care.

“We cannot hope to confront the epidemic without ‘all hands on deck,’” Fitzpatrick says. “The team approach to care will be ever more critical as we more effectively align our resources to improve care and reduce cost. And of course, the patient, the family member and the community are key members of that team.”

ACC’s creation of the chief innovation officer position in January is one sign of the rapid changes occurring in health care. One of Fitzpatrick’s top goals is to explore new coalitions between health care systems and retailers, med-tech incubators, biometric specialists, manufacturers and patient advocacy groups such as Mended Hearts.

“The point of intersection between these entities will yield some of the most profound and unexpected innovations in patient care,” he says, adding that the beneficial potential of groups like Mended Hearts has never been greater.

“Mended Hearts has been integral in helping the profession understand the critically important roles of the family and caregiver in the recovery of the patient,” he says. “As measures of patient satisfaction and patient-reported outcomes are increasingly important in our evaluation of quality, we’ll need the guidance of groups like Mended Hearts in setting those standards.”

Fitzpatrick, trained as a medical associate at Duke University, has several decades of experience in the health care industry, including heading business development at two medical data publishers: Ovid Technologies and Lippincott Williams & Wilkins. ACC hired him as senior vice president for business development in 2008 and promoted him to executive vice president five years later, a title he continues to hold.

In his new role, Fitzpatrick’s duties will include leading ACC’s team of Innovation Ambassadors in a partnership with 1776, a global incubator and investment fund, to identify startups trying to solve major health care issues.

“There is no discipline in health care riper with innovation opportunity than cardiovascular medicine,” he says. Even though heart care has had “a stunning record of successful innovation over many decades,” he says, there is still room for improvement, especially with the new data banks that are providing “stunning new insights,” into heart disease.

“The term Big Data is often misused, but in health care we truly do have massive data sets that we can now interrogate to identify gaps in care, derive new clinical insights and drive CQI (continuous quality improvement),” he says.
How do you raise money for a disease that isn’t fully on everyone’s radar?

In the U.S., twice as many children die from CHD than from all forms of pediatric cancer combined, yet funding for childhood cancer research is five times higher than funding for CHD.

For people to donate money toward a cause, they must first be aware of the problem. That’s why online events like the Mended Little Hearts annual “Rock Your Scar” Instagram photo contest and its virtual charity race Roar ‘N Run are crucial — they help get the word out about CHD, beyond those affected by it.

Roar ‘N Run 2015 participants raised money for CHD by soliciting sponsors for a run of their choice (5K, 10K, half marathon or marathon) that they completed on their own time, in a location of their choosing, during CHD Awareness Week, Feb. 7-14.

Rock Your Scar took place Jan. 22 – Feb. 13, also coinciding with CHD Awareness Week. The campaign encouraged MLH members to submit photos of their children or themselves showing their courage and strength via Instagram, with the hashtag #RockYourScar. Open to CHD patients of all ages, the contest segmented photos by age group 0-3, 4-8, 9-12, 13-17, 18-99. There were 478 entries this year. The judges, MLH celebrity spokesperson Valerie Azlynn and Fox News anchor Bret Baier, selected a winner for each age group based on how well the photos embodied the “rock star” theme, as well as empowerment,
creativity and individuality.

The contest embraced heart warriors with catheterization and open-heart surgery scars as well as patients without visible marks. “There are plenty of CHD patients who don’t have a visible scar yet,” says Don Wilson, who organized the campaign with fellow MLH Awareness co-chair/MLH Steering Committee member Lauren Gray. “My son [Jacob, age 6] is one of them; he’s scarred from CHD — we all are, it’s been very tough — even though he doesn’t have a physical scar.”

Visibility: CHD’s Identity Crisis?
CHD is the number one birth defect in the U.S. and a leading cause of birth defect-associated infant illness and death. Even past infancy, there’s a 5% chance that children with non-critical CHDs won’t make it to their 18th birthday. The risk is even higher for those with critical CHD. More children die from CHD than cancer and diabetes combined.

“We’re not trying to minimize those other illnesses, those are awful too, but the challenge that’s coupled with CHD is that when you see my little guy running around, you go, what’s wrong with him?” Wilson explains. “Even if a child has had multiple open-heart surgeries, when you see them in public you don’t see anything [unhealthy about them] unless their

Rock Your Scar: By the Numbers
This year’s contest yielded impressive results:

On Facebook
■ 470 photos were entered in the contest
■ 84,300 people viewed the contest website

On Twitter
■ MLH was retweeted 296 times during the contest time frame
■ MLH had 105,700 impressions on Twitter during the contest time frame

Shelby Givens, 15, was born with a mitral valve cleft and three holes in her heart. She loves spending time with friends and going on mission trips. She wears her heart scar with honor and says that it’s only through God’s grace that she was given a second chance at life.

Isabella Johnson, 5, from South Carolina, knows how to rock her scar and her rollers.

This photo of Lily Grace Christie was taken just three weeks after her open heart surgery in August 2014.
The lack of awareness about CHD stems partly from the fact that “there’s not one clear, cohesive, consistent message out there from the CHD community,” Wilson says. “There are so many groups doing it so many different ways.”

**Expanding MLH’s reach**

“We touched a lot of the CHD community itself through Rock Your Scar — through MLH, hospitals, and other organizations — but our biggest goal is to reach people outside of the CHD community so they can understand how devastating it is, that it affects 1 in 110 babies.”

The judges had a tough time choosing just one photo from each age group. Wilson, who was on the judging committee last year, says there are no losers when it comes to living successfully with CHD. “They’re all winners, from babies to adults.”

Maria Carter is a health and lifestyle writer living in New York City. She has contributed to more than 40 publications including *Vegetarian Times*, the *L.A. Times*, MensJournal.com and more. Visit her online at mariacarter.net.
Cholesterol Counts

A new poll shows 71% of Americans don’t know their cholesterol levels. Left unchecked, high cholesterol can lead to heart attack and stroke. By Heartbeat Editors

In December 2014, Mended Hearts teamed up with Sanofi US and Regeneron Pharmaceuticals, Inc., along with Foundation of the National Lipid Association (FNLA) and Preventive Cardiovascular Nurses Association (PCNA), to launch Cholesterol Counts, an awareness program to rally Americans to take an active role in understanding there is more to be done to control high LDL-C (bad cholesterol). The program aims to reinvigorate the conversation on cholesterol management between patients and their health care providers (HCPs).

The focal point of the program is the Cholesterol Counts Poll, which asks a range of questions about individual health and perception of cholesterol management and associated risks, to gauge how much Americans really know about cholesterol. The poll is available on www.CholesterolCounts.com and was also fielded by Harris Poll, one of the world’s leading market research firms.

In February 2015, the initial results* of the poll were unveiled, showing that 71% of Americans surveyed (n=2,033) are not sure of or do not recall their LDL-C (bad cholesterol) levels. Additionally:

- 29% of Americans surveyed report they have been told by a doctor or healthcare professional that they have high LDL-C (bad cholesterol).
- 44% of Americans surveyed report they are not sure if LDL cholesterol is referred to as “bad” cholesterol.

“The results of the Cholesterol Counts Poll uncover a concerning situation. About a third of Americans surveyed self-reported high levels of LDL-C, but many of those surveyed are not sure that LDL-C is bad cholesterol,” said Michele Packard-Milam, CAE, executive director of Mended Hearts and a spokesperson for the program. “There seems to be a gap in knowledge about LDL-C — we need to rally Americans to become educated about their LDL-C numbers and what they mean to their heart health.” 1,2

This gap in knowledge is important to be aware of, because high cholesterol, and specifically high LDL-C (bad cholesterol), is a serious condition that can lead to heart disease (including heart attack and stroke),1 the number one cause of death in the U.S.3 Cholesterol Counts continues to take a pulse on how much American adults know about cholesterol and their own cho-

44% of Americans surveyed report they are not sure if LDL cholesterol is referred to as “bad” cholesterol.
The results of the Cholesterol Counts Poll uncover a concerning situation.”
— Michele Packard-Milam, CAE, executive director of Mended Hearts.

*Results are based on a survey of 2,033 adults 18+ across the U.S. and approximately 200 adults 18+ in each of the 50 states. The results are weighted demographically and attitudinally to be representative of the national population and the population of each state.

References
Jill Bene, president of Mended Hearts San Diego and Assistant Regional Director of the Western Region, was stunned by her first encounter with the organization. “I was blown away that some complete stranger would come to visit me and be concerned about how I was doing and feeling,” she says.

These days, she pays that kindness forward every Friday by visiting patients at the same hospital where she had her surgery, an aortic heart valve replacement and pacemaker procedure, in 2006. She joined Mended Hearts Chapter 62 just four months after leaving the hospital and served two years as secretary, two as treasurer, and one as vice president before becoming president in August 2013.

Bene’s heart health concerns began many years before her surgery, when a doctor informed her that she had a heart murmur. She was later diagnosed with mild to moderate aortic stenosis and told by a cardiologist that she could need surgery within the next 20 years or so. “It was a shock, but I put it to the back of my mind and carried on, checking in with the cardiologist every year,” she says.

About six years later, during a vacation in New Zealand, she began to have shortness of breath that was “manageable,” but a bit worrying. Soon after returning to the U.S., she got bronchitis and found herself unable to breathe without sitting up in bed. “Valves do not like bronchitis,” she says.

Surgery was scheduled to replace her aortic valve with a cow’s valve and to place a pacemaker, but first, she wanted to talk with someone who had been through a similar surgery. She asked her cardiologist to put her in touch with a mentor, and he did: a man 15 to 20 years her junior who had successfully had two valves replaced. She never met that mentor in person, but says their phone calls did a lot to ease her mind: “I was still apprehensive, but it took a lot of fear away when he walked me through what to expect. That was really valuable.”

Like that influential mentor, Jill did all of her Mended Hearts visits via telephone during the years when she was busy working as an office manager for a manufacturing company. Last July, she retired at the age of 71 and began doing in-person visits for the first time. She says, “After I retired and became a hospital visitor, I learned it’s the core of what we do. I concentrated on learning more about that area, and I love it! It’s so gratifying.”

She says she finds that although people are surprised to be facing heart problems, she is quick to remind them that, “they’re there because they went to get a check-up and found out that they have a problem that they are able to get fixed. Who knows what would have happened if they hadn’t gone to see their doctor?”

Bene was born in England, moved to Australia (which she claims as her home country) at the age of 9, and got married in Gibraltar in 1972 before settling down in the U.S. Today, she lives in the San Diego area with her two fuzzy “children,” two cats named Spice and Radar.

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
Local Chapters Gear Up for Big Conference

Members of Mended Hearts of Osceola and Mended Hearts Orlando are working hard to make sure this year’s annual conference is spectacular.

By Kimberly Turner

The Mended Hearts 63rd annual conference will be held June 24 – 27 in sunny Orlando, Fla., where the average high temperature will be a balmy 90 degrees. Covering chapter and member development for both Mended Hearts and Mended Little Hearts and featuring a new patient symposium with nationally renowned experts, this year’s conference requires more work than ever to organize. Fortunately, Ed Wainwright (president of Mended Hearts of Osceola, Chapter 364), Mike Weber (assistant regional director of the Southern Region), Lee Meneses (assistant regional director for the Southern Region), and other local leaders have stepped up to provide invaluable assistance with this year’s event.

Weber, who got involved with Mended Hearts Orlando (Chapter 296) shortly after his quadruple bypass surgery in 2001, attended his first conference in 2008 in Hartford, Conn. “Orlando was hosting the next year, and I asked [my] wife, ‘How can we host a conference if we’ve never experienced one?’” He has attended every one since.

“The conferences are a one-of-a-kind experience. They have tremendous learning opportunities...” — Assistant Regional Director of the Southern Region, Mike Weber

A conference of this scale needs plenty of volunteers as well, and both Weber and Wainwright are organizing local members to help with tasks like attendee check-in, bag stuffing, and merchandise sales. They are also, of course, encouraging area members to attend — a task made easier by this year’s registration fee, which is the lowest since 2005.

Wainwright, a heart transplant patient who has attended
every Mended Hearts conference since 2011 in New Orleans, will be handling the fun green-screen photo opportunity for the fourth year in a row. “We take pictures of attendees then superimpose a background related to where we are,” he explains. “We’ll be doing that during the five-hour registration and two-hour lunches each day.” He’s also been busy securing storage for all the necessary equipment and taking inventory of items as exhibitors and sponsors send materials.

Wainwright is particularly excited about the affordable ($45) patient symposium, which he believes will “give us an opportunity to expand membership, especially in the Orlando and Kissimmee area, because the public will be able to come to learn about Mended Hearts and how we support folks in both our monthly meetings and hospital visits.”

The host chapters are excited to welcome attendees. Wainwright says there are 20 to 30 shopping and dining destinations within a mile or so of the Buena Vista Palace Hotel & Spa, where the conference is being held. Weber points out that in addition to the area’s seven theme parks, those who want to extend their visit are just an hour from gorgeous beaches. “We’ve got sunshine every day,” he says. “It’s invigorating!”

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
Adult CHD Survivors Form Tight-Knit MLH Groups

By Kimberly Turner

Carol Raimondi loved her job as a cardiac nurse, but she loves being around for her 15-year-old daughter more, so when her health took a turn for the worse, she reluctantly stepped away from her career. “It was very hard emotionally,” she says. “Being a nurse always meant so much to me. I loved what I did with a passion, but I was coming home after work and sometimes I wouldn’t even want to eat. I would just lay down because I was so exhausted. It wasn’t worth the risk of not being able to be with my daughter.”

Carol, 40, was born with congenitally corrected transposition of the great arteries as well as a ventricular septal defect, atrial septal defect, pulmonary stenosis and dextrocardia. She has had four open-heart surgeries, suffered strokes and worn a pacemaker since the age of 6. Yet even through these challenges, she continues to find ways to give back to the congenital heart community. After her internist told her, “Just because you’re not working, doesn’t mean you can’t do something,” she began co-chairing a patient/family advisory council at her local hospital.

Bringing Adult CHD Survivors Together
It was that council that helped inspire Raimondi to create the Adult Congenital Heart Network of Chicago, as a division of Mended Little Hearts Chicago. “A new member with congenital heart defects came onto our council and I found out I was the first person she’d ever met who also had congenital heart defects. She was in her 40s. I felt like something just wasn’t right. I live in this big city — based on the statistics of 1 in 110 babies being born with a CHD and based on Chicago’s population, there should be an astronomical number of adults living in Chicago with heart defects varying from simple to complex. I thought, ‘Where are all these people?’”

Last October, Raimondi decided to do something to bring that community of adult CHD survivors together. She had been an adult liaison with MLH for five years and approached Regional Group Coordinator Melanie Toth with the idea, telling her, “I want to do this group, not just for the adults now, but to lay a foundation so that when all of your kids get older, they don’t have to form it. I want to have something that’s already there for them.” Toth was all for it and offered to include it under MLH.

The idea picked up steam. Raimondi reached out to find ACHD patients via Facebook and message boards, talked with adult members of a teen CHD group she had been part of through the Children’s Heart Foundation and passed out cards at cardiology offices. She also approached doctors from the CATCH Network (Chicago Adult Congenital Heart
Network), who offered to help in any way they could. CATCH’s medical director cautioned her that the ACHD group they tried to start had “fizzled out” due to poor attendance, but rather than discouraging her, the failure of the other group only challenged Raimondi more. By now, it’s clear that this woman is anything but a quitter.

‘They’re Going to Think I’m Nuts’
The Adult Congenital Heart Network of Chicago group had about 10 people at its first meeting and is “moving fast and growing fast” with about 75 members across the greater Chicagoland area. Because of the large geographic area covered by the group — members come from as far as Milwaukee to the north, Kankakee to the south and Huntley and Montgomery to the west — the monthly meetings rotate locations.

Raimondi came into the project with so many ideas, she thought, “They’re gonna think I’m nuts.” But as it turns out, the other members were just as enthusiastic, vowing to combine social activities with educational and support programs as well as fundraising.

Some of the group’s early initiatives include in-hospital care partners (if any member of the group is hospitalized, a contact from the group will check to see what they need and what can be done to help); educational speakers on topics such as exercise physiology, diet, insurance concerns, psychosocial issues, and navigating disability payments; and social outings such as picnics and trips to Navy Pier. The group has also started delivering grown-up versions of MLH Bravery bags to local hospitals. The first bags, assembled in February, included homemade blankets from local charities, heart pillows, superhero socks, hard candy, toiletries, and crossword puzzles.

Be Your Own Best Advocate
Raimondi says another goal of the group is to give one another the information, support and strength to advocate for themselves: “You should always know what your rights are as a patient. I always use the example of a friend of mine who told her doctor she wasn’t feeling good. The doctor kept saying, ‘It’s not your heart. It’s probably a respiratory thing.’ But she kept pushing until finally the doctor did a cath and she was in severe diastolic heart failure. She’s being evaluated for transplant. So many of us always just went by whatever our doctors and parents told us, growing up. We never questioned it, but now we just need to be stronger advocates for ourselves.”

Raimondi’s ACHD group isn’t the first one of its kind and won’t be the last. Shannon Tucker started the first MLH spin-off group for adults in Sacramento. Danielle Fritsch has formed a Surviving CHD group as part of MLH of Cincinnati, and Raimondi recently met with a woman in Michigan who hopes to start a group in that area.

MLH of Houston Raises $45,000 in Superhero Heart Run
By Maria Carter

Organized by MLH and Heart Heroes, the Superhero Heart Run attracted more than 1,000 participants, including 80 adolescents with CHD. Photo courtesy of Jason Snow Photography.
Hospital, among others, and raised more than $45,000.

The money will go to Heart Heroes, an organization that supports children with CHD worldwide, and to MLH for the creation of Bravery Bags. “Texas Children’s needs 120 bags a month, and Children’s Memorial Hermann needs about 40 per month,” Schaffhausen says. The bags cost an average of $30 each when filled with items the families need in the hospital, but MLH coordinators try to stretch that budget by soliciting donations for many of the items, including toiletries, pens and paper.

Families were able to make a day of the fun run, which was followed by festivities such as face painting, balloon-animal making, and jumping in bounce houses. Everyone’s favorite superhero allies were on hand as well: the Sugar Land Police showed their support by showing off their SWAT gear and demonstrating how they fight bad guys. “The kids loved it,” Schaffhausen says.

In many ways, the event served as a microcosm of one of MLH’s greatest missions: bringing CHD families together. Three large teams — Fraser’s Fighters, Heinle’s Heroes, and McKenzie’s Marvels — formed in tribute of Drs. Charles Fraser, Jeffrey Heinle, and Dean McKenzie, respectively, all congenital heart surgeons at Texas Children’s Heart Center. “Patients who had had the same surgeon got to meet each other for the first time,” Schaffhausen explains. “Meeting other CHD families is a huge help because they know what you’ve been through. These kids really are super heroes: they go through rough childhoods and are resilient.”

Mathias Schaffhausen, Alex Da Vera Cruz and Owen Hart participated in Parker’s Posse for the fun run. Mathias’s sister, Parker (not shown), was born with a congenital heart defect. Photo courtesy of Jason Snow Photography.

Jace Jurek (Baby Batman) was born to Justin and Lauren Jurek on November 5, 2014, with Tetralogy of Fallot. Jace did not survive this devastating heart defect. He passed away April 21, 2015, not long after his family completed the Heart Hero run. Photo courtesy of Jason Snow Photography.

Superhero Heart Run participants raised more than $45,000 to support Heart Heroes and Mended Little Hearts. Photo courtesy of Jason Snow Photography.
IMAGINE A DAY THAT YOU ANTICIPATED BEING ONE OF THE GREATEST OF YOUR LIFE ENDING UP BEING ONE OF THE SADDEST. IT’S A REALITY FOR TOO MANY PARENTS OF CHILDREN WITH A CONGENITAL HEART DEFECT (CHD).

Jen DeBouver, 35, lost two children within the timespan of one year. Her daughter, Olivia, was stillborn in November 2011; son Asher died of CHD complications in October 2012, at 6 weeks old.

“Twice now I’ve left the hospital empty handed,” she says, speaking of what prompted her to begin making keepsake kits for the parents of “angels” — MLH’s euphemism for children lost to CHD. DeBouver, MLH Bereavement Chair and member of the Chicago chapter, fills these “Angel Boxes” with mementos: a stuffed teddy bear, a pillow that can hold a lock of the child’s hair, and a special receiving blanket created by her sister-in-law that’s meant to be cut in half (one side is left with the child; the parents keep the other). DeBouver does this as part of an MLH program called Mended Little Angels, which was created to support families going through the loss of their child to CHD. Many MLH groups have a Mended Little Angels program.

The memory boxes also include brochures on the local MLH chapter. “A lot of these parents are thinking, ‘I’ve got [a] Bravery Bag, but now that I’ve lost my child, I don’t belong to this group,’” DeBouver explains. “But they’re not alone. There are other MLH families in their situation…the group is still there for them.”

For parents who may be struggling with guilt and self-blame, “it’s good to talk to other people who’ve been there, who can let them know that it’s not [their fault], it’s just part of CHD,” says DeBouver, adding that MLH has a closed Facebook group where the newly bereaved can seek solace and words of wisdom from those who’ve lived through the same trauma.

In addition to Angel Boxes, MLH spearheads a number of remembrance activities during CHD Awareness Week in February, such as nightly candle lightings and social media campaigns encouraging parents to share their children’s stories through special hashtags. DeBouver and her colleagues also plan to organize a butterfly release and candle lighting ceremony in October for Pregnancy and Infant Loss Awareness Month.

Maria Carter is a health and lifestyle writer living in New York City. She has contributed to more than 40 different publications, including Vegetarian Times, the L.A. Times, MensJournal.com and more. Visit her online at mariacarter.net.
Gifts from the Heart
Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from February 3, 2015 through April 28, 2015.

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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.”
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**September – November 2015**

- **45 years**
  San Diego, CA · Chapter 62 · Western Region

- **40 years**
  Richmond, VA · Chapter 28 · Mid-Atlantic Region

- **35 years**
  Lancaster, CA · Chapter 112 · Western Region

- **30 years**
  Cape Girardeau, MO · Chapter 183 · Midwest Region
  Pawtucket, RI · Chapter 185 · Northeast Region

- **25 years**
  Elk Grove, IL · Chapter 102 · Midwest Region

- **20 years**
  Billings, MT · Chapter 275 · Rocky Mountain Region

- **5 years**
  Citrus County/Inverness, FL · Chapter 367 · Southern Region
  Salinas, CA · Chapter 370 · Western Region

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**Mended Hearts is dedicated to educating its members and other audiences on preventing and coping with heart disease, including congenital heart defects. One of the ways we do this is through our Speakers Bureau.**

Trained members of our Speakers Bureau are available to speak about heart disease and heart health, along with the programs and services that are offered by Mended Hearts. We do this for national, state and local organizations; hospitals; civic groups; schools; companies; and other groups interested in hearing from experienced speakers on a variety of topics related to heart disease.

To request a speaker for your group, please contact Mended Hearts at 1-888-HEART99 (1-888-432-7899) or at info@mendedhearts.org.
Each year, about 40,000 children are born with a congenital heart defect. That means there are about 80,000 parents who need help caring for their child immediately after diagnosis, while sitting by their child’s side after surgery, and when they get home from the hospital.

To help meet this need, Mended Little Hearts is proud to announce that we’re partnering with St. Jude Medical — the global medical device manufacturer — to provide a one-of-a-kind digital resource for parents and families of children with CHDs. This online tool will be an expanded, updated digital version of the Little Heart Pack, an abbreviated print version released earlier this year that left families wanting more. Offering this resource in digital format means that families will have access to it anywhere they are and when they need it most.

The Little HeartGuide will provide accurate and reliable information and much-needed support and educational resources at a critical time for families of children affected by CHD. It will be filled with educational content, medical concepts, and information about tests and procedures as well as practical advice to help parents cope with and navigate the CHD diagnosis.

To spread the word about this new resource, Mended Little Hearts and St. Jude Medical participated in a media interview featuring Jennifer Page (mother of Max Page, who played the mini Darth Vader in the Volkswagen Super Bowl commercial) and pediatric cardiologist at Children’s Hospital of Los Angeles, Dr. David Ferry. This interview, highlighting the importance of peer-to-peer support and the Little HeartGuide, was broadcast in almost 400 markets in just the first two weeks.

The guide is expected to debut this fall. For details, visit sjm.com/weheartkids or mendedlittlehearts.org/littleheartguide.shtml