STRENGTH IN SHARING

How one person’s story can lead to better health for all

PLUS:

- Botox for heart arrhythmia?
- Helping kids with CHD succeed in school
- The patient’s perspective in medical research
Let Your Voice Be Heard

When patients, caregivers and families come together for a common cause, they have a powerful voice. Mended Hearts and Mended Little Hearts created the Patient Advocacy Network so that patients, moms, dads, caregivers, children and family members can bring a united voice to the issues that affect cardiovascular patients and their loved ones.

Learn more about how you can advocate for heart patients at:

www.mendedhearts.org/get-involved/volunteer

Mended Hearts gratefully acknowledges the support of Amgen, AstraZeneca, Edwards Lifesciences Foundation, Novartis, and Sanofi Regeneron.
Features

8 Strength In Sharing
How sharing our stories can help all heart patients live better lives.

14 U.S. Department of Defense: An Unlikely Partner for Heart Patients
Department of Defense Peer Reviewed Medical Research Program welcomes input from heart patients and families.

18 Making the Grades with Neurodevelopmental Challenges
Heart kids face hardships in school, but neurodevelopmental clinics and caregivers can help them get to the head of the class.

Departments

Heart to Heart .................................. 2
State of the Heart ............................... 3
Pulse Check ..................................... 4
CHD & School .................................. 4
Heart Hero ...................................... 5
Medication Adherence ....................... 6
Heart Health & Work ......................... 7
Vitals ............................................ 24
Conferences on the Road .................... 24
Online Visiting ................................ 25
Gifts from the Heart ............................ 27
Historical Hearts .............................. 29

On the Cover: Peter Palumbo, Chapter 216 of Mission Viejo, Calif., returned to the Cardiac Rehab Center at Mission Hospital for this issue’s cover shoot, shot by local photographer Darnell Renee. The Heartbeat team thanks Mission Hospital for its support of Mended Hearts.
As a heart patient, you’ve probably gotten this advice before: “Be your own advocate.” But what does that mean, exactly?

It means a lot of things: managing your medical records; paying close attention to your medical bills; and knowing how your health insurance plan works.

It also means not being afraid to ask questions and knowing when it’s time to get a second opinion. This doesn’t always come naturally.

Many of us were taught not to question our doctor. After all, the doctor went to medical school, so who are we to question her? If this is how you view your relationship with your doctor, I challenge you to think of it differently.

The doctor-patient relationship is a two-way street. Yes, our cardiologists have spent many years in medical school, internships and fellowships. This is honorable. Yet nobody knows your own body like yourself. This is the expertise that you bring to the table, and it should be honored, too.

I know firsthand that this isn’t always the case. Several years ago, I noticed my cardiologist seemed irritated when I’d ask a lot of questions about a test or medication, and he didn’t respond to my calls promptly . . . so I fired him.

So I fired him and found a new cardiologist. My new cardiologist is a delight. He lets me talk his ear off. I have his cell phone number and text him when I have a question, and he answers me back. He’s my buddy.

I would hope that most of us have a great relationship with our doctor, but if that’s not the case, then we should feel empowered to get a second opinion or even a new doctor. This is one way — an important one — of how you can be your own advocate.

Donnette Smith
President
Mended Hearts
It’s an Honor to Meet You

At the time of this publication, we are preparing for the third of six National Education and Training Conferences we’re conducting all over the United States. It has been a wonderful experience, all the more because 75% of the attendees so far were attending their first national conference. Many of the repeat attendees have said that this year’s conference was their favorite.

What makes these conferences so outstanding could be characterized as accessibility. With six locations, more people can take part, and because of the size of the gatherings, we’re able to truly meet and get to know each other. That makes these meetings more personal — even intimate, if that’s not too strong a word. Is this something we can bring to all of our meetings and offerings? If so, how? What makes this personal connection so powerful?

It’s an honor to meet so many members who do the work of our organization at the bedsides and in the rehab centers. It helps me understand the powerful and varying dynamics of our relationships with hospitals, health care providers, patients and their families.

I’m learning new things as I meet with members at our conferences. An important one is that there seems to be a different system for translating on behalf of patients in nearly every hospital, but Mended Hearts chapters adapt and make it work. There seems to be a powerful need for more Spanish language materials, so we’re going to look into creating at least some Spanish translations of our feature articles in Heartbeat, to accompany the Spanish version of the HeartGuide. This will help us engage an underserved population that is in dire need of the support and information we have to offer.

I have left the national meetings feeling supported, appreciated and proud to be part of something profound and immensely valuable. I can only hope the folks I met have left feeling the same way.

Michele Packard-Milam, CAE
Executive Director
Mended Hearts
Neurodevelopmental Issues and CHD

Not all children who have a congenital heart defect will have neurodevelopmental issues, but some will. What is a neurodevelopmental issue? There are two types.

Developmental disability: A limitation or disability of the cognitive function of the brain or the way the brain handles emotion, behavior and learning. It may also be a physical limitation.

Developmental delay: Developmental, physical and/or mental skills that are not at the same level as children of the same age.

CONGENITAL HEART DEFECTS

Neurodevelopmental Issues in Kids with CHD

Heart Hero: Andrea Himmelberger:

Why Aren’t You Taking Your Meds?

Heart Disease Takes a Toll at the Office

And More...

The Mended Little HeartGuide is a parent and caregiver resource for families living with congenital heart disease.

Learn more by downloading the Mended Little HeartGuide at www.mendedlittleheartguide.org. Turn to page 18 for more on CHD and neurodevelopmental issues.

BRIDGE TO TRANSPLANT

1,374

That’s the number of days (nearly four years) that a person has lived with the Total Artificial Heart. The patient, Pietro Zorzetto of Padova, Italy, was implanted with the temporary artificial heart on December 6, 2007, while he waited for a matching donor heart. He received a heart transplant on September 11, 2011. Pietro, now in his early 60s, is doing well and enjoys walking, working out at the gym and riding his bike.

The SynCardia TAH-t is an implantable system designed to assume the full function of a failed human heart in patients suffering from end-stage biventricular (both sides) heart failure.

— Melanie Medina

Pietro Zorzetto had a Total Artificial Heart from SynCardia for nearly four years before receiving a heart transplant.
HEART HERO

Andrea Himmelberger: Mended Little Hearts Is Her Calling

When Andrea Himmelberger sees a need for a congenital heart disease support group, she starts one of her own. In Sacramento, Calif., she helped an existing group charter with Mended Little Hearts. When she moved with her family to Palo Alto, Calif., she started a group from scratch. When her family moved again to Superior, Colo., she discovered that the area already had a growing Mended Little Hearts group. With no need to start another group, she got involved on a national level.

Now Himmelberger is Mended Little Hearts’ National Growth and Development co-chair. “We work with new groups to help them through the process,” she says. “We also work with existing groups to help troubleshoot problems, and to help them continue to grow and develop.” Considering her background, she has the right skills for the job.

In between her son Drew’s three open-heart surgeries (he was born with interrupted aortic arch, among other conditions), multiple moves, full-time nursing studies at University of Colorado Denver-Anschutz Medical Campus, and her own health challenges, Himmelberger gives countless hours to Mended Little Hearts.

“Mended Little Hearts is a passion of mine,” she says. “It’s a calling. We take something hard in our lives and use it to help other people. That’s why I want to keep doing this.”

Himmelberger took a six-month break from volunteering after she was diagnosed with lymphoma in July 2015. It was hard to let go, she says, but she also wanted to give her best self. Now technically cancer-free, Himmelberger is knee-deep again in Mended Little Hearts, nursing school, and raising Drew and her heart-healthy daughter, Ava. Prioritizing tasks helps her manage her many roles. “I make a list each day of what needs to be accomplished right away and what can wait,” she says. “Lately there’s been a lot of waiting on emptying the dishwasher!”

When she graduates at the end of this year, Himmelberger says she may volunteer for her local group. Whether she’s helping on a local or a national level, Himmelberger will continue to be a Heart Hero any way she can. “What we’re doing really makes a difference in people’s lives and I want to be a part of that.” — Heather R. Johnson
Why Aren’t You Taking Your Meds?

If a medication makes you feel better, you’re more likely to take it. But if you have a condition like high blood pressure or high cholesterol, you probably don’t feel any symptoms — which means you don’t necessarily feel better by taking the medicine you’ve been prescribed.

The key to sticking with meds is understanding how they’re helping you, even if you can’t feel them working. “No one likes to be told what to do,” Sandhya Murthy, M.D., a cardiologist for Montefiore Einstein Center for Heart and Vascular Care, Bronx, N.Y., told Managed Healthcare Executive. “But when a patient understands that medication will prevent long-term vascular damage that can lead to heart attack, strokes, and so forth, they are more likely to comply.”

— Melanie Medina

43%
That’s the number of Democratic voters who say that health care is “extremely important” to their vote for President. By comparison, 37% of Republicans and 30% of independents, respectively, rate health care as “extremely important” to their vote.

— Source Kaiser Family Foundation

2017-2019 Mended Hearts and Mended Little Hearts Elections

Elections for Mended Hearts and Mended Little Hearts national officers will be held in early 2017. Election procedures and forms are available to download in the officers’ section of the website. Anyone interested in running for a national officer position should return completed forms to Wayne Lawson, Chairman, MHI/MLH Elections Committee, 731 Plaza Dr., Joplin, MO 64804.

Completed forms will only be accepted if postmarked on or before Friday, Sept. 16. If you should have any questions, please contact Janette Edwards at 214-390-3268 or Janette.edwards@mendedhearts.org.

Become a Candidate
Want to be considered for a national MH or MLH officer role? Forms are due in September.

MH & MLH ELECTIONS

MEDICATION ADHERENCE

Photo of man with medication: iStock / Squaredpixels; Photo: of ballot box: iStock / YinYang

Photo of man: iStock / PhotoDune

43%
That’s the number of Democratic voters who say that health care is “extremely important” to their vote for President. By comparison, 37% of Republicans and 30% of independents, respectively, rate health care as “extremely important” to their vote.

— Source Kaiser Family Foundation

The key to sticking with a medicine is understanding how that drug is helping in the long run, says one New York cardiologist.
Heart Disease Takes a Toll at the Office

One-third of workers with heart disease have lost three or more workdays because of their condition, according to a 2016 HealthMine survey. More stats from the survey, which was based on responses from 501 consumers with known heart disease or who are at risk for it:

- 16% have lost more than six working days because of their condition
- 19% say their condition lowers their productivity a lot
- 32% report that their condition lowers their productivity somewhat

Employer-based wellness programs can reduce lost productivity from heart disease by identifying those with the condition or those who are at risk for it and providing them with personalized health recommendations, including smoking cessation, diet modification, weight management, stress reduction, medication adherence and more. If you have heart disease, take advantage of wellness benefits like these that your employer may offer. — Melanie Medina

Botox For Heart Arrhythmia

Botox may soon have a new use outside your dermatologist’s office. Researchers recently investigated whether botox — a popular remedy for diminishing wrinkles — could stabilize heart rhythms after surgery.

Patients who had irregular heart rhythms and were scheduled to have heart bypass surgery were divided into two groups. One received botox injections into the fat surrounding the heart, while the other group received saline injections. Of the patients who got botox, only 7% developed arrhythmias 30 days after surgery, compared to 30% from the group that received saline. A year later, none of the patients in the botox group showed signs of heart arrhythmias. Yet 27% in the saline group did.

Dr. Jonathan Steinberg, director of the Arrhythmia Institute of the Valley Health System and adjunct professor at the University of Rochester, who led the investigation, told Time: “We believe these findings may be relevant to other forms of atrial fibrillation. Our patients all had atrial fibrillation prior to surgery and demonstrated long-lived atrial fibrillation reduction...extending out to one year.” — Melanie Medina
The Patient Advocacy Network empowers us to share our personal stories to improve health care for all heart patients. By Melanie Medina

As a member of the Patient Advocacy Network, Peter Palumbo wants to help expand patient access to cardiac rehab. "I recently visited the Cardiac Rehab Center at Mission Hospital and saw how the staff there is still doing what they did for me, which is rehabilitating those who are going through what I went through."
We all love a good story. When we get together for lunch with friends, we share stories. Our religious leaders almost always start their sermons by sharing compelling stories that will help us understand their message. And as members of Mended Hearts and Mended Little Hearts, we share our stories every day with the heart patients we visit.

But what about the patients we don’t get to visit? What if we could somehow harness our collective stories to help people we never get to meet?

That’s exactly what Mended Hearts and Mended Little Hearts leaders have in mind with the newly launched Patient Advocacy Network, or PAN, which was formed to equip and teach members how to be advocates for all heart patients.

While the PAN won’t allow us to personally visit with every single heart family, it will allow us to push for health care policies that affect heart families, provide a patient perspective for cardiac device makers and pharmaceutical companies, and educate other heart patients so they can make informed decisions about their health.

**Peter Palumbo’s Story**

The Patient Advocacy Network hinges on one thing: a patient’s story. Take Peter Palumbo’s story:

“In 2009, when I was 44, I had chest pains while travelling on business in Houston. I was ignoring the pain and thinking it was a bad case of heartburn. I ended up flying home that day and was in pain on the airplane.

“As soon as I got home, I went to an urgent care facility in Mission Viejo. The doctor called 911 and I ended up at Mission Hospital and had to have an angioplasty.”

While the PAN won’t allow us to personally visit with every single heart family, it will allow us to push for health care policies that affect heart families, provide a patient perspective for cardiac device makers and pharmaceutical companies, and educate other heart patients so they can make informed decisions about their health.
“Weeks later, I was instructed to go to the Cardiac Rehab at Mission Hospital. I went three days a week for several weeks. There, I was able to recover from my heart attack. The staff at the cardio rehab was very helpful in my recovery from heart surgery.”

Palumbo, of Chapter 216 of Mission Viejo, Calif., has shared this story many times and is excited for the opportunity to share it on a broader stage through the PAN. By talking about his experiences, he says he can help not only other heart patients, but also the senior citizens whom he serves every day in his job as a certified senior advisor.

“With my line of work, I am in hospitals, skilled nursing facilities and doctors’ offices daily,” Palumbo says. “I am an advocate every day for seniors and want to help those heart patients who need the services of Mended Hearts.”

Palumbo and other PAN members will talk about their heart journeys with elected officials, either at the state or federal level, by setting appointments with them or communicating with them through email campaigns. They may also share their stories with the media, as PAN members work with local or national reporters who cover health issues. Or they may volunteer for a cardiac-device maker’s patient advisory panel to give them a real-life perspective on living with one of their devices. And at the most intimate level, advocacy can mean sharing our stories with new heart patients so that they are better informed.

“We want to teach people how to be empowered to make their own health care choices and be their own best advocate,” says Andrea Baer, Director of Patient Advocacy for Mended Hearts and Mended Little Hearts. “Then we want them to advocate for these policies and regulations that are going to make a difference in the lives of heart patients everywhere,” adds Baer, mother of 7-year-old Trenton, who has a congenital heart defect.
What Are We Advocating For?
While there are hundreds of health issues that need addressing, the PAN has narrowed down its priorities to these five:
• Making life-changing innovations accessible and affordable for all cardiovascular patients
• Encouraging medication adherence and medication therapy management
• Promoting, ensuring access to and expanding the use of cardiac rehab
• Reducing health disparities in those with congenital heart defects
• Encouraging innovation in pediatric devices for the treatment of congenital heart disease

As the PAN grows and evolves, these priorities may change, but for now, they are the key issues to focus on.

Advocating Via Elected Officials
To help guide the PAN with its advocacy efforts among members of Congress, MH and MLH have turned to the Federal Group, an agency that helps groups like PAN reach their objectives in the public policy arena. They do this through expert analysis, strategic planning, coalition building and aggressive advocacy.

Scott Leezer, a congenital heart disease patient and the Director of Government Affairs for the Federal Group, spoke to PAN members during an advocacy training event in May. Having served as an aid to a senator for several years, Leezer was able to give PAN members a firsthand account of the day-to-day work that happens on Capitol Hill. Leezer emphasized that members of Congress do, indeed, listen to what advocates have to say.

“Members of Congress are well-meaning people,” Leezer says. He cited a recent survey where Congressional members rated the most important aspects of their job. The top three most important aspects of their job, according to this survey, were:
• Feeling that they’re performing an important public service
• Being invested in what they’re doing
• Understanding that their job contributes to society as a whole

“We want to teach people how to be empowered to make their own health care choices and be their own best advocate. Then we want them to advocate for these policies and regulations that are going to make a difference in the lives of heart patients everywhere.”
— Andrea Baer

Photo credit: Marcia Baker

John Salin of New Hampshire demonstrates Heartbeat Now, the mobile app version of Heartbeat, to Ron Manriquez, Western Regional Director of California.
Congressional members also rate “staying in touch with constituents” as being a job aspect most crucial to their effectiveness, according to the survey.

“Yes, these are people who want to stay in touch with their constituents,” Leezer says, adding that it’s often easier to meet with Congress members and their staff while they’re at home in their districts, as opposed to Capitol Hill in Washington, D.C.

“I encourage you to set up meetings, to invite them to hospitals, to show them the work that Mended Hearts is doing. ... I think it’s something that members of Congress would take an interest in, to see volunteers going into the hospital on their own time and giving back to the community. I think that’s something that they would be moved and touched by.”

By doing this, our elected officials can see how any health-related bills they are considering actually affect their constituents at home.

**Beyond the Legislators**

While getting the ear of legislators is certainly a component of advocating, it’s not the only way. Donnette Smith, President of Mended Hearts and Chairman of the Board of Directors, has served as an advocate on several occasions by talking with pharmaceutical companies and speaking at cardiology conferences — something anyone can volunteer to do.

“It’s encouraging when I go to meetings at the American College of Cardiology or other conferences and I see that they want to hear the patient’s perspective,” Smith says. “All they ever hear is the physicians’ side. We want them to know what it’s really like because we’re the only ones who know that. I encourage you that if you ever hear of an opportunity to speak about your experiences in your heart journey, volunteer for that job.”

Another group that’s always looking to hear and share meaningful human-interest stories? Journalists. You can be an advocate by calling news stations or papers and asking if a reporter would be interested in writing about the work that your Mended Hearts chapter is doing. (If you do this, be sure to work with the hospital’s media relations person, who can help get the reporter access within the hospital.)

“I think it’s something that members of Congress would take an interest in, to see volunteers going into the hospital on their own time and giving back to the community. I think that’s something that they would be moved and touched by.”

— Scott Leezer
Online Tools for Reaching More Heart Patients

Later this year, the PAN will launch a tool to allow members and other heart families to interact in a new way: an online patient database. “We’re already overhauling our database system to create one that can hold millions of patient records,” says Michele Packard-Milam, CAE, Executive Director of Mended Hearts. This new database will hold contact information for each and every patient visited by a MH or MLH visitor (with their permission, of course) — even if that person doesn’t want to become a member right away. “Instead of us just visiting a patient and discarding their contact information after 90 days, we’re going to invite them to become a part of a community that’s not about dues. It’s not about ‘You have to join.’ It’s about ‘How can we help you?’ This is a club you never wanted to be a member of, but you’re one of us, and we’re going to take care of you when you need us,” Packard-Milam says.

The patient database will include online support groups moderated by MH and MLH members. Through these groups, patients will be able to connect with one another, ask questions and get answers. “This happens in the office about once a week where somebody calls us and says, I’m having surgery tomorrow and I’m so scared. I’ll take their information and have someone call them back,” Packard-Milam says. “We’re going to scale this process through the Patient Advocacy Network.”

Perfect timing for MH, MLH and Patients

The launch of the PAN comes at a good time for Mended Hearts. Over the past few years, MH has seen chapters close and membership decline slightly. The volunteer base is tired, and the model of face-to-face visiting — while still very much a part of the mission and DNA — needs updating. The PAN is this update.

By training and empowering members to be advocates for all heart patients, MH and MLH have an opportunity to touch the lives of not only those families we meet in the hospitals, but of those who we may never meet face-to-face.

With the addition of the PAN, Mended Hearts and Mended Little Hearts is simply an amplified version of its original concept: a network of patients who are grateful to be alive and are helping others — not only those we meet in hospital rooms, but all heart patients.

WANT TO JOIN THE PATIENT ADVOCACY NETWORK?

Send an email to Andrea Baer at andrea.baer@mendedhearts.org and let her know that you’re interested!
The Department of Defense Peer Reviewed Medical Research Program welcomes input from heart patients and families. By Heather R. Johnson
Donnette Smith, President of Mended Hearts and Chairman of the Board of Directors, has served in numerous national-level roles and participated in multiple national media campaigns. But for all of the time spent spreading the word about heart health, she hadn’t had the opportunity to make a difference in medical research.

That changed a few years ago when the Department of Defense reached out to Mended Hearts to recruit volunteers for its Congressionally Directed Medical Research Programs (CDMRP). Through CDMRP’s Peer Reviewed Medical Research Program (PRMRP), Mended Hearts members can advocate at the biomedical research level.

Launched in 1992, the CDMRP funds high-impact, high-risk projects that other agencies won’t touch, filling in gaps in traditional medical and scientific research. With the PRMRP, created in 1999, consumers — patients, survivors, family members and advocates — sit alongside scientists and clinicians to review potentially groundbreaking projects that need funding. Consumer input helps ensure that researchers consider the patient and family perspective in their work.

Offering a Patient’s Perspective in Medical Research
Patricia C. Modrow, Ph.D., Program Manager for the Department of Defense PRMRP, states that consumers use their own experiences, as well as those of the community, to offer “fresh perspectives and insights” that other panel members may not have.

The scientist may not have a child with CHD. The researcher probably hasn’t suffered a major heart attack. By sharing their opinions based on these experiences, consumers help researchers find new ways to develop projects to provide even better treatments.

When Mended Hearts nominated Smith to participate in the program in 2014, she immediately said yes. “I’ve learned so much it’s mind-boggling,” she says. “Whether it’s a device or a drug that they discuss, it’s incredible to see what’s out there. We get to review them and grade the merit. To be in that conversation with doctors and scientists is quite an honor.” She’s participated every year since.

Patients, survivors, family members and advocates sit alongside scientists and clinicians to review potentially groundbreaking projects that need funding.

Although you don’t have to have a medical background to participate, you do have to be willing to spend time in a peer review meeting and in pre-meeting preparation. It typically takes about 40 hours over a four- to six-week period to complete pre-meeting preparation. During this time, participants receive training, review applications, and write comments in those applications. Smith says her groups generally review 25 to 30 applications. The panel grades each grant

WHAT MAKES A GOOD PEER REVIEWER CANDIDATE? HERE IS CDMRP’S SHORT LIST.

• Be willing to share your personal story.
• See beyond that story to the stories of fellow heart patients to represent the entire community.
• Have knowledge about the full spectrum of family and patient heart concerns.
• Have the confidence to express opinions that may differ from scientific reviewers.

For a full eligibility checklist, visit http://cdmrp.army.mil/cwg.
request and the projects are rated accordingly. The panelists discuss the scoring during the peer review meeting.

The peer review meeting either meets over one to three afternoons via videoconference or teleconference, or in person over two to three days in Washington, D.C. (The program does pay travel expenses.) “Two days in a room with a computer and a bunch of people!” Smith laughs. “But you learn so much.”

### Funding for Heart-Related Research Projects

PRMRP covers a wide range of conditions, from alcoholism to PTSD to eye injuries. During fiscal years 2015 and 2016, the program funded women’s heart disease projects. Congenital heart disease (CHD) has been a topic area for the past three fiscal years. Other heart-related topic areas include cardiovascular health and diabetes.

Modrow states that Congress recognizes CHD as “an issue of importance” to military families. It supports CHD research that will benefit not just service member families, but all families. She also states that, as directed by Congress, PRMRP will continue to support research to promote heart health.

In fiscal year 2014, PRMRP awarded grants supporting five CHD research projects. Nikolay Vasilyev, M.D., of Boston Children’s Hospital, proposed to design and build an implantable intracardiac device that, according to a CDMRP news article, “will support circulation with a dynamic pulsatile force timed to the heart contraction.” The device will require less anti-coagulation treatment and will use a patient’s own ventricular chamber as the pump.

Thomas Barker, Ph.D., of Georgia Tech Research Corporation, is part of a team that developed synthetic platelet-like particles (PLPs) that share many features with natural platelets. He plans to demonstrate that the PLPs can decrease bleeding problems associated with cardiopulmonary bypass.

### Mended Hearts Makes an Impact

Mended Little Hearts nominated Andrea Baer, Director of Patient Advocacy for Mended Hearts and Mended Little Hearts, to serve as a consumer peer reviewer in 2014. She also served in 2015 and is on the docket for 2016.

“I thought that it was a great opportunity to really be the voice of the patient,” she says of her reason to volunteer. “I love the idea of being part of research and new treatments in the beginning stages. The peer review program gives the consumer a voice in the process.”

For Baer, serving as a peer reviewer gives her one more way to make a difference in the lives of children affected by CHD. As a mother of four, including Trenton, who had open-heart surgery to repair a defect at 11 weeks old, Baer recognizes the impact the program can have on heart patients. “Having the ability to give input on what I felt the community could use in terms of research is really important,” she says.

Smith brought decades of personal experience to her peer reviewer role. Born with a bicuspid aortic valve and aortic stenosis, Smith has had five open-heart surgeries and has five stents. “Anything related to the heart or the medical field interests me of course,” she says, noting that heart disease runs deep in her family. “In these meetings, you can get your point across as a patient or a mother or a caregiver. We can make a difference at the level of getting projects funded.”

Smith stresses that caregivers and heart patients should consider getting involved in initiatives such as the PRMRP. “That’s when we have a real voice.”

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“I’ve learned so much it’s mind-boggling,” says Donnette Smith of her participation in the Department of Defense’s Peer Reviewed Medical Research Program, which allows consumers to weigh in on groundbreaking medical projects that need funding.

“I love the idea of being part of research and new treatments in the beginning stages,” says Andrea Baer, who also participates in the Peer Reviewed Medical Research Program.

“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.

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

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Watch Donnette’s video

Photo of Andrea Baer courtesy of Mended Hearts; Photo of Donnette Smith courtesy of Jeffrey J. Hanshaw
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
For Lydia Butler, the Heart Institute Neurodevelopmental and Education Clinic at Cincinnati Children’s feels like a second home. “Going there just makes me happy,” says the bubbly 11-year-old. “And I got to be in a video!”

Diagnosed with congenital heart disease when she was only five days old, at age 7 she appeared in the hospital’s “Tell Me a Story” video to talk about being a “heart kid.” Lydia was born with the single-ventricle lesion called tricuspid atresia and needed an artificial tube inserted to allow blood to flow from her heart to her lungs and “pick up” oxygen. “It was like ‘replumbing,’” her mom, Lisa, says. The condition required three open-heart surgeries by the time Lydia was 4 years old. But the surgeries were only one small step in Lydia’s heart journey. As Lydia began preschool, Lisa began to realize that her daughter may have cognitive problems.
Many CHD Patients Face Neurodevelopmental Problems
The most common birth defect in the United States, congenital heart disease or CHD, occurs in nearly 1 percent of — or about 40,000 — births per year. In addition, some CHDs bring risk factors for neurodevelopmental problems that include underlying syndromes or genetic and developmental disorders, according to a 2012 American Heart Association Scientific Statement (see sidebar, “If Your Hospital Doesn’t Have Neurodevelopmental Services”). This means children with some forms of CHD may face developmental delays and challenges in school, and with living independently. According to the Cleveland Clinic’s Neurocardiac Clinic, approximately 30% to 50% of children who have undergone cardiopulmonary bypass for complex CHD will require remedial school services, and 15% will need full-time special education. However, with early screening for neurodevelopmental issues, children with CHD can thrive in school.

‘Variability In How Children Do’
In general, milder forms of CHD result in fewer issues (or no issues at all) compared to complex forms, according to Caitlin Rollins, M.D., Instructor of Neurology at Boston Children’s Hospital and co-author of a 2014 paper on the subject in the journal Circulation.

“There’s enormous variability in how children do because of so many different influences, and what’s true for one isn’t true for all,” says Dr. Rollins. “For example, some forms of heart disease can alter blood flow during the fetal period that affects in-utero brain development. Some children incur specific injuries that can have neurological consequences. I recommend parents be prepared to act preemptively and continue to think positively about a good outcome.” Infants may show developmental delays such as low muscle tone, and then face challenges with feeding, language and social skills. Later, school attendance may unmask problems such as difficulty with calculation or concentration. In high school, as students balance multiple courses, they may have trouble with higher-level organizational issues.

Dr. Rollins adds that parents are often first to notice anything unusual, and that early identification is so important. A primary care doctor can refer a child to a developmental specialist — such as someone who works in early intervention services — or to a psychologist or other specialist if or when parents notice any concerns. “For certain forms of heart disease that carry higher risk, children should be evaluated even before concerns arise,” Dr. Rollins says.

For CHD children younger than
3 years, Dr. Rollins urges families to seek out free, federally mandated early intervention services that include periodic evaluations — “even if things appear to be going well.”

**How Early Medical Issues Affect Learning**

“We call ourselves ‘heart moms’ and we’re all a little ‘nuts,’” says Lisa Butler. “We handle ourselves differently than other moms do.”

Lisa recalls how she handled Lydia’s neurodevelopmental issues, beginning with kindergarten, where her daughter “lagged.” When Lisa blamed Lydia’s heart defect, school officials didn’t think the problems merited a special education curriculum. Then in first and second grade, when Lydia had trouble remembering things, teachers said she was “lazy.”

Her mom knew it was time to take action, and so she turned to the neurodevelopmental clinic, or NDEC, at Cincinnati Children’s. Here, heart kids like Lydia go through a five-step process, starting with an initial screening, followed by a comprehensive evaluation and then a case conference. With detailed documentation and recommendations, an NDEC team member shares results with the child’s school, either in person or on the phone, to make sure the child has every opportunity to excel.

Long-term monitoring continues as the child grows and develops, with age-appropriate support, follow-up appointments every six to 12 months, reevaluation and assistance with recommended treatments.

The program sounded ideal for Lydia. Once at the clinic, Lydia saw a comprehensive interdisciplinary team of experts all at once without needing individual visits. Specialists followed a “whole child” approach with her treatment; Lydia had access to pediatric cardiologists, neurologists, nutritionists and occupational therapists.

Lydia is doing well in school and is a competitive figure skater. Her T-shirt and boxing gloves were part of her costume for a skating championship competition, where she won first place. She performed to the popular *Fight Song.*

**Who Is at Risk?**

Children with milder forms of CHD, such as atrial septal defects, do not seem to have a higher incidence of developmental disabilities than their peers. Children who were on cardiopulmonary bypass during surgery or children who were born cyanotic (decreased blood oxygen) seem to be at the highest risk. Some types of CHD that increase the risk of neurodevelopmental issues include:

- Coarctation of the Aorta
- Tetralogy of Fallot
- Ventricular septal defect with comorbidities
- Total anomalous pulmonary venous return
- Single ventricle defects
- Hypoplastic left heart syndrome
- Hypoplastic right heart syndrome
- Tricuspid atresia
- Double outlet right ventricle
- Double outlet left ventricle
- Transposition of the great arteries
- Truncus arteriosus
- Interrupted aortic arch
- Children with syndromes associated with CHD
- Down syndrome
- 22q11 deletion
- Noonan syndrome
- Williams syndrome

Children with syndromes associated with CHD
- Down syndrome
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therapists, as well as social workers, child life specialists, a school liaison and educational specialists.

“Lydia initially received a diagnosis of attention deficit hyperactivity disorder or ADHD — common among children with CHD — and was referred to occupational therapy to work on fine motor and functioning issues,” Lisa says. Lydia was also diagnosed with developmental coordination disorder.

A clinical special educator at the hospital who helped Lydia, Gretchen Carroll, M.A., works with schools to determine eligibility and implement necessary intervention services for children. These can involve speech therapy, occupational therapy, physical therapy and educational support under an Individualized Educational Program or IEP.

“We’re not just dealing with kids in a bubble, but trying to affect change for them in school,” Carroll says. “Many schools don’t know a child’s cardiac issues can impact school performance. We explain how early medical issues affect learning, attention, emotional anxiety, language, motor skills and more.”

The educator can help support a child’s case for a plan, and her suggestions also help school personnel better understand the child’s specific needs. Her own detailed outline differs from a school’s IEP, however.

“No outside agency can dictate to a school just because we think a child is qualified for an IEP,” Carroll says. “We want to be a partner, but schools go through their own eligibility process and sometimes this is a ‘dance.’”

“We got our 504 plan and later, the IEP,” says Lisa. “When you bring Children’s Hospital into the mix, schools do seem to listen better.” The goal of any educational plan is to provide appropriate services while the student needs them — and eventually to get to the point where he or she no longer requires them.

Extra Help Is Here
As a school intervention specialist at Children’s Hospital of Wisconsin’s Herma Heart Center, Kyle Herma sees heart kids with neurodevelopmental needs. And yes, those surnames are the same.

When Kyle’s sister was born with hypoplastic left heart syndrome, the cardiology department was later named in her family’s honor to recognize their extensive contributions to eradicating heart disease. As a former classroom teacher, Kyle was hired to head the pilot neurodevelopmental program that began in February 2015.

Need More Info?
The Mended Little HeartGuide includes a full chapter on neurodevelopmental issues in children with congenital heart defects. Written by Bradley Marino, M.D., MPP, MSCE, one of Lydia Butler’s physicians who is now at Northwestern Medicine, and edited by parents of heart kids, the chapter features recommendations such as when children with certain types of CHD should be screened for neurodevelopmental issues.


She presented a poster — a “mini” scientific paper — at the International Society for Heart Lung Transplantation Scientific Sessions and Pediatric Academic Society’s annual meeting, both in late April. A full manuscript is in the works on the complete pilot study.

In the paper, Kyle’s team noted that children with complex health needs are at greater risk of poor student engagement, disruptive behavior, low academic achievement and exposure to bullying. They also cited the rarity of structured programs for school re-entry and intervention.

At Children’s Hospital of Wisconsin, patients receive individualized assessments and tailored interventions to be shared with their schools, Kyle says. Kyle meets with and counsels school staff on best practices to foster children’s progress, coaching teachers on appropriate modifications and accommodations and helping parents understand their rights and responsibilities when partnering with schools.

This means determining the problem first, then putting supports in place to address it, she says. These might include creating a personal and individualized checklist or schedule so the child can cross off tasks accomplished in anticipation of what’s coming next. Maybe a child could benefit from a peer note-taker, sitting closer to the blackboard or teacher, or just carrying a water bottle throughout the day.

Kyle’s previous teaching job at a high-risk school taught her about sending kids “off into the real world,” she says. “They may not know how to interact with society in a meaningful, productive way. Keeping them in a protective little bubble doesn’t help, so I want parents and teachers to encourage safe risk-taking.”

Bright Future for Lydia

Lisa Butler does just that for Lydia, who has more big plans thanks to the neurodevelopmental support she received and continues to benefit from in Cincinnati. Lydia is always eager to go ice skating and play volleyball with her friends, while working on getting good grades at school.

“I want to do more fun things,” Lydia says. For those who love her and have followed her progress, there’s no doubt she’ll do much more.

“Having a heart kid is never easy,” says Lisa. “But having a team behind you that you know genuinely cares about your child — that is a priceless experience.”
**CHOLESTEROL COUNTS: YEAR IN REVIEW**

**Cholesterol Counts** rallied Americans to take an active role in understanding there is more to be done to control high LDL, or “bad” cholesterol, and reinvigorated the conversation on cholesterol management between patients and healthcare providers.

**OUR GOAL**

Educate Americans about the risks associated with high LDL cholesterol, encourage them to learn more about their individual cholesterol numbers, and empower individuals to talk to their healthcare providers about how they can lower their numbers.

**REVEALING LDL CHOLESTEROL LEVELS ACROSS AMERICA**

Together, Sanofi US, Regeneron, the Foundation of the National Lipid Association, Mendes Hearts and Preventive Cardiovascular Nurses Association (PCNA), developed this program to help educate Americans about LDL cholesterol.

The cornerstone of the program was the Cholesterol Counts Poll, which gauged how much Americans know about cholesterol, their numbers and the risks associated with high LDL-C cholesterol.

The results of the Poll were visualized through interactive maps, which depicted the levels of LDL cholesterol awareness and knowledge across the country.

The Poll and interactive maps, along with additional resources on LDL cholesterol, were shared on CholesterolCounts.com.

**WHAT WE LEARNED**

We raised cholesterol awareness by encouraging dialogue around cholesterol, fostering a better understanding of cholesterol numbers, and increasing cholesterol knowledge by surveying more than 15,000 American adults and showcasing the results.

**CHOLESTEROL COUNTS** gauged how much Americans know about LDL cholesterol and visually represented Americans’ knowledge and awareness about LDL cholesterol.

**POLL RESULTS SHOW THERE ARE GAPS IN KNOWLEDGE ON THE TOPIC OF LDL CHOLESTEROL AND MORE NEEDS TO BE DONE TO EDUCATE AMERICANS ABOUT HIGH LDL CHOLESTEROL.**

Patients should go to their healthcare provider to get their cholesterol checked, learn their numbers, and encourage friends and family to do the same.

41% of respondents report they are not sure if LDL cholesterol is referred to as “bad” cholesterol.

49% of respondents report they are not sure if LDL cholesterol is referred to as “bad” cholesterol.

74% of respondents report they are not sure of or do not recall their LDL-C (bad cholesterol).
REGIONAL CONFERENCES

What Members Are Saying About National Conferences

Because 2016 is the first year that Mended Hearts and Mended Little Hearts have organized multiple national conferences on the road instead of hosting a single event, we decided to ask attendees what they thought. Here’s what they’re saying.

**Howard Milewski, Chapter 382 of Bellingham, Wash.**

What made you want to attend the conference in your region?

“We have a son, daughter-in-law and three grandsons who live in Mission Viejo. Combine that with wanting to learn how other chapters operate and interest in some of the scheduled talks, it made for a simple decision to attend.”

**Marilynn Huffman, Chapter 382 of Bellingham, Wash.**

What was the single most important thing that you learned by attending the conference?

“While I enjoyed and learned from the professional medical presentations, I was most interested in what lies ahead for chapters as well as the national organization. The presentation “Raising a Ruckus” given by Michele Packard-Milam gave a clear picture of the future and what we need to be doing, as chapters, to support the national organization.”

**Michael Mariscal, member at large**

What made you want to attend the conference in your region?

“To fulfill a promise to myself just minutes before open heart surgery on September 30, 2015 (6-artery bypass): If God blessed my journey in recovery, I would step forward to help others.”

What was the single most important thing that you learned by attending the conference?

“The most important ‘one thing’ came in the form of many: overwhelming unity, loving-acceptance, and support amongst my peers and leadership — ultimately the assurance that I was not alone.”
Email and social media can serve as powerful tools to connect members of the heart community. As a result, many Mended Hearts and Mended Little Hearts chapters are using “online visits” more frequently to reach out to patients.

“Some patients prefer email because it’s less committal,” says Stan Gurka, the official “online visitor” for the Hamilton County Mended Hearts Chapter 350 in Noblesville, Ind. “If I call, they have to respond. But if I email, there’s less of an obligation. They can respond when they feel ready.”

Chapter members visit patients in cardiac recovery and in the ICU with heart disease or congestive heart failure. As a follow-up, Gurka emails the patient, introduces himself, and asks how they are feeling and if they are following doctors’ orders and taking their medication correctly.

“Quite a few patients give us their email addresses — it’s definitely becoming more common,” says Gurka. “In my email, I also give them my cell phone number and remind them of our upcoming meetings.”

Because many Mended Hearts patients are older, some are not as comfortable with electronic communication. But those who provide their email address obviously have one and use it, says Gurka.

For Mended Little Hearts of Evansville, Ind., online visits are a huge part of the group’s outreach. Set in a rural area, the closest hospital that conducts open-heart surgeries is three hours away, so the chapter does not conduct in-person hospital visits.

Instead, families of children with congenital heart defects can find the chapter online and through social media. The group also has a good relationship with cardiologists at the two local hospitals, who refer patients to the chapter.

“We have a strong presence in our community and on social media. New families will reach out to us with
questions or members of the community who know of a family that needs us will contact us through our website or our Facebook page,” says Tiffany Horn, co-coordinator of the Mended Little Hearts of Evansville. “After that first contact is made, we follow up immediately — sometimes within the hour.”

Often, online visits offer a convenience to families juggling the news of a congenital heart defect with doctors’ appointments and lengthy hospital stays. The Indiana chapter, which began seven years ago, does about 40 to 50 online visits a month and its Facebook page has over 800 members.

“A lot of our families find us on Facebook and then go to our website,” says Horn. “Our newsletters, calendars and announcements are all online now. We still have meetings every other month, but our families are busy and more responsive to information in an electronic format.”

Julie Stucki, co-coordinator of the chapter in Evansville, handles the group’s online visits. Once a family reaches out, she makes a connection online and then tries to meet face-to-face before a child goes into surgery.

“On any given day, I have 30 emails that say, ‘My cousin was just diagnosed and I heard you were the one to talk to,’ but I don’t reach out until Mom or Dad reaches out,” says Stucki. “When we first started, I reached out to a mom when I found out her daughter was going to have open heart surgery and she never called back. Later, she told me it was because she wasn’t ready. From that moment on, I changed my approach. Some families may have the diagnosis, but not be ready to face it yet.”

For Stucki, a congenital defect survivor who has had four open-heart surgeries herself, an online connection is often the first step to a longer, more meaningful relationship with families.

Stucki remembers one family whose son was getting ready to have open-heart surgery. Her relationship with them, which began online, soon became much closer. One night, she brought the family dinner. Later, their daughter asked when their “new family member” was coming back to visit.

“She was talking about me — her daughter thought I was part of their family,” Stucki says.

One of the keys to a successful online visiting program is having a resource dedicated to making follow-ups.

“Having someone dedicated to online visits is key. We have also discussed having the member who visited the patient in the hospital do the follow-up email if they want to, but we’re still looking into that,” says Linda Mason, assistant regional director of the Hamilton County Mended Hearts Chapter.

Though online visits are increasingly popular with some groups, they are not a replacement for phone calls and face-to-face meetings, Mason says.

“If online visits are the best you have, at least it keeps us in contact with the patients and keeps the community connected and engaged,” she says. “Even those who don’t initially want to meet or talk with us will ask that we send them our newsletter, which lists all of our phone numbers and e-mails.”

Ultimately, online visits are just another way to reach out to patients and keep them connected.

“Any visit — any time we have a patient or family member reach out — to us is a success,” says Horn. “We are doing something right with getting our name out there in the community and people are reaching out to us for support.”

— Scotty Fletcher
Gifts From the Heart

Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from April 8, 2016 through June 15, 2016.

In Memory Of:
Marion Neufeld
Loren Resenthal
Carol Smith
Mended Hearts of Zanesville, OH
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Anna Amato
Ed Tatge
Joann & Jerry Jackson
Parado Ann Deitch
Vicki & Thad Bechtelheimer
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Thanks For Giving:
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My Heart Beats For....
Mr. and Mrs. Stan Hann

For my family and friends
Jana Stewart

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Heart Failure Survivors Inspire and Educate Through National Contest

“I got to walk my daughter down the aisle.” “I am able to raise my children.” “We travel everywhere!” “I got to see my grandson be born.” These are among the many reasons that more than 250 people said they are thankful that they—or a loved one—received a left-ventricular assist device (LVAD). These individuals recently shared their personal stories through the national “Thanks to an LVAD …” video contest. Mended Hearts hosted “Thanks to an LVAD …” to raise awareness and education about LVADs, a little known but potentially life-saving treatment for some people with advanced heart failure.

“We were touched and amazed by the entries we received,” said Michele Packard-Milam, CAE, executive director of Mended Hearts. “Many brave people shared their personal experiences with LVAD therapy to help us educate and inspire others suffering from advanced heart failure, and we are grateful to them.”

The American Heart Association reports that 50,000 to 100,000 advanced heart failure (AHF) patients in the United States could benefit from an LVAD. Without this treatment option, many could have poor prospects for survival and significantly limited lifestyles. Unfortunately, LVAD awareness is low among both patients and physicians, and patients often die without ever knowing that an LVAD may have been a treatment option for them.

With support from St. Jude Medical, Mended Hearts launched the “Thanks to an LVAD …” Video Contest in February 2016 to help recognize and celebrate the AHF survivors who are living with an LVAD, and to increase awareness about LVADs as a treatment option for others with the condition. The contest invited participants to submit a video featuring an LVAD recipient and potentially a friend or loved one discussing what they believe is the best thing about the recipient having received an LVAD. From among the more than 250 entries, a panel of independent judges selected five winners. The winners and their videos are featured at the “Thanks to an LVAD …” website (www.ThanksLVAD.com), which also highlights several Honorable Mention winners and offers information about LVAD therapy.

“I work with advanced heart failure patients every day and see the impact the disease has on their lives,” said Dr. Susan Joseph, advanced heart failure cardiologist, Baylor University Medical Center and a “Thanks to an LVAD …” contest judge. “I am thankful to Mended Hearts for hosting this important program, because we really do need greater awareness around treatment options for AHF patients, including LVADs.”

LVADs are designed to restore blood flow throughout the body, potentially enabling recipients to breathe more easily and feel less fatigued. Recipients’ organs will receive more blood than they did prior to the LVAD being implanted, and this can help to improve organ function. An LVAD can be used as a permanent therapy for patients who are not eligible for heart transplantation. LVADs may also be used to support patients and improve...
their quality of life while they wait for a donor heart to become available.

While LVAD therapy helps most patients, not everyone responds the same way. Risks include death, bleeding, cardiac arrhythmia and local infection.* Be sure to discuss the risks and benefits of LVAD therapy with your doctor.

For more information, visit www.thankslvad.com

* The “Thanks to an LVAD …” campaign highlights actual patient stories. The stories are the experience of these individuals only. There can be risks and potential complications associated with the use of medical devices. Complications of LVAD surgery are similar to the potential complications of any open heart surgery procedure. Patients will be asked to sign a surgical consent form prior to the operation, as well as a consent form for blood transfusions. A surgeon will discuss potential risks and benefits with the patient prior to the procedure. Adverse events that may be associated with the use of Left Ventricular Assist Devices are listed here. Adverse events are listed in decreasing order of frequency, except for death, which appears first because it is a non-reversible complication: Death, bleeding (perioperative or late), cardiac arrhythmia, local infection, respiratory failure, device malfunction, sepsis, right heart failure, driveline or pump pocket infection, renal failure, stroke, neurologic dysfunction, psychiatric episode, peripheral thromboembolic event, hemolysis, hepatic dysfunction, device thrombosis and myocardial infarction.

Historical Hearts

Chapter Anniversaries: July/August 2016

40 Years
- Northern, KY and Cincinnati, OH — Chapter 35 — Central Region

30 Years
- Granite City Beaters (Central MN) — Chapter 10 — Midwest Region

20 Years
- Y-Bridge Zanesville, OH — Chapter 51 — Central Region

15 Years
- South Georgia Mended Hearts, Valdosta GA — Chapter 295 — Southern Region
- Central Florida Orlando, FL — Chapter 296 — Southern Region

10 Years
- The Woodlands, The Woodlands, TX — Chapter 341 — Southwest Region

5 Years
- Old Pueblo Mended Hearts, Tucson AZ — Chapter 374 — Rocky Mountain Region
- Waterman Mended Hearts, Tavares FL — Chapter 376 — Southern Region

Mended Little Hearts Anniversaries: July/August 2016

5 Years
- Mended Little Hearts of Dallas, Dallas, TX — Southwest Region
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.

Mended Hearts gratefully acknowledges the support of our conference sponsors:

- **Novartis Pharmaceuticals**
- **Gilead**
- **AstraZeneca**
- **Sanofi**
- **Regeneron**
- **Boehringer Ingelheim**
- **Edwards**

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2016 Conference Schedule

**Mended Hearts/Mended Little Hearts Conferences**

**Central/Midwest Region**

July 21-23

Rosemont, Illinois

**Southwest Region**

September 23-24

Austin, Texas

**Southern Region**

October 28-29

Huntsville, Alabama