



Mended Hearts™

Fall 2015

# Heartbeat

## Magazine

# NEW WAYS TO TREAT OLD DISEASES

Four novel drugs fight heart failure and cholesterol

**PLUS:**

- ▶ MZH member designs for Nike
- ▶ 2015 conference coverage & awards

# Basketball Legend Jerry West and Sports Icon Billy Jean King Encourage People with AFib to Know Their Risk of Stroke

Two legendary American athletes have teamed up to talk about a heart condition they share in common with millions of Americans: atrial fibrillation, or AFib, an irregular heartbeat that puts them at a one in three chance of having a stroke. AFib is the most common serious heart-rhythm abnormality in people over age 65.

Since diagnosis, basketball legend Jerry West and sports icon Billie Jean King have been working with their doctors to start and stay on a treatment plan to help prevent a stroke due to AFib. Now, for AFib Awareness Month this September, the two are speaking out to encourage others to do the same.

More than half of people with AFib don't believe that they are at an increased risk of stroke. People with AFib also may not realize that their stroke risk can change over time.

That's why Janssen Pharmaceuticals, Inc., Billie Jean King and Jerry West are teaming up to help those living with AFib understand their risk by offering a simple tool they can use to calculate their personal stroke risk at [MyAFibRisk.com](http://MyAFibRisk.com).

It's eight easy questions that can help those with AFib understand their risk and talk with their doctor about stroke risk management and treatment options.

For every [MyAFibRisk.com](http://MyAFibRisk.com) visitor who calculates their stroke risk, Janssen will make a contribution to Mended Hearts, a nonprofit peer-to-peer support network that helps heart disease patients, their families and caregivers.\*



BY [janssen](http://janssen.com)

\* Janssen Pharmaceuticals, Inc. will make a non-tax-deductible contribution (minimum \$35,000; maximum \$50,000) to Mended Hearts, Inc., for every unique stroke-risk assessment completed between September 8, 2015, and December 31, 2015. Mended Hearts' participation is not an endorsement of any Janssen product or service.

**Mission:** *Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support*

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**Et cetera...**

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

**Visit us online:**

[www.mendedhearts.org](http://www.mendedhearts.org)  
[www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)



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Mended Hearts and Mended Little Hearts presented dozens of awards at the 63rd annual conference. Have a look at the winners.

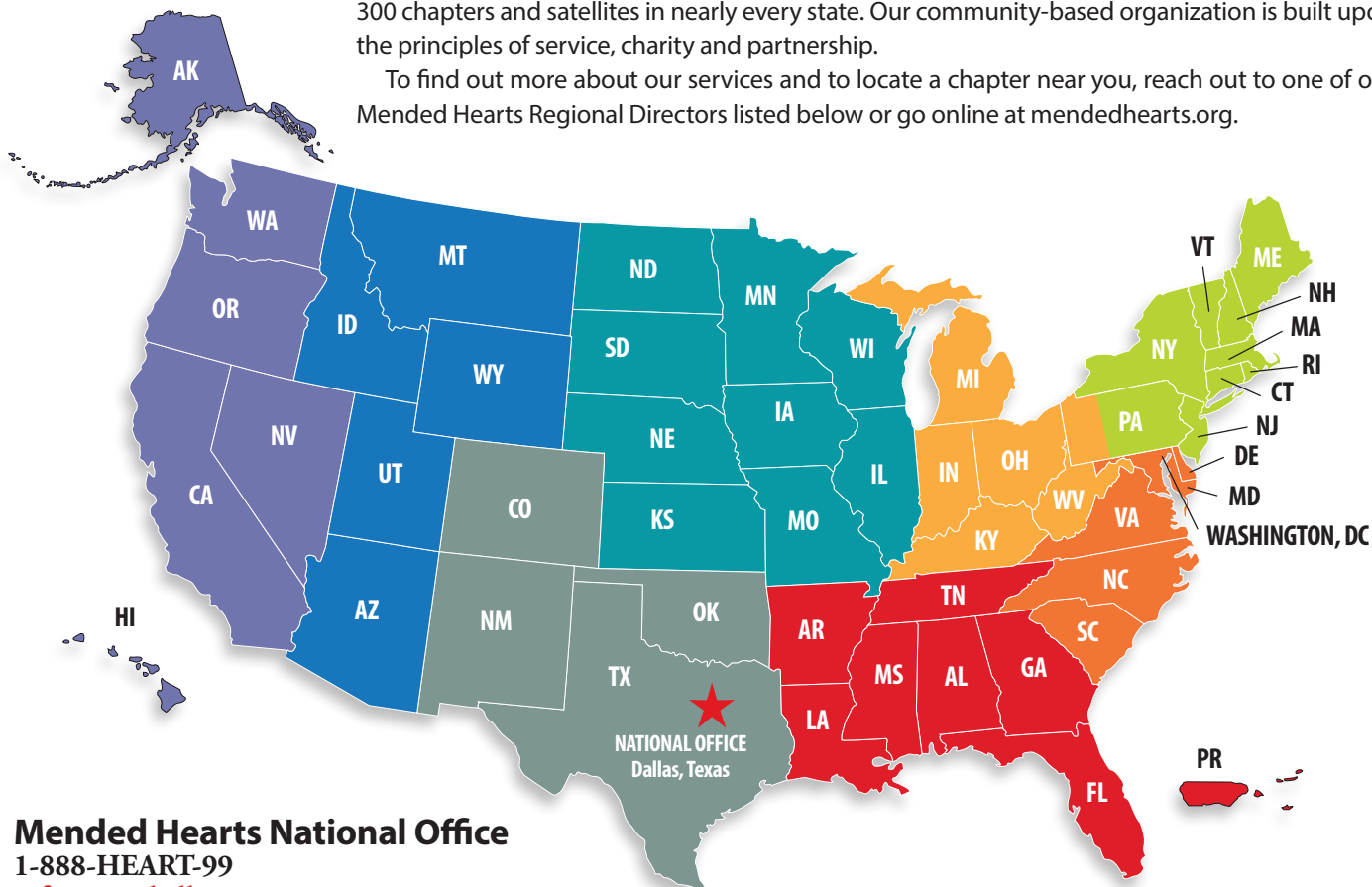
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**“It’s great to be alive... and to help others!”**

# 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](http://mendedhearts.org).



**Mended Hearts National Office**  
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# WANTED: Your Ideas for Membership Growth

**L**ET'S NOT BEAT AROUND THE BUSH: MENDED HEARTS' membership was down last year, and we lost a few chapters — nine to be exact. And we only gained four new ones.

Now that *that's* out of the way, here's the good news.

Mended Hearts members aren't the type of people who cross our fingers and hope things will get better. We take action, whether that's to improve our diet, take our medications like we're supposed to — or by coming up with solutions to recruit new members and open new chapters.

What will we do to boost membership? I'm going to share several of my ideas. I'm sure you have some, too, and I'd love to hear them. Feel free to email them to [info@mendedhearts.org](mailto:info@mendedhearts.org)

## Reaching Younger Heart Patients

Attracting younger members can be difficult because they're juggling careers, children and their heart disease. But it's possible. I started working with Mended Hearts when I was 40 years old. I was still working at my job, had kids in school, and was running around like a crazy person trying to accomplish everything. So, I know what it's like.

To make it easier for them, we can host lunch-and-learn meetings at the workplace (or a nearby restaurant), instead of evening meetings. Also, younger people are all online. We need to focus on reaching members on Facebook, online forums, blogs — anything that would attract them in a way that they could be involved without having to attend a meeting.

## Virtual Visits Via Video

Even with all the dedication of our accredited visitors, we still miss some heart patients while they're in the hospital. But most hospitals have in-room TVs, which nurses use to show educational videos about the patient's diagnosis. It would be great to shoot videos of our accredited visitors talking about Mended Hearts and have these shown in heart patients' hospital rooms. The videos would provide

**“Increasing our membership will not be a quick fix. It's going to take a lot of thought and work. But there is no shortage of heart patients who we can help.”**

that one-on-one vibe, even though the visitor wouldn't physically be in the room. Plus, patients could watch the video at their convenience.

## Seeking More Diversity

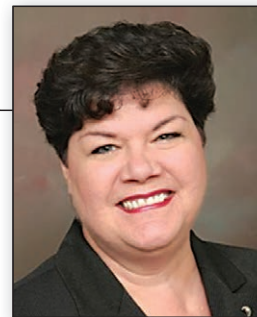
We continue to offer *HeartGuide* educational information in English and Spanish. If you'd like them for your chapter, call the Mended Hearts national office at 1-888-HEART-99.

And as we look to increase membership among African Americans, we need to think outside the hospital walls and consider working with churches. We could easily host chapter meetings on a Sunday afternoon after church services have ended.

## Trial and Error

There are many more ideas out there. We could offer free membership for a year. We could work more closely with the cath labs, where patients are often in and out of the facility so fast that there's no time for them to receive a visit. And we could partner with hospital volunteer organizations. One fellow visitor told me how after he had become an official hospital volunteer, he specifically asked to work on the cardiac unit. He was able to help out busy nurses by walking with heart patients on the floor.

Increasing our membership will not be a quick fix. It's going to take a lot of thought and work. But there is no shortage of heart patients who we can help. We just have to get more creative in how we reach them. ❤️



# Growing Our Organization: Patient Advocacy Network and Matching System

ONE OF THE THEMES OF OUR RECENT NATIONAL conference was how to get our member numbers growing again. It's common knowledge that all organizations go through growth and recession phases over time. Sixty-four years is a long time, and during these decades, we have grown from the original four patients put together by Dr. Harken to 10,600 Mended Hearts and 9,300 Mended *Little* Hearts members. This is a tremendous achievement, but over the past few years, our numbers of chapters, visitors and members have been declining. Even if this is a normal recession phase, though, we have to react and change our models in order to start growing again.

Our core is, and always will be, our visiting program, which is currently delivered exclusively by our dedicated chapters. This work is profound and it brings immense good into the world. We are still the largest and oldest peer-to-peer heart patient support network in the world, and we should be fiercely proud of that.

That said, however, we hear — quite often — that the people running the chapters are exhausted and need more help. We hear that visitors retire because of health or other reasons, and that there aren't visitors lined up to replace them.

So, what should we do?

## First: More and Better Chapter Support

This will include more easy-to-use tools, from programming to newsletters to recruitment support. Your new Vice President, Patrick Farrant, is already working on updated training and support components for the ARDs and Chapter Presidents. The Regional Directors and field operations staff will help develop these. You can expect to hear from your ARDs a lot more in the coming year, as we work to provide infrastructure to ARDs and RDs in the important “front line” of communication and support.

## Second: Adapt our Meetings to Reality

Maybe it's harder to get people to come to meetings these days because meetings aren't the way some people want to receive their support. This seems to be particularly true of patients who are still in the workforce or those with kids still living at home. This doesn't mean we stop having meetings, but maybe we need to take some of the pressure off of them. Perhaps we can reduce the number of medical lectures and increase the frequency of socializing and networking events, which are easier to execute. What are your ideas for attracting more people to our meetings, and for making them easier to set up and host? Send them to me at [editor@mendedhearts.org](mailto:editor@mendedhearts.org).

## Third: Recruit Friends Instead of Members

Maybe joining (paying dues) isn't the decision we should be seeking in the first 90 days following a heart event. What if we were able to say to all patients something like, “while this isn't a club you wanted to join, now that you're a heart patient, you're one of us,” and just provide support to them for the whole first year? Dues aren't a major part of our revenue stream, but they certainly are a major barrier to lots of people who might otherwise say “Yes!” when we come calling.

Could we just put them into our national database (with their permission, of course) and start sending them virtual *Heartbeat Magazine*, the chapter and national newsletters, invite them to attend meetings and social events, and just see what happens? Several of our national volunteers say that it took them years to make the decision to join — Donnette Smith and Ron Manriquez are among them. These are two stellar volunteers who would have been lost to us if the people who visited them had not persisted for much longer than the normal 90 days.

#### Fourth: Open Up New Channels for Peer-to-Peer Support

We have already received funding for a new, bigger and more sophisticated infrastructure that will give us the ability to invite patients from everywhere to become part of Mended Hearts. The idea here is to create a support system that isn't solely reliant on visiting or having a chapter in a specific hospital. We serve 460 hospitals, which is a great number — but there are more than 5,000 hospitals in the United States. How can we reach those other patients?

By creating support systems that allow the patients to come to us *when they need us*. By creating a large community of patients whom we can support — and who could potentially support each other — online and by phone, we can become the source of hope and resources for thousands of patients we don't currently serve. In addition to a larger database, we will need a large group of virtual visitors, a staff that monitors and supports everyone, and chapters that are willing to take on patients whenever they call on us.

Once this is built, which we hope will be by early next year, we can allow patients to find each other based on the factors

**“When you are through changing, you are *through*.” —Bruce Barton**

that matter most to them as people and as patients — heart failure patients can be grouped together, and we'll be able to channel resources directly to them because we'll know who they are. The same goes for people with stents, AFib, specific CHDs, clots and stroke: whatever the disease, we can put people together to share their stories and learn from each other. We've done a version of this for years with Mended *Little* Hearts, and it can make all the difference in the world to the number of people we can serve.

It's a new day. The Patient Advocacy Network will allow us to use our combined voices to help more patients get access to new treatments and better information, and to make sure our legislators and the public know who we are. We are Mended Hearts, the largest heart patient peer-to-peer support network in the world. There are millions of us. How can we help you? ❤️

## Get Pumped for the New Heartbeat Now Mobile App

Coming in Fall 2015, the brand-new Heartbeat Now mobile app is going to make waves.

**B**ased on *Heartbeat* magazine, the app will feature all of the articles from each issue, as well as Mended Hearts and Mended *Little* Hearts news, videos, stories from survivors and more. App users can save their favorite stories, share them on social media, contact their regional representatives and post comments about the stories throughout the app. Updated with each issue of *Heartbeat*, the app is a great way to stay up-to-date wherever you are.

Available on iPhones as well as Android and Google devices, Heartbeat Now is a tool to supplement our members' experience as givers of hope to heart disease patients and caregivers. Stay involved and connect with us whether you're at home, on the go, or volunteering as a Mended Hearts or Mended *Little* Hearts member! As always, we aim to help our members pave the way toward happy, healthy post-diagnosis living.



Download the Heartbeat Now mobile app from your device's app store today!



# Jim Bushnell: Meet the 2015 'Mended Heart of the Year'

By Maria Carter

**P**ATIENTS SUFFERING FROM UNPRECEDENTED CHEST pains, or those without a personal or family history of cardiovascular problems, may not have the slightest desire to hear from Mended Hearts, but Jim Bushnell knows it's important.

He's an advocate for visiting all heart patients, whether they're in need of a transplant or are just seeking answers for sudden, intense tightness in the chest. "Probably 60 percent of the patients I visit who only have chest pains as their admitting diagnosis turn out to be suffering from heart failure," he says.

Bushnell knows firsthand how serious a seemingly innocuous symptom can be: Chest pains landed him a hospital catheterization lab a little more than 10 years ago. It was around that time that he was introduced to Mended Hearts. "The first time you go in for a cath procedure you go, 'Wait a minute, I have a heart problem? I've never had a heart problem.' Well, guess what? You do. Suddenly your mind spins because you have all kinds of questions," he recalls.

In 2004, Bushnell co-founded Chapter 348 in West Plano, which later disbanded and merged into Dallas chapter 30 and Plano chapter 142. Jim has been an active leader of Dallas chapter 30 ever since. He's served as the newsletter editor, vice president, and acting president of West Plano; the National Newsletter Chairman from 2011 to 2013; and three terms as the Dallas chapter 30 president. This past June, Mended Hearts recognized Bushnell's exceptional service and named him "Mended Heart of the Year."

Millie Henn, the executive vice president of Mended Hearts, nominated Bushnell for the award. "I admire and appreciate his energy and willingness to work hard and to promote Mended Hearts," says Henn, adding that Bushnell is very generous with his time and his talents. "He's been an ongoing visitor of heart patients and their families for years, and has an outstanding record of visiting."



**"I admire and appreciate his energy and willingness to work hard and to promote Mended Hearts..."**

– Millie Henn

Indeed, when asked about his biggest accomplishment within the organization, Bushnell is most proud of his time spent talking with heart patients. As former president and, now, chair of the visiting committee for Chapter 30 in Dallas, he's personally visited 10,000 heart patients on a one-to-one basis at hospitals in Dallas and nearby Plano.

It's important to catch people when they are at the beginning of having a heart issue, a time when they've got more questions than they have answers, says Bushnell. "That's what keeps me going." ❤️





# The New *HeartGuide* Is Here!

**F**OR NEW HEART PATIENTS, LIFE CAN QUICKLY BECOME overwhelming. They hear unfamiliar medical terms, undergo complicated procedures, take new medications and begin making major lifestyle changes.

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

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

**Order copies of the *HeartGuide* for your chapter online at [www.mendedhearts.org](http://www.mendedhearts.org). There is no cost for the guides or for shipping.**

Rx

PATIENT NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_  
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# New Heart Drugs: The Promise and the Price

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Four groundbreaking new drugs could help keep heart patients out of the hospital and extend their lives. **By Melanie Medina**

**I**F YOU'RE ONE OF THE 5 MILLION AMERICANS LIVING WITH heart failure, or among the 10 million who have uncontrolled cholesterol despite being treated for it, 2015 may be your lucky year. Starting this past April, drug companies have brought several new groundbreaking medications to market that offer people with heart failure or high cholesterol totally new approaches for treating their conditions.

These drugs are creating quite a buzz in the cardiology community, and for good reason. For starters, there's the sheer number of them: Two drugs, Corlanor and Entresto, were

approved by the FDA for heart failure patients. Two other medications — Praluent and Repatha — were approved for treating high cholesterol.

What's more is that these products aren't merely improvements to what's already out there. They work differently than standard drugs prescribed to patients with high cholesterol or heart failure.

"New medications come out all the time, but they're often in the same class as the medications that are already out," says Parin Parikh, M.D., an interventional cardiologist with Presbyterian Heart and Vascular Group in Dallas, a Texas Health Physicians Group practice. "What's nice about these is that they offer novel mechanisms of action."

In clinical trials, each of these drugs showed promising results not only in treating the condition they were intended to treat, but also in reducing re-admissions to hospitals.

This could mean huge advantages for hospitals as they look for solutions to help them avoid financial penalties that the Centers for Medicare and Medicaid Services now place on those that have excessive readmissions for certain conditions, including heart failure.

But the excitement should be tempered with caution. Any new drug entering the marketplace is expensive, and the four discussed in this article are no exception. Two of them, in fact, can cost upwards of \$10,000 a year per patient. Patients may not be willing to pay this much, nor may pharmacy benefit managers.

Also, it will take time to see if the benefits seen in clinical trials will bear out when given to more patients. Without much clinical data yet, cardiologists want to see what patients are paying for before they start prescribing these new drugs widely.

So just what could patients be paying for? Let's take a look.



Parin Parikh, M.D., F.A.C.C.

## New Options for Chronic Heart Failure Patients

If you have chronic heart failure with reduced ejection fraction you may be a candidate to take Corlanor, by Amgen, or Entresto, by Novartis. Both drugs are for heart failure where the lower-left part isn't contracting well, and in studies, Corlanor and Entresto were shown to reduce hospital readmissions. Entresto also significantly reduced the risk of cardiovascular

death when compared to a common ACE-inhibitor called enalapril. The similarities between the two end there, though, as the drugs fall into different classes of medications.

### Corlanor: A Closer Look

In April this year, Corlanor became the first new chronic heart failure drug approved by the FDA in nearly a decade. In an international clinical trial, researchers divided 6,500 patients into two groups. One group received Corlanor while the other received a placebo. Participants in both groups continued taking their current heart failure medications (including beta blockers, ACE inhibitors, ARBs, diuretics and anti-aldosterone agents). The study compared each group's risk of hospitalization and found that those taking Corlanor in addition to their standard treatment lowered their risk of hospitalization by 18 percent.

How does it work? By targeting and slowing down the heart's pacemaker cells, which control the heartbeat. While beta blockers can also slow the heart rate, they lower the blood pressure as well.

"One of the challenges that we have when we treat patients who have heart failure with a depressed ejection fraction is the fact that, especially when they are first diagnosed, their heart rates are high but their blood pressures are not real good," says Dr. Sreenivas Gudimetla, a general cardiologist with Consultants in Cardiology in Fort Worth, Texas. When these patients are given the standard therapies — including beta blockers such as Carvedilol — their heart



Corlanor is the first new chronic heart failure drug approved by the FDA in nearly a decade. In studies, it was shown to reduce the risk of hospital readmissions due to heart failure by 18 percent.



Praluent is one of two in a new class of drugs called PCSK9 inhibitors, which have been shown to drastically reduce cholesterol.

rates tend to improve, but their blood pressures drop, he explains.

"With Carvedilol, we'd coach patients that, 'OK this will make you feel lousy for a while, but you've got to trust me and stick it out,'" Dr. Gudimetla says. "Beta blockers reduce workload of heart, but these patients are fragile, and it can make them feel bad."

Corlanor, by contrast, "is a drug that helps lower the heart rate without affecting the squeeze of the heart," he explains.

### Entresto: A Closer Look

Entresto, which the FDA approved in July, is also for heart failure patients with poor ejection fraction. It is in a different category of drugs than Corlanor and actually contains two medications in one pill: valsartan (an ARB that has been around since 1997) and sacubitril. Sacubitril, is the first of a new class of drugs called neprilysin inhibitors, which stop an enzyme called neprilysin from breaking down peptides that lower blood pressure.

"Compared to what we've been treating patients with, this drug actually has better outcomes," Dr. Gudimetla says. A recent clinical trial supports this. In the study, Novartis com-



In a large clinical trial, Entresto was shown to reduce the risk of heart failure-related hospital readmissions and cardiovascular death when compared to a common ACE inhibitor.

Name	Maker	What it's for	Who it's for	List price*	How it's taken	What it does	How it's different than current drugs	Possible Side Effects	Details
Corlanor (ivabradine)	Amgen	Chronic heart failure	Heart failure patients with poor ejection fraction, a resting heart rate higher than 70, and who are either on the maximum dose of a beta blocker or who can't use a beta blocker	\$4,500 per year/ about \$12.50 per day	Oral pill, twice daily	Helps with heart rate by specifically targeting pacemaker cells in the heart	Current drugs used for heart failure slow the heart rate but also drop patients' blood pressure.	Bradycardia (slowing of the heart rate), atrial fibrillation (irregular heart rate), vision changes, increased blood pressure	Usually given with other heart failure therapies
Entresto (valsartan/sacubitril)	Novartis Pharmaceuticals	Chronic heart failure	Class II to Class IV chronic heart failure with reduced ejection fraction. Novartis has a study under way to see if the drug is effective for those with preserved ejection fraction.	\$4,500 per year/ about \$12.50 per day	Oral pill, twice daily	Sacubitril inhibits an enzyme called neprilysin	Valsartan lowers blood pressure by helping blood vessels relax; sacubitril stops neprilysin from breaking down substances in the body that lower blood pressure	Low blood pressure, high levels of potassium in the blood, kidney problems, allergic reaction causing swelling of the face and lips	Usually given along with other heart failure therapies, in place of an ACE inhibitor or ARB
Praluent (alirocumab)	Sanofi and Regeneron Pharmaceuticals	High levels of LDL ("bad") cholesterol	Those with heterozygous familial hypercholesterolemia, or HeFH. Also for those who cannot tolerate statins.	\$14,600 per year/ about \$40 per day	Self-injection, taken every two weeks; dosages are 75 mg or 150 mg	Stifles a protein called PCSK9 that is involved in regulating cholesterol	Statins, which are commonly used to treat cholesterol, work by blocking the liver's production of LDL cholesterol. PCSK9 inhibitors stop a particular protein in the liver, therefore reducing cholesterol in the blood. PCSK9 inhibitors are injectables.	Itching, swelling, pain, or bruising where injection is given, common cold and flu	Usually given with highest-tolerated dose of statin
Repatha (evolocumab)	Amgen	High levels of LDL ("bad") cholesterol	Those with homozygous familial hypercholesterolemia (HoFH), a genetic disorder that causes extremely high cholesterol; those with heterozygous familial hypercholesterolemia (FH). Also for those who cannot tolerate statins.	At press time, Amgen had not disclosed pricing; however, analysts estimate it could cost \$10,000 or more per year.	Self-injection, taken either every two weeks at 140 mg/injection, or monthly at 420 mg/injection	Stifles a protein called PCSK9 that is involved in regulating cholesterol	This drug is in the same class as Praluent and works similarly.	Common cold, respiratory tract infections, back pain	Repatha is already approved in Europe. The FDA is expected to approve it by the end of August.

\*Price for patients depends on their insurance plans and pharmacy benefits.  
Sources: Manufacturers' press releases, FDA, Forbes, CNN, Reuters, New York Times

pared Entresto to the common ACE inhibitor enalapril. (ACE inhibitors are one of the main treatments for heart failure.)

Entresto was shown to not only reduce the risk of heart failure hospitalization by 21 percent, but it also reduced the risk of cardiovascular death by 20 percent. In other words, by the end of the study, patients taking Entresto instead of enalapril were more likely to be alive and less likely to have been in the hospital because of heart failure.

"The results were really promising in that it showed a pretty drastic reduction in readmission rates, and even in mortality, which you really don't see in trials now," says Dr. Parikh, who is also on the medical staff at Texas Health Presbyterian Hospital Dallas.

### The Personal and Economic Costs of Heart Failure

What will heart patients pay for these new drugs? Both Corlanor and Entresto will cost about \$12.50 per day, or \$4,500 per year. Compared to some heart failure medications, many of which are available as inexpensive generics, the price for Corlanor or Entresto may seem steep.

On the other hand, the estimated total lifetime direct cost of heart failure is \$110,000, with hospitalizations accounting for about \$73,000 per person, according to Novartis. That means the price of a newer, promising drug may be worth it if it can keep patients out of the hospital.

And heart patients aren't the only ones trying to keep themselves from making multiple trips to the hospital. The health care system as a whole has an interest in keeping patients well outside the walls of a hospital. Heart failure costs were approximately \$31 billion in 2012 — \$21 billion was from direct costs, and \$10 billion was attributed to indirect costs, according to the American Heart Association.

"Heart failure is chronic, and that's why it's often difficult to manage. Patients think they are cured, so they stop taking their medication and then they end up back in the hospital," says Dr. Parikh. "These medicines are good both for patient's sake and hospital's sake. It takes up a lot of health care dollars when patients aren't managed properly."

### "Melting Away" Bad Cholesterol, For a Price

Two of the four drugs discussed in this article target a health problem that could eventually lead to heart failure, and that is high cholesterol. While statins and other types of cholesterol-lowering drugs work well for many patients, some people simply can't tolerate the side effects, and others don't respond to them.

In fact, there are an estimated 10 million people in the United States who have trouble managing their LDL ("bad") cholesterol, even with the standard treatment, according to



When the European Commission granted marketing authorization for Repatha this past July, the injectable drug became the first PCSK9 inhibitor to be approved in the world. It is expected to be approved by the FDA in late August.

PhRMA, the Pharmaceutical Research and Manufacturers of America. High cholesterol can increase a person's risk for heart disease, heart attack and stroke.

Enter a completely new class of drugs called PCSK9 inhibitors. Praluent, by Sanofi and Regeneron Pharmaceuticals, is one of them. It won FDA approval in July. A competitor, Repatha, from Amgen, received FDA approval a month later in the United States.

"In comparing PCSK9 inhibitors to statin therapy, the stuff almost melts away cholesterol," Dr. Parikh says. "Praluent was shown to reduce cholesterol by 50 to 60 percent after following patients for a year to a year and a half. There's pending data on whether it can reduce heart attacks, stroke and death."

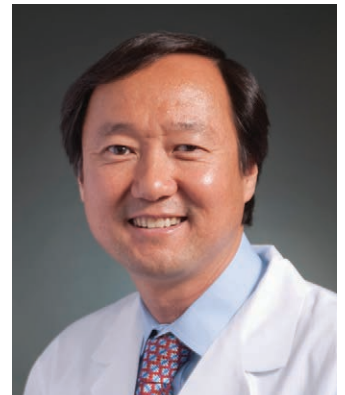
Who will benefit from these drugs? "If you have a hereditary form of familial hypercholesterolemia, or FH — so you have a genetic reason to have very high cholesterol. That's not a common indication. The second one is for patients who have known heart disease, who've had a heart attack, had stents, and they are truly intolerant to statins — they either don't work or they don't tolerate it," Dr. Parikh says.

There is some debate, though, on how widely PCSK9 inhibitors will be used. The fact that Praluent and Repatha are self-injected may turn off some patients or cause problems with patient compliance.

Another factor that may turn patients away is the price tag. The list price for Praluent is \$560 per injection, which is about \$40 per day, or \$14,600 a year. Pricing for Repatha is similar, although the dosing of it is different. "The issue is not if it's going to work, it's the cost of it," says James Park, M.D., an interventional cardiologist who is also with Presbyterian Heart and Vascular Group, and director of the



Dr. Sreenivas Gudimetla



James B. Park, M.D. F.A.C.C.

Heart and Vascular Program at Texas Health Presbyterian Hospital in Dallas.

Health insurers worry that if too many people take the drugs, and they take them for life, it could cost billions of dollars a year, according to an article in the *New York Times*. The Pharmaceutical Research and Manufacturers of America, however, says on its website that PCSK9 inhibitors "will not replace existing treatment options and will address a significant unmet medical need in a small subset of people." It also stated that patients can expect to see discounts ranging from 30 to 65 percent on the medicines.

If patients and insurers can bear the cost, these new medications offer lots of hope for those living with chronic heart failure and those trying desperately to lower their cholesterol. "There's more excitement about these new drugs than I've seen in a while," Dr. Park says. "They're essentially new ways of treating our most common diseases.

*Heartbeat* thanks Drs. Gudimetla, Parikh and Park for reviewing this article. ❤️

# 12 Takeaways From Orlando

Missed the Mended Hearts and Mended *Little* Hearts Education and Training Conference in Orlando? Don't despair. We took copious notes to share them with you. **By Melanie Medina**

The conference was held at the Buena Vista Palace Hotel and Spa, just a short walk from Downtown Disney.

**T**HE 63<sup>RD</sup> ANNUAL MENDED HEARTS AND MENDED *LITTLE* Hearts Education and Training Conference, which took place June 24 – 28 in sunny Florida, drew in nearly 300 attendees from across the nation. The conference is designed to educate and train volunteers, provide the latest cardiovascular health information, and offer networking opportunities.

If you missed the event, you'll appreciate these 12 highlights from the conference. And if you were there, then you'll enjoy the recap of Mended Hearts and Mended *Little* Hearts achievements, health information and tips for staying healthy.

These dozen takeaways are a small representation of the many educational presentations at the conference. We appreciate all of our speakers who shared their knowledge with our members.

## 1. Mended Hearts was set back in 2014, but we're poised for growth.

During the Annual Meeting General Session, attendees learned that 2014 brought its share of challenges. Mended Hearts lost nine chapters and gained four (Mended *Little* Hearts lost three and gained several). And, for the first time in our organization's history, in 2014 we cut financial ties to larger organizations that were partially subsidizing us.

Still, Mended Hearts leaders say we're plowing ahead with plans for growth. Speakers at the General Session explained how Mended Hearts will work toward increasing membership by:

1. Growing our number of sponsors. Mended Hearts already has a number of loyal sponsors, and we plan to expand this by partnering with consumer goods markets.
2. Working with hospitals at the system level, so that we gain access to multiple hospitals.
3. Expanding donations to 85 percent of revenue, which is commensurate with the national average among non-profit organizations.
4. Attracting younger heart patients, as well as adult CHD patients, heart failure patients and even those with chronic obstructive pulmonary disease (COPD patients are at high risk for heart problems).
5. Creating a Patient Advocacy Network, which will be sponsor-supported and allow heart patients to connect virtually through Mended Hearts. (Read more about this new network in *News from National*, page 5.)
6. Making it easier to conduct visitor training. Members wanting to become visitors can now do their training online, at their convenience. Chapters can also conduct online group training.

*Michele Packard-Milam, CAE; Gus Littlefield; immediate past president; Donnette Smith, president; Lynn Berringer, former vice-president; Dale Briggs, former treasurer; and Andrea Baer, MLH vice president, each presented during the general session.*

## 2. Follow this formula to inspire volunteers.

Together, Mended Hearts and Mended *Little* Hearts have nearly 20,000 members, including 4,000 trained, accredited visitors. That's a lot of people to help care for adult and pediatric cardiology patients. But how can we keep everyone inspired?

Pamela Landworth has a formula for inspiring volunteer leadership, which she shared at the conference. As president of Give Kids the World, a non-profit organization that helps fulfill the wishes of children with life-threatening illnesses, she encourages and inspires nearly 15,000 active volunteers. Her formula is simple:

**Training + Communication + Care = Inspired volunteers**

*Training* includes a thorough orientation to the organization, as well as teaching new volunteers the Give Kids the World core values and operating principles. *Communication* techniques include volunteer recognition, newsletters, social media interaction and town hall-style meetings. *Care* includes providing a fun gathering place, celebrating Volunteer Appreciation Week and even hosting special Pancake Days.



Pamela Landworth shared a formula for inspiring volunteer leadership. As president of the non-profit Give Kids the World, she works with nearly 15,000 volunteers.

"If you can do these," Landworth said at the conference, "your volunteers will have pride in your organization. And if they have pride, they will do anything."

## 3. Variety is the spice of chapter life.

In the *20 Tried & True Ways to Spice Up Your Chapter* session, which was moderated by Cathy Byington, Regional Director of the Midwest Region and President of Chapter 214 – Sioux Falls, South Dakota, several members contributed ideas on how to keep chapter meetings exciting.

**Have a drawing for prizes.** Give members a raffle ticket at the beginning of the meeting. The member keeps one part of the ticket stub, while the other part goes into a bowl. At the end of the meeting, the leader can draw a winning ticket from the bowl. Prizes can include things like movie passes and gift cards. *–Idea submitted by Lupe Torres, Chapter 331, Anaheim, Calif.*

**Host a Mystery Soup contest.** Have four members bring a crock-pot of homemade soup. Provide small cups to attendees to try all four soups and vote on their favorites. The person who made the winning soup will get a prize. Also, don't put a name on the soups. Ask members to guess the names of each soup. If anyone can name all four, they receive a prize. *–Idea submitted by Bobbi Cecco, Chapter 140, Bergen-Passaic/Hackensack, N.J.*

**Give out special seeds for heart patients.** Several seed companies sell seeds in unlabeled packets. Order them for special events and use them as prizes. The winner can plant the seeds, and in several weeks or months, determine what they produce. *–Idea submitted by Shirley Kell, Chapter 230, Pontiac, Mich.*



Mended Hearts members started a conga line during a session about how to spice up chapter meetings.

#### 4. Get sleep apnea under control, and realize it takes a team to treat heart failure.

"Sleep apnea is my No. 1 nemesis," Dr. Ashish Gupta, M.D., told attendees at a luncheon presentation about living with heart failure, which was a joint program of Mended Hearts and the American College of Cardiology. He discussed how sleep apnea causes patients to stop breathing during their sleep and limits blood flow to the brain. This can cause problems with blood pressure and worsen symptoms of diabetes.

Currently, the most-recommended treatment for sleep apnea is a C-Pap machine, Dr. Gupta explained. There are a few patients who may benefit from seeing an ENT for uvuloplasty, or by using prosthetics to lift the jaw while sleeping.

Dr. Gupta also stressed the team approach to managing heart failure. "Get to know your pharmacist," he said, and encouraged the audience to also work closely with nurse practitioners and dietitians in their cardiologist's office.



Dr. Ashish Gupta specializes in cardiovascular disease and serves several hospitals in the Orlando area. He visited with members, including Donnette Smith, after presenting at a "Living with Heart Failure" luncheon—a joint session with American College of Cardiology and Mended Hearts.



Randy and Sherry Gay (left) from Missoula, Mont., first met Louise and Bruce Norris (right) of Bellfontaine, Ohio, at the Mended Hearts conference in 2008. The couples have made it a tradition to connect with each other at every Mended Hearts conference since then.



## 5. Take note of this website:

During his presentation, Dr. Gupta encouraged attendees to take advantage of tablet and smartphone apps, as well as websites, to help them keep track of health needs. One website in particular, [www.CardioSmart.com](http://www.CardioSmart.com), offers an app that reminds users when to take their medications.

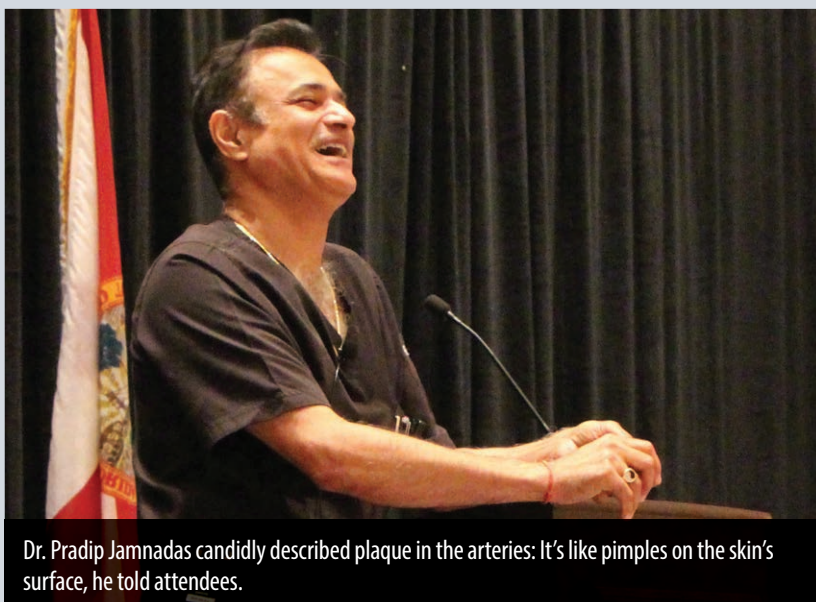


Donnette Smith, the swashbuckling Mended Hearts President, and Marcia Baker, Director of Field Services, were hardly recognizable at the Pirates and Princess party.

## 6. If you go back to the same lifestyle you had before your heart attack, you're going to have the same thing happen to you again.

This was the main message from interventional cardiologist Pradip Jamnadas, M.D. During his presentation, *Lifestyle Changes After a Heart Event*, he used layman's terms to describe how plaque forms in arteries and leads to trouble. He likened plaque buildup to pimples on the surface of the skin.

"Eventually, [the plaque] ruptures in the wall of the artery. Plaque that ruptures in the artery is like a pimple that ruptures on your skin," he said. He followed that up on a lighter note: "Call me a coronary cosmetologist."



Dr. Pradip Jamnadas candidly described plaque in the arteries: It's like pimples on the skin's surface, he told attendees.



(Left) Families took the Pirates and Princess-themed party very seriously. The event featured food and entertainment for Mended Little Hearts members.

## 7. If you change your diet to one that is plant-based, you can reduce plaque in the arteries.

Dr. Jamnadas didn't mince words when he talked about changing eating habits after a heart attack. "Let's not pussyfoot around this," he said. "The trouble with this is that so few physicians will tell their patients to eat a plant-based diet." If you're not a big fan of the way vegetables taste, Dr. Jamnadas had a straightforward, if less-than-compassionate, response: "I'm not asking you to taste it. I'm asking you to swallow it," he joked.

## 8. If you don't wake up refreshed, you're doing it wrong.

"Making sure you sleep well, this is a lifestyle change you should make," Dr. Jamnadas said. "You age much faster when you don't get delta sleep at night." (Delta sleep is the deepest stage of sleep.)



After his presentation, Dr. Jamnadas took time to visit with attendees, including Michael Weber, left, Southern Assistant Regional Director for Mended Hearts.

## 9. Risk factors aren't risk factors. They're subclinical disease.

The correlation between atherosclerosis and risk factors begins very early, according to Dr. Ralph Vicari, M.D., vice president of the National Lipid Association, associate professor of cardiovascular medicine at the University of Central Florida College of Medicine. "By the time patients have identifiable risk factors, they are no longer risk factors; they are subclinical disease," he said. (A subclinical disease is an illness that has no recognizable clinical findings.)

Dr. Vicari said that all children should be screened for cholesterol once between the ages of 9 to 11, and again between the ages of 16 to 18, a recommendation supported by the American Academy of Pediatrics. Why? Because if a child has risk factors in childhood, there is an increased likelihood that he or she will develop heart disease as an adult.



Dr. Fredonia Williams, National Visiting Chair in Huntsville, Ala., Chapter 260, gave an interactive presentation about recruiting, training and retaining members.



Jim Oldfield led a 7 a.m. walk each morning of the conference. Oldfield is a member of chapter 230 in Pontiac, Mich.



These Mended Little Hearts youngsters got creative with some straws during Kids Camp, hosted by Daniel Horgan, who inspired the kids to think differently, identify and use their strengths, grow and take action.

### 10. Consider whether your child with a CHD needs a 504 plan.

Parents of children with congenital heart disease who have restrictions or limitations on activity should request that their child have a 504 plan, unless they already have an Individualized Education Plan (IEP). This plan helps students who have a physical or mental impairment that limits a major life activity, such as learning. A 504 plan lists how an individual child's specific needs are met through various accommodations, modifications and services. "We're not giving [students with CHD] a leg up," said school program specialist Lorilynn V. Bowie, who works with Marion County Public Schools. "We're leveling the playing field."

If your child receives special education, he or she needs an Individualized Education Plan, which provides a higher level of support than a 504 plan. With an IEP, goals are outlined for the student and measured throughout the school year.



Dr. William Bartnick, a certified school psychologist in Florida, answered questions about 504 plans and Individualized Education Plans.

### 11. When a child is diagnosed with a CHD, parents must make a choice.

Dawn Silverman, a licensed mental health counselor and mother of a 6-year-old son who has hypoplastic left heart syndrome, said that learning your child has a CHD is equivalent to loss — the loss of a perfect child. "You have a choice toward redefining that loss," she said. "You can't control medically what happens to your child, but you can control how you react to it."

### 12. If you're annoyed with parents on Facebook who seem to make it a contest as to whose child is the sickest, don't engage.

If you talk about your child's CHD with other parents in social media, it can be easy to get wrapped up in conversations about whose child has the worst case. "It almost feels like a comparison — like my child is sicker than yours," said one mother during a session about the emotional side of CHD. "When parents act that way," Silverman said, "there's something emotionally going on. You're not going to change their minds to get them out of that victim mentality." Her recommendation? Don't join in the conversations. ❤️



# And the Awards Go To...

Mended Hearts and Mended *Little* Hearts presented dozens of awards at the 63rd annual conference. Have a look at the winners. **Compiled by the *Heartbeat* editors**

**A**NATIONAL CONFERENCE IS NOT A NATIONAL conference without an awards ceremony. That's why, to make it official, Mended Hearts and Mended *Little* Hearts gave out the following awards at the 63rd annual conference and training session. In addition to this listing, you'll also find stories about some of the award winners in this issue of the magazine. Congratulations to all of the 2015 winners!

## Mended Heart of the Year

**Jim Bushnell**, immediate past National Newsletter Editor, Dallas Chapter 30. (Read Jim's story on page 6.)



## President's Cup Award

Learn more about these winners in *Chapters on the Move* on page 20 of this issue.

### 1-39 Members

**Chapter 91-Greater Wenatchee, Wash.**

Runner-Up: West Central Ohio chapter 111, Lima, Ohio

### 40-99 Members

**Chapter 138-Greater Cleveland**

Runner-Up: Memorial Regional Chapter 161, Hollywood, Fla.

### 100+ Members

**Chapter 382-Bellingham, Wash.**

No Runner-Up

## Mended *Little* Hearts Group Excellence Award

Mended *Little* Hearts of Chicago



## Mended *Little* Hearts Group Excellence Runner-Up

Mended *Little* Hearts of West Michigan



## Hospital of the Year

CaroMont Regional Medical Center  
Gastonia, N.C.



## National Newsletter Awards

### Monthly Newsletter:

#### Honorable Mention

Heartbeat Away, Chapter 91  
Greater Wenatchee, Wash.

Editor: Ann Diede

### Monthly Newsletter:

#### Honorable Mention

Bridge to the Heart, Chapter 51  
Y-Bridge, Zanesville, Ohio

Editors: Genevieve &  
Tony Maniaci

### Monthly Newsletter:

#### Winner

The Rhythm Section,  
Chapter 367

Citrus County (Inverness), Fla.

Editor: Rick Hosea

### Bi-Monthly Newsletter

Honorable Mention

The Tri-State Thumper,  
Chapter 107

Greater Evansville, Ind.  
Editor: Jana Stewart

### Quarterly Newsletter

Honorable Mention

Heartsome in the Heartland,  
Chapter 342

Mad River, Springfield, Ohio  
Editor: Carol Haytas

## Dwight Harkin Award

Stanton "Stan" Rowe, Edwards Lifesciences

The 2015 Dwight Emory Harkin Award went to Stan Rowe of Edwards Lifesciences for contributions to the invention of the transcatheter aortic valve replacement (TAVR), which allows doctors to repair a patient's aortic valve in a minimally invasive surgical procedure. Since the invention of TAVR and a similar procedure called transcatheter aortic valve implantation (TAVI), more than 100,000 implants have been performed worldwide.

In a healthy heart, the aortic valve passes blood from the heart throughout the body. In those with aortic stenosis, the valve becomes clogged with calcium buildup and can't move enough blood to meet the body's needs. Symptoms can include energy loss, fainting and even sudden death. TAVR and TAVI are now established therapies to treat aortic stenosis in patients who are deemed too high risk for surgery.

Rowe, a Huntsville, Ala., native, attended the awards ceremony and visited with Mended Hearts members after the event. "It is a privilege to meet the many members of Mended Hearts and to better understand their impactful mission," he said. "I am so grateful to know that Edwards' technology makes a big difference in their lives and the lives of patients around the world."

The Harken Award was created to recognize people or organizations for their excellence in the field of cardiovascular medicine. It is named in honor of Dwight Emory Harken, a pioneer heart surgeon considered the "father" of Mended Hearts. Mended Hearts was co-founded in Massachusetts in 1951 by one of Dr. Harken's patients, Doris Silliman. ❤️



Back in his home office at Edwards Lifesciences, Rowe proudly displays his award. Photo: Edwards Lifesciences



Stan Rowe, winner of the 2015 Dwight Harkin Award, met with many Mended Hearts members, including Betty Drinkard, president of Chapter 16, Blue Ridge Mended Hearts, Lynchburg, Va.

# This Year's "President's Cup Award" Winners Share Trials and Triumphs

Leaders of the three exemplary groups are working hard to increase membership, grow meeting attendance and visit more patients. **By Maria Carter**

**E**ACH YEAR, MENDED HEARTS AWARDS PRESIDENT'S Cup Awards to chapters that exemplify engagement and involvement. These chapters are greatly appreciated by their communities and the hospitals they serve; they show year-over-year growth in membership as well as the number of patient visits they make.

Three chapters, one for each size category, took home the coveted prize in 2015. Greater Wenatchee, Wash., snagged the title in the 0-39 members division, while Greater Cleveland, Ohio, took the cup for chapters with 40-99 members. Bellingham, Wash., earned the designation in its category of more 100 members.

Ann Diede, president of the Greater Wenatchee chapter, says her group has had its ups and downs, namely fluctuating membership, just like any other chapter. There have been some "downhill slides" with uncertainty about leadership's roles. They struggled for a little while, a few years ago, after their former president suddenly relocated, leaving them without a commander in chief. Diede stepped forward to take his place, and the chapter began a "rebuilding process."

Now Greater Wenatchee, which serves a rural four-county



Chapter 91-Greater Wenatchee, Wash., won the President's Cup for chapters with 1 to 39 members. Patrick Farrant accepted the award on the chapter's behalf.

**Ten trained visitors for the Greater Wenatchee chapter made more than 600 visits to heart patients in 2014, a 15% improvement over the previous year.**

region in north central Washington, draws members who travel up to 100 miles to get to meetings. Diede and her colleagues work with the cardiovascular services director at their partner medical center to book doctors and other guest experts who regularly speak and educate at meetings. The



Jana Stewart accepted the President's Cup for chapters with 40 to 99 members. The award went to Chapter 138 of Greater Cleveland.

**These chapters are greatly appreciated by their communities and the hospitals they serve; they show year-over-year growth in membership as well as the number of patient visits they make.**

chapter's achievements are quantifiable, too: Its 10 trained patient visitors made more than 600 visits to heart patients in 2014, a 15 percent improvement from the previous year. Getting there hasn't been easy: "It's a lot of work, but it's paid off," says Diede.

In Cleveland, visitors in Chapter 138 visit between 200 and 300 patients per month at four hospitals. They only recently restarted their program at the county hospital. "Our previous chapter president passed away in 2012," says chapter president Scott Eitman. "It was a tough loss, personally and organizationally, and we lost our presence [at the county hospital]."



The President's Cup award for chapters with more than 100 members went to Chapter 382 of Bellingham, Wash. President Marilynn Huffman, shown here with her husband, Jim, has hosted many social gatherings with previously visited patients at local coffeehouses, resulting in about 20 new members in one spring.

Eitman feels there's always more to be done, and believes other chapters can relate. "We all probably feel that way, all the presidents want their chapters to do more, and want to see more people at meetings," Eitman says. "My advice is to not work full time and try to be chapter president," he adds.

By comparison, the Bellingham, Wash., chapter is fairly new. It began three years ago after a local surgeon put a call out for volunteers. Peter Olsen was one of the first to step forward, becoming the chapter's founding president. There were 33 members in the beginning, a number that's grown to nearly 100. Average attendance hovers around 30 to 45, but has swelled to 145 a time or two (meetings are open to the public). In the last year they've completed more than 3,000 visits to patients and caregivers.

Olsen says being diagnosed with cardiovascular disease is disorienting. He compares the experience to being picked up off the earth and being planted somewhere else with no recognition of who you are, where you are, or what happens next.

"Mended Hearts gives our members an opportunity to share their experiences so that a [newly diagnosed] person sees that what they're going through for the first time, others have gone through and were still able to lead productive lives," he says. ❤️

# Secrets to Growing Your Group

By Melanie Medina

**A**NY MENDED *LITTLE HEARTS* GROUP — HECK, ANY Mended Hearts chapter — that’s looking for ways to increase its membership should take a look at Mended *Little Hearts* of Chicago for ideas. With more than 200 members and growing, MLH of Chicago won this year’s Group Excellence Award.

Granted, some of the group’s earlier success came by chance when two Chicago-area groups combined. But they keep the momentum going by working closely with hospitals, seeking donations and organizing some fun, family-friendly events.

Here, Melanie Toth — who serves as both the National Visiting Chair Coordinator, as well as the Regional Group Coordinator for MLH of Chicago — sheds some light on what keeps this group moving and shaking.

## Keeping Families First

The Chicagoland area is vast. There are five hospitals within the area that perform cardiology surgeries on pediatric patients. Prior to 2011, there were separate MLH groups that served the hospitals. In 2011, the leaders of two different MLH groups serving these hospitals realized that they were competing against each other when it came to membership and fundraising. So, Toth’s group joined forces with the other, which was led by Christine Olson. “We realized it’s not about serving a hospital, it’s about serving the patients and their families,” Toth says. “To accomplish this partnership, we assembled an amazing team of heart moms, heart dads, adult heart warriors and angel families.”

## Being Persistent with Hospital Administrators

Toth says some hospitals are more lenient than others when it comes to accessing patients. “I can hand deliver a Bravery Bag



MLH of Chicago created a mascot for the group: Stitch the CHD Lion. Stitch stopped by the Pirates & Princess party, where he hung out with Julie Stucki, MLH Conference Committee Chair and MLH of Evansville Lead Coordinator.

to patients at one of our hospitals, but another hospital won’t even let us on the cardiology floor,” she says. In the hospitals with tighter restrictions, MLH of Chicago remains persistent by delivering Bravery Bags on a consistent basis, asking hospital personnel to distribute them as needed.

“By remaining persistent, we’re showing the hospital leadership that we’re not just a group that’s here for a couple months and then we’re done. And that’s really helped open the doors. One of our hospitals told us a while back, ‘You’ll never get on this floor.’ But they’re letting us have our first meeting there on Saturday,” Toth says.

She adds that some hospital administrators fear that MLH members will try to provide medical advice to patients’ families. To ease that fear, Toth reassures the hospital staff that MLH leaves medical advice to the physicians. “We tell them, ‘You guys are the professionals, but you don’t know what it’s like to go home with a child with CHD.’”

Toth also says that when MLH members take their children to cardiologists, they will sometimes mention the name of another MLH member to the doctor. The doctor is often pleased to know that his or her patients’ families are connecting with and helping each other outside of the clinic setting. “Once they see the correlation with their patients and our group, that’s a big seller,” Toth says.

## Asking for Help

Toth admits, “Never in my life have I been good at fundraising. I’m not an outgoing person.” Yet the longer she’s in her role, she has realized just how much people are willing to give. Simply by asking, Toth and others in MLH of Chicago have had big-name vendors donate food and volunteers to help at





Jodi Lemacks (left), MLH Program Director, and Andrea Baer (right), MLH Vice President, presented the Group Excellence Award to Melanie Toth (center).

events. Someone even gives them free warehouse space where members meet several times a year to assemble Bravery Bags — usually several hundred at a time. Many of the items in the bags are, of course, donated.

Kohl’s department store has come through for MLH of Chicago on many occasions, thanks to the company’s Associates in Action program. Nonprofits can submit requests to individual Kohl’s stores for \$500 grants to support various events. With that grant, Kohl’s will also allow its employees time off to volunteer at the event. Through this program, MLH of Chicago has been able to secure funding and volunteers for its events.

### Taking a Cue from Disneyworld

Last year after snapping photos of her husband, Ben, and two children with Mickey and the gang at Disneyworld, Toth decided that MLH should have its own mascot. That’s how Stitch the CHD Lion came to be. Toth sourced a lion costume that can be worn at MLH of Chicago events so kids and families can take a pic with the new mascot — and share those photos in social media to help create awareness about CHD. The mascot even had a cameo at the MLH “Pirates & Princesses” party during the conference. A small, stuffed toy version of the lion is also available to groups nationwide to be used in their Bravery Bags. 🦁

### Interested in including some plush lions in your group’s Bravery Bags?

Simply order online through the national office. Also, keep your eyes peeled for periodic sales of the lions online at [Mendedlittlehearts.org](http://Mendedlittlehearts.org). The national office runs this promotion periodically throughout the year.



Order plush lions for Bravery Bags through the national office online.

# Nike Teams Up with Mended *Little* Hearts Member

Jacob Burris, 13, partners with Nike to raise money for the hospital that corrected his heart defect. **By Ariel Bailey**

**L**AST FALL, 13-YEAR-OLD JACOB BURRIS UNDERWENT open-heart surgery to correct a life-threatening heart condition — coarction of the aorta. The condition had gone undiagnosed until his pediatrician discovered it during a routine well-child check-up.

After a 7-hour surgery, surgeons at Doernbecher Children’s Hospital in Portland repaired the defect. And this fall, Jacob has the opportunity to give back to the hospital that saved his life, thanks to Nike’s Doernbecher Freestyle program. Through the program, which is in its 12<sup>th</sup> year, Nike has helped raise more than \$11 million for the hospital.

Jacob and five other young patients were selected from nominees across the region to partner with Nike designers in creating limited-edition shoes and apparel. Sales of these items will directly benefit Doernbecher Children’s Hospital. While this will be Jacob’s first experience with design, he says, “I’m grateful for the opportunity, and I won’t disappoint other Mended *Little* Hearts members!”

Jacob, now a passionate advocate for heart health, most looks forward to “making a lot of money for the children’s hospital at Doernbecher.” The Burrises had an exceptional experience at the hospital. “Everyone was so kind to me,” Jacob says. “They made it easy to relax and look toward the future.” Their experience has inspired the family to take an active role in advocating for heart health.

“It’s scary to think about all those times in Jacob’s life when he could have been in danger and we had no idea,” Janice Burris, Jacob’s mother, said. “We feel like we have a responsibility to bring awareness to this condition.” With this in mind, the family stays active as advocates in their community and online at [www.jacobsheartstory.com](http://www.jacobsheartstory.com).

Look for Jacob’s designs on Nike products, available online and in stores this November. ❧



(Left) Jacob is a heart patient-turned-advocate, saying, “I want people to know what I went through so they don’t have to deal with the same thing I did.” Jacob had several surgical procedures to correct coarction of the aorta last fall.

(Below) Jacob frequently distributes these pins, urging people to “Check Your BP,” at the local farmer’s market in his hometown of Eugene, Ore. High blood pressure above the heart, with low blood pressure in the extremities, is one symptom of coarction of the aorta.



**“We feel like we have a responsibility to bring awareness to this condition.”**

– Janice Burris, Jacob’s mother



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*"Tell your cardiologist exactly how you're feeling. Don't hold anything back."*

Donnette, angina patient

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

Watch Donnette's video



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Tips, information, and more from real angina patients Donnette, Ralph, and Claudia.



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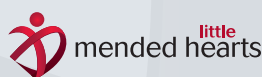
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 Mended Hearts Chapter #40  
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**Marcia Wittig**  
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**IN HONOR/CELEBRATION/SPONSORSHIP OF:**

**Lotte**  
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**Zoey Baxter**  
 Don and Tamara Barthel

**Thomas Julian Frye's 1st Birthday**  
 David Fischer  
 Franziska Huettner  
 Kenneth Morrow  
 Ryan and Jessica Schmucker

**Avery Sophia Garrett's 5th Birthday**  
 Jason and Janelle Gilbert

**Graham Goodfellow**  
 Matt Kubik

**Earl P. Hutchens Birthday**  
 Geraldine School

**Tita Hutchens, Founder of Mended Little Hearts**  
 Geraldine School

**Kylie Jacomet's Wedding**  
 Mark Brinkman

**Lillian Flynn Keogh**  
 Charlotte Stewart

**Oliver Loeb**  
 Tess Callard

**Ryan Mason, CHD Survivor**  
 Marcie Hernandez

**August O'Connell**  
 Eleanor Wilson

**Gabe Rainish**  
 Debra Freed

**Logan Rascoe**  
 Marlyn Rascoe

**The Smith Family – Roger, Jesse, Luke and Laney**  
 Heather Ancheta

**Team Distefano**  
 Jane Heinz

**Henry Wiora's 1st Birthday!**  
 Traci Flowers

**BRAVERY BAG DONATIONS:**

Patrick "Kelly" Cunningham  
 Landon Davis  
 Jimmy and Bertha Hughes

**2015 M/H LEADERSHIP TRAINING:**

Alderson Family Foundation – *designated for speaker fees*

Kohl's Associates in Action

Mended Little Hearts of Evansville, IN – *designated for the Pirates and Princesses Reception*

Mended Little Hearts of Western, NY – *designated for the Pirates and Princesses Reception*

Mended Little Hearts of Central, VA – *designated for Pirates and Princesses Reception.*

Orlando Regional Medical Center – *designated for conference t-shirts*

**IN KIND DONATIONS:**

Cheryl Dickens

**GENERAL DONATIONS:**

Holly Cottrell  
 Dustin and Amy Dinnat  
 Michael Hruska  
 Jo Anne Hurley  
 Cathy Lynn Lockhart McAllister  
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 Mended Little Hearts of South Central Illinois  
 Zabrina Mihelic via AT&T Employee Giving Campaign in support of iHeartSophia  
 Students and Families of the Old Brooklyn Community School  
 Beverly Tomlinson  
 Heather Underwood via Milliedot

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

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."

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

**Mended Little Hearts • 8150 N. Central Expwy., M2248, Dallas, TX 75206-1815**

Or contribute online using your credit card at [www.mendedhearts.org](http://www.mendedhearts.org)



**Mended Hearts Chapter Anniversaries  
December 2015 – February 2016**

**35 years**

Lexington, KY · Chapter 115 · Central Region

**20 years**

Las Vegas, NV · Chapter 277 · Western Region  
Scranton, PA · Chapter 276 · Northeast Region

**15 years**

Tucson, AZ · Chapter 116 · Rocky Mountain Region  
Wenatchee, WA · Chapter 91 · Western Region

**Mended *Little* Hearts Anniversaries  
December 2015 - February 2016**

**5 years**

Mended *Little* Hearts of Chicago, IL · Midwest Region  
Mended *Little* Hearts of South Central, IL · Midwest Region  
Mended *Little* Hearts of Western, CO · Southwest Region



# Speakers Bureau

**M**ENDED 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](mailto:info@mendedhearts.org).**

The Mended Hearts, Inc.  
8150 N. Central Expwy., M2248  
Dallas, Texas 75206-1815

# Mended Hearts

Compassion.  
Hope.  
Encouragement.

## Coming Soon: New Mended *Little* HeartGuide from MLH and St. Jude Medical



**E**ACH 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](http://sjm.com/weheartkids) or [mendedlittlehearts.org/littleheartguide.shtml](http://mendedlittlehearts.org/littleheartguide.shtml)

