THE POWER OF PEER SUPPORT

New study proves value of Mended Hearts

Little Hearts, Big Ambition
MLH adds new volunteer role

PLUS: How Visiting Benefits Visitors
If you have been limiting your work or your activities because of your chronic angina, be sure to talk about it with your cardiovascular healthcare provider.

For tips on how to talk with your cardiologist, information about living better with angina, and support and stories from real angina patients—including Debbie—visit www.SpeakFromTheHeart.com.

“'My cardiologist and nurse practitioner help me manage my angina long-term.'”

Debbie, angina patient

Watch Debbie’s video

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

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Et cetera...

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

Visit us online:
www.mendedhearts.org
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Features

Can Peer Support Keep You Out of the Hospital?
See what new studies reveal about the effect of Mended Hearts’ programs on heart-failure readmission rates.

Proving Our Worth
Take a deep dive into the results of the Mended Hearts patient survey.

Visiting Has Its Benefits
A new study shows that Mended Hearts visitors report improved quality of life and lower symptoms of anxiety and depression.

Work of Heart
Mended Little Hearts kids, tweens, and teens step up to help CHD families during nationwide service campaign.

Little Hearts, Big Ambition
As Mended Little Hearts expands nationally, a new team of Assistant Regional Directors makes sure things run smoothly at the community level.

SNL Alum, Golf Legend Team Up to Help Mended Hearts
When people view new videos of Kevin Nealon and Arnold Palmer talking about heart disease, Janssen Pharmaceuticals will make a donation to Mended Hearts.

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On the Cover: Members of Chapter 142 in Plano, Texas, modeled a typical Mended Hearts visit. From left are Richard Falkow, vice president; his wife, Sheila, treasurer; and Lynn Pridgen, visiting chair. Special thanks to Mike Meyer, president, and Carol Loe, hospital liaison, for coordinating the photo shoot with photographer Juan Pulido, and to the Medical Center of Plano, an HCA facility.

“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. To learn more about Assistant Regional Directors, a new role for Mended Little Hearts, please read “Little Hearts, Big Ambition,” on page 21.

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My Mended Hearts story isn’t unique. It was 17 years ago, and I’d just spent two days in a Scottsdale, Ariz., operating room with my chest opened up: once for quintuple bypass surgery, and again to repair some internal bleeding.

Sometime during my 10-day hospital stay, the president of the local Mended Hearts chapter stopped by to share his story with me. I, like many heart patients who are realizing that they’ve just dodged a bullet, was feeling depressed. My visitor told me about his own triple bypass surgery, and I could see how well he was doing.

“If he can do it, so can I,” I said. That personal interaction was what helped me snap out of it.

We all have stories like this, and we could spend years talking about each of them. But no matter how compelling our stories are, they’re not enough to prove Mended Hearts’ value. We needed data to support the anecdotes.

And now we’ve got it. We have it in spades thanks to our “Quantifying the Impact” study that we just completed with the American College of Cardiology.

To see the nitty-gritty details, I encourage you to read our feature story on page 6, “Can Peer Support Keep You Out of the Hospital?” You’ll get all the numbers and learn about how the study was conducted. And Mended Hearts’ Executive Director Michele Packard-Milam’s column on page 4 will also shed some light on what the study means for the future of this great organization.

What I will tell you is this: We now have empirical data to show that Mended Hearts helps keep heart failure patients from being readmitted to the hospital.

Now, on a personal level, we know that’s good. If you’ve ever had a major heart procedure, you don’t want to be readmitted to the hospital any time soon for another one.

On a broader level, this data has major implications. Why? Because hospital administrators hate early, unplanned readmissions. Readmissions cost hospitals money — even more now than in previous years, because the Centers for Medicare and Medicaid are penalizing hospitals when patients are readmitted within 30 days of their initial hospitalization. Hospitals are under intense pressure to keep readmission rates as low as possible.

Armed with the new data from the “Quantifying the Impact” study, we can go to hospital administrators and show them how we can help keep their heart failure patients from being readmitted. Even with the data, our task won’t be easy. It will require a lot of education and marketing to get the word out. You’ll see that Mended Hearts will put forth a lot of effort toward this in the months ahead.

The data will also allow us to show our value to other important groups as well — think potential conference sponsors and magazine advertisers, such as pharmaceutical companies, makers of heart devices and similar groups. It will also help support us as we write grant requests.

As an individual Mended Hearts or Mended Little Hearts member, what can you do with this data? I ask you to consider it when you’re sharing your heart story with others. Your Mended Hearts story is strong as it is, and even stronger with numbers to buoy it.
A Game Changer

As you read this, I am celebrating my first anniversary with Mended Hearts and Mended Little Hearts. What a year this has been! We have a lot to look forward to in 2015, much of which is based on work we did in 2014, including the following:

Quantifying the Value of Visiting — a Game Changer! The Quantifying Value Research Project has given us new, empirical data demonstrating that patients who are visited are more optimistic, more likely to comply with doctors’ instructions, less likely to be readmitted to the hospital within 30 days, and happier with their overall experiences. Additionally, data from the Centers for Medicare and Medicaid Services (CMS) indicates that a heart failure patient in a hospital with a visiting program is significantly less likely to have an unplanned, early readmission than a patient in a hospital without a visiting program. THIS IS HUGE!

Why is this a game changer?
Because we can now prove what you have known all along — that Mended Hearts helps patients and families live healthier and happier lives as they go through their heart journeys.

What will we do with this information?
We will present this exciting data to new hospital systems to create more channels for Mended Hearts to reach more patients, some through visiting and some in other ways.

We will attract more patients, healthcare providers, hospital administrators and families to our organization. Whether or not they become members, increased reach will make us more visible, which will drive awareness, and that will help us generate more revenue of all types.

What will we do with all of these new people?
At the beginning, we should start a conversation with patients and caregivers that’s not just about joining, but also what we can do to help. Let’s send them our magazine and our newsletters.

The membership conversation can happen both before and after our traditional 90-day window. Lots of people are not ready to make a joining decision in the first 12 weeks after they’ve had a heart attack or surgery. We should not turn them away — or throw away their contact info — a mere 90 days into their journey, which we all know will be many months, possibly years, long. As always, if they say “no” at any point, we would mark their file “do not contact” and that would be the end of it. But if they want to hear more, or if they just aren’t sure whether joining is the answer for them, let’s keep them in the fold.

How can we grow our organization and do more for more patients?
We have some wonderful sponsors that have supported us for many years. But it’s always a good idea to diversify funding sources. For instance: We’ve added new strategies to our corporate development process, including:

Foundation Grants — we have submitted nearly $3 million in requests since July, and continue to produce five requests per month. This will all be new revenue!

More Sponsors — we’re working to expand our sponsor lists, with more pharmaceutical, medical equipment and (new!) consumer brands. These will be new sponsors!

Direct Appeal — we have started requesting donations twice each year: Day of Giving in June and Thanks for Giving in November. These campaigns help us cover the cost of infrastructure.

Planned Giving/Major Gifts — Families can honor their loved ones through bequests and lasting legacies. We want to create life-long relationships with patients and their families!

Affinity Programs — ways to save our members money on services and products, generating revenue at the same time. Examples include Amazon Smile, GoodShop and GoodSearch, with many more to come. This is all new money, too!

Advertising — we will begin seeking paid advertising from outside our network for Heartbeat, the conference program and our websites. Again, new money and a way to extend our relationships with companies in the cardiovascular marketplace!

Part of getting from $2 million to $10 million in five years will be finding ways — lots of ways — to grow. Consider these ideas and let me know what you think. 🌟
HEART HERO

Julia Carter
In sickness and in health, Julia and Bill Carter are both patients — and caregivers.
By Kimberly Turner

At the heart of things, Julia Carter’s story is a tale of true love. As a teenager in small town Arkansas, she started dating a charming young man named Bill. The high school sweethearts fell in love and married young but still managed to finish college as married students. “I don’t recommend it,” Julia laughs, “but it worked for us.”

Today, the couple has three adult children, six grandchildren, and 55 years of wedded bliss. But the years have not been without their challenges. In 1994, Bill woke up and told his wife, “Call 911. I’m having a heart attack.” He was rushed to the hospital and ended up undergoing a double bypass surgery. Though it would be several years before they volunteered with Mended Hearts, their first encounter with the organization came when Bill was recuperating; a Mended Hearts volunteer stopped by Bill’s Dayton, Ohio, hospital room to offer support and hope.

Julia became Bill’s caregiver for the next 21 years — a role she still holds today. Recently, however, the tables were turned and Bill earned his own caregiver badge after Julia experienced a cardiac event of her own. She had been suffering from episodes where she lost consciousness and became nauseated. Even after six emergency room visits over the course of several years, doctors had been unable to determine the cause. Her cardiologist remained convinced that her problems were heart-related and fitted her with an event monitor.

Just two weeks later, Julia was attending a conference in Washington, D.C., with Mended Hearts representatives Ron and Angela Manriquez, and executive director Michele Packard-Milam, CAE. The group was eating dinner together when Julia passed out once again.

“It was ironic because I became not only a caregiver but a patient myself, so now Bill is a caregiver too.” — Julia Carter

Back home in Aiken, S.C., Bill got a call after Julia’s monitor recognized that her heart had stopped. Fortunately, Packard-Milam, who Julia calls her “guardian angel” during the episode, had prepared Bill by letting him know that his wife had been taken to George Washington University Hospital. There, she was fitted with a pacemaker.

“It was ironic because I became not only a caregiver but a patient myself, so now Bill is a caregiver too,” she says.

These days, the Carters are both extremely active in Mended Hearts Chapter 294 in Aiken. She is the former newsletter editor and is about to take on responsibility for scheduling visits. He is the Assistant Regional Director of the state of South Carolina. “We get a lot out of it and enjoy the work,” Julia says. “One Christmas, Bill and I didn’t have our kids here so we put on little Santa Claus hats and went out to visit. People were astonished that we would visit them on Christmas day... It’s always nice to bring a little joy into people’s lives.” 😊

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
Can Peer Support Keep You Out of the Hospital?

What new studies reveal about the effect of Mended Hearts programs on heart failure readmission rates

By Maria Carter

Spending another night on a hospital gurney is the last thing a heart failure patient wants, yet nearly 25 percent of people hospitalized with heart failure are readmitted within 30 days. If you’re keen to keep the cardiologist at bay, there’s good news: a little peer pressure may do the trick.

A recent analysis of data from thousands of hospitals concludes that hospitals with organized Mended Hearts visiting programs are significantly more likely to have better readmission rates for heart failure patients than other U.S. hospitals. In other words, the report, called Quantifying the Impact of the Mended Hearts, showed that heart failure patients at Mended Hearts hospitals are less likely to return to the hospital within 30 days post-procedure than their counterparts at other hospitals.

The findings confirm what many Mended Hearts members, as well as cardiologists and researchers, have long surmised. “We’re excited to have empirical data that supports what we’ve known for a while, which is that a peer-to-peer support network makes a big difference in the outcomes for patients,” says Michele Packard-Milam, CAE, executive director of Mended Hearts.
How Do Support Programs Make a Difference?
The correlation between Mended Hearts and patient success may stem from the fact that heart failure is a chronic illness. Managing it requires patients to alter their daily habits, some of which they’ve acquired over a lifetime.

“It’s much easier to take a pill than to make these changes in the way you live,” says Brenda J. Hott, M.D., a cardiologist at The Heart Center of Northeast Georgia Medical Center who is board certified in advanced heart failure and transplant cardiology.

The number one reason for heart failure readmission, according to Hott, is patient indiscretion. “They may have had a high load of sodium, stopped doing their daily weights, or had some other sort of falling off with the program,” she says. “When we have a chronic illness that needs to be managed every single day, we need support from other people to help us stay on the right path.”

Recent similar studies also confirm the value of peer support groups for heart failure patients: An August 2014 study in Heart & Lung: The Journal of Acute and Critical Care concluded that “self-management peer support programs” provided heart failure patients with comfort, restored confidence, and offered practical solutions.

‘If They Made It, I Can.’
Tom Southwell, visiting chairman of the Evansville, Indiana, Mended Hearts chapter, spends three days a week visiting patients at The Heart Hospital at Deaconess Gateway. He says patients find particular encouragement in hearing from volunteers who’ve been where they are. “We tell them what we eat, how we try to follow the diet, and we talk about cardiac rehab,” says Southwell, who had a heart attack at age 41 and triple bypass surgery at 57.

“We hit on the same bases as the people who work for the hospital; the only difference is we personally follow these habits, each one of us, and that’s what keeps us from having to go through another procedure. We’ve been there, but the dietitians, the nurses and the doctors — they haven’t.”

A new diagnosis of heart failure can be frightening, says Hott, but Mended Hearts volunteers can offer hope. “It’s good for patients to see someone who has been living well with chronic disease and having quality of life,” she says.

Southwell and fellow volunteers from his chapter aim to visit each patient three times during their stay. Recently he bumped into a patient he had visited 10 weeks prior, a woman who had undergone open-heart surgery. “She remembered me and told me she was impressed with our visits,” says Southwell. “She said, ‘It’s nice seeing someone at the foot of your bed that’s been through the same experience. It gives you a kind of hope: If they made it, I can.’”

What Does Mended Hearts Mean to Patients?
Following the comparative analysis, Mended Hearts and the American College of Cardiology conducted a field survey that looked at how cardiovascular patients were recovering 30 days after discharge from a hospital stay in which they were visited by a Mended Hearts volunteer.

Overall, patients said they found Mended Hearts helpful and were very satisfied with both the visit from volunteers and the educational materials. Southwell says the patients he’s visited appreciate the clear-cut, short-and-sweet nature of...
the organization’s info packets, a welcome alternative to the “overwhelming” three-ring binder the hospital provides.

The survey also found that:

■ More than 90 percent of patients are “very likely” to recommend Mended Hearts to another patient like themselves.
■ More than 50 percent have become Mended Hearts members since their visit.
■ Less than 20 percent were readmitted to the hospital after their earlier stay in which they met with a Mended Hearts volunteer.

Southwell had never heard of the organization until 2011 when he had triple bypass surgery and a Mended Hearts volunteer spoke with his wife while he was in the operating room. After returning home, he attended a few meetings and decided to join. He finds the social aspect of meetings especially important: “It helps to talk to someone 10, 15 or 20 years down the road [post-surgery] and to see them up and going,” he says. “It gives me a lot of confidence.”

In turn, Southwell tries to impart some of that confidence to the younger patients he comes across. He sees denial and depression in some, “especially the younger ones,” he says. “I have a hard time getting through to them because they think it’s over.” Indeed, the ACC patient survey found that 28 percent of patients have suffered from depression recently. Of that 28 percent, half said they’re dealing with the emotional side effect by talking with friends and family, while another 35 percent said they’d joined a support group to help them cope.

“There are so many more patients that need to be reached,” Southwell says. “The Mended Hearts program is making a difference.”

Hott notes that Mended Hearts has had a tremendous impact at her hospital. “Several of my patients are also Mended Hearts volunteers,” she says. “They’re very good about talking to the new heart failure patients and telling them how important the lifestyle changes (cutting back on sodium and fluids, getting exercise) are. We’ve gotten a lot of positive feedback from patients.”

Following a Hunch

Proof of the effectiveness of peer-to-peer cardiac support networks has been largely anecdotal up until now, which is part of the reason Mended Hearts commissioned the comparative analysis of hospitals with Mended Hearts programs versus those without. Mended Hearts wanted to assess the impact of its support programs on patient outcomes.

The study’s conclusions aren’t exactly surprising, given Mended Hearts’ beginning. The organization started in 1951 when heart surgeon Dr. Dwight E. Harken asked four of his post-surgery patients, some of the first people to ever have open-heart surgery, to meet.

“When we have a chronic illness that needs to be managed every single day, we need support from other people to help us stay on the right path.” — Brenda J. Hott, M.D., a cardiologist at The Heart Center of Northeast Georgia Medical Center

Patient Survey Objectives and Methodology

The Mended Hearts Patient Survey was conducted in two phases from February 15 to August 20, 2014. For Phase I, Mended Hearts’ volunteers asked the patients they visited to complete an online survey. A total of 294 patients completed the Phase I survey, providing insight into their perceptions regarding their experience in meeting with a Mended Hearts volunteer at the hospital or care facility.

Phase II consisted of a follow-up survey approximately 30 days after patients’ discharge from the hospital or care facility. This survey gathered information on how patients were recovering and their impressions of Mended Hearts. A total of 94 patients completed the Phase II survey, a 39 percent response rate.

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“We’ve been there, but the dietitians, the nurses and the doctors — they haven’t.” — Tom Southwell, visiting chairman of the Evansville, Indiana, Mended Hearts chapter 107

“I instict told him that people would do better if they could share the experience,” says Packard-Milam. The patients found they had more in common than medical history; they also shared newfound feelings and challenges that had emerged post-surgery. They decided they wanted to help others dealing with heart disease and enlisted Dr. Harken to help them form Mended Hearts.

The organization’s reach has grown exponentially since then — its 20,000 members visited more than 200,000 heart patients last year — but Packard-Milam says awareness of Mended Hearts and its many benefits hasn’t yet reached critical mass. This latest data, she hopes, will expand the network’s visibility to heart patients throughout the country.

What the Study Results Mean for Mended Hearts

Packard-Milam plans to take the study’s data to hospital systems to show how Mended Hearts can help with their unplanned readmission rate. This is especially important in light of Medicare’s new Hospital Readmissions Reduction Program, which penalizes hospitals for heart failure, heart attack, and pneumonia patients who return within 30 days of discharge. Hospitals can lose up to 3 percent of their Medicare payments under the program, which is monitored by the Centers for Medicare & Medicaid Services (CMS).

“Some hospitals see [support programs] as a nicety and not a necessity,” says Packard-Milam. “I would argue that, given the changes in CMS policy regarding early readmission, everybody needs to do everything they can to make sure patients are being managed as they transition from hospital to home so they don’t come back to the hospital too soon.”

She’d also like to use the research to increase the organization’s visibility with cardiac patients. “We have about 4,000 visitor volunteers, each of them trained and accredited — that’s a wonderful point of difference Mended Hearts has that is not duplicated anywhere else,” she says. “We are the largest heart patient peer-to-peer network in the world, with 300 chapters, 20,000 members, and monthly meetings in almost every chapter, but that support system isn’t being tapped into because most patients have never heard of us.”

Mended Hearts’ patient visitors would like to see the data used to expand the organization’s visiting program. Southwell says Mended Hearts has a great relationship with its Evansville, Indiana-area hospitals, particularly the Heart Hospital at Deaconess Gateway (“they are more or less giving us a key…we couldn’t do what we do without them”), and hopes his chapter can use the study’s findings to gain entry into new hospitals where they can build the same kind of rapport.

The more hospitals Mended Hearts can gain entrance into, the more good it can do. “We can help their patients feel more in control and be more optimistic, which will help the patients be more compliant with directions they’re getting from their healthcare providers,” says Packard-Milam. “It’s a win-win all the way around if we can help people be more successful in their heart journeys.”

Chapters win prizes for survey participation

The Mended Hearts Patient Survey would not have been possible without the generous support from local chapters. To drum up as many survey responses as possible, Mended Hearts national offered some incentives. Chapters were eligible to win $50, $100 or the grand prize—a four-night stay at the 2015 Conference hotel for one attendee.

As expected, our chapters delivered. With nearly 300 respondents to the Phase I survey and nearly 100 for the Phase II study, we were thrilled with the participation rate. Mended Hearts national is grateful for the work chapters did on this project and what they continue to do each day in their communities.

At long last, here’s a look at the survey-incentive winners:

Grand Prize
■ Gastonia, North Carolina (Chapter 379)

These chapters received either $100 or $50 incentives
■ Temple, Texas (Chapter 12)
■ Charlotte, North Carolina (Chapter 372)
■ Cookeville, Tennessee (Chapter 127)
■ Lynchburg, Virginia (Chapter 16)
■ Boise, Idaho (Chapter 380)
■ Oak Ridge, Tennessee (Chapter 299)
■ Orlando, Florida (Chapter 296)
■ Evansville, Indiana (Chapter 107)
■ Scottsdale, Arizona (Chapter 126)
■ Northern Virginia (Chapter 200)

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

Proving Our Worth

By Heartbeat Editors

When Mended Hearts volunteers talk about the value of our organization, we’re preaching to the choir. We know how valuable peer-to-peer support is because we live it day in and day out. But our personal experiences need to be backed by evidence—and now we have it, thanks to a two-part survey given to cardiovascular patients. Here’s a look at how the survey was conducted, along with highlights from the survey results.

Survey Objectives and Methodology
The Mended Hearts Patient Surveys were designed to:

- Understand the perceptions of cardiovascular patients regarding their experience in meeting with a Mended Hearts volunteer at the hospital or care facility (Phase I field study)
- Enroll them in a follow up survey concerning their impressions of Mended Hearts to take place approximately 30 days after their discharge from the hospital or care facility (Phase I field study)
- Understand how the Phase I patients were recovering approximately 30 days post-discharge from the hospital or care facility stay in which they were visited by a Mended Hearts volunteer (Phase II study)
- Gather their perceptions about the Mended Hearts organization after the initial visit from the Mended Hearts volunteer (Phase II study)

The patient survey was conducted in two phases from February 15 to August 20, 2014. For Phase I, Mended Hearts volunteers asked the patients they visited to complete an online survey. A total of 294 patients completed the Phase I survey, providing insight into their perceptions regarding their experience in meeting with a Mended Hearts volunteer at the hospital or care facility.

Phase II consisted of a follow-up survey approximately 30 days after patients’ discharge from the hospital or care facility. This survey gathered information on how patients were recovering and their impressions of Mended Hearts. A total of 94 patients completed the Phase II survey, a 39 percent response rate.

Patient Heart Procedure/Condition Resulting in Hospital Treatment
Most patients who met with a Mended Hearts volunteer were recovering from open-heart surgery, either coronary artery bypass graft or valve repair/replacement.
Impact of Mended Hearts Volunteer Visit on Patient Experience
Nine out of 10 patients said that their visit with the Mended Hearts volunteer had a favorable impact on their experience at the hospital/office where they received their care.

Resources/Support Networks Provided by Mended Hearts Visitor
Almost all patients (90%) recall receiving resources from the Mended Hearts visitor, with local Mended Hearts Chapter information (70%) being the most popular.

In What Way Was Your Mended Hearts Volunteer Helpful?
Patients perceived their Mended Hearts volunteer visitors to be helpful in a number of ways.

Helpfulness of Mended Hearts Volunteer
Eighty-nine percent of patients felt that the Mended Hearts volunteer was helpful to them.

Patient Evaluation of Diligence with Self Care
Patients evaluate themselves extremely high in terms of following their medical regimen.

Making sure you are taking the right medications

Being diligent about taking all medications as prescribed

Taking diuretics as prescribed
**Patient Post-Discharge Conditions**
Most patients (76%) have not experienced any new conditions after they were discharged from the hospital. However, approximately 24% of patients have experienced one of these conditions.

**Patient Heart Condition Resulting in Treatment**
Among patients who responded to the Phase II study, which was done approximately 30 days post-discharge, most were being treated for hypertension.

**Patient Readmission and Treatment Procedures**
About 19% of patients were readmitted to the hospital after their earlier hospital visit in which they met with a Mended Hearts visitor. For more than 1 out of 4 of those readmitted patients, no procedures were performed.

**Post-discharge Hospital Readmission? (n=94)**

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**Which Procedures Performed on Readmission? (n=18)**

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Patient Satisfaction with Mended Hearts
Approximately 30 days post-discharge from the visit where they met with the Mended Hearts visitor, patients are overall very satisfied with Mended Hearts. This is true for both the encounter with their Mended Hearts visitor, as well as for the Mended Hearts educational materials that they received. More than 9 out of 10 patients (92%) are extremely/very likely to recommend Mended Hearts to another patient like themselves.

Your Visit With Mended Hearts Volunteer

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Likelihood to Recommend Mended Hearts

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Patient Engagement with Mended Hearts
Sixty-six percent of respondents have been contacted by Mended Hearts after their discharge. Slightly more than half (52%) have become a member of Mended Hearts.

Contact by Mended Hearts After Discharge?

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Become a Member of Mended Hearts?

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Do people who spend more time volunteering enjoy better quality of life and wellbeing? Does volunteering provide benefits to some groups more than others? What explains the positive effects of volunteer visiting on people’s lives?

These were some of the questions to be answered by the collaborative research project between Mended Hearts and Peggy Thoits, Ph.D. member of Chapter 78, Indianapolis, and Professor of Sociology at Indiana University in 2011.

The project unfolded in two stages. In the first stage, a random sample of Mended Hearts chapters across the nation was selected. Visiting chairs distributed questionnaires to their visitors that queried about quality of life and wellbeing. In the second stage, participants who were willing to be interviewed by telephone were asked about the reasons they visit, the types of support they give to patients and families.
Background of Visitors Participating in Survey

Here is a quick summary of the characteristics of the survey respondents:
- The average age was 73, with ages ranging from 41 to 91.
- 96 percent described themselves as white and non-Hispanic.
- About 60 percent were men.
- On average, participants had some years of college; 46 percent had earned a college degree or more.
- The majority were married: 77 percent.
- 23 percent were employed either full-time or part-time.
- On average, respondents reported no financial difficulties or only occasional difficulties, so in general were middle-class.
- The majority were patient visitors: 87 percent.
- Study participants had been Mended Hearts members about eight years, ranging from four months to 36 years.
- Visitors spent an average of three hours per week visiting, with a range from zero (due to illness, traveling, or work demands) to 23 hours.
- 85 percent volunteered for at least one other organization (including church), so were very committed to volunteer work in general.

that are most helpful, and the meaning that visiting has in their lives.

This report focuses on the responses to the questionnaire. Of the 70 chapters that took part in the study, 52 percent of their visitors returned questionnaires (a total of 458 visitors). Although this rate of participation means that the study results cannot be generalized to the entire population of Mended Hearts visitors, the findings do yield insight into the main questions of the project.

Visiting’s Effect on Quality of Life and Wellbeing

Researchers commonly use two measures of subjective quality of life: satisfaction with one’s life in general and overall happiness. The concept of wellbeing includes several aspects of mental and physical health, including high self-esteem, a strong sense of control over life, low levels of psychological distress and good physical health. The questionnaires assessed all of these elements.

Surprisingly, the numbers of hours people spent visiting per week were not associated with a higher quality of life or greater wellbeing. Those who spent one hour a week, those who spent 10 hours, and still others who spent 20 hours were equally satisfied, happy and healthy. It is not the total number of hours that one invests that appears to matter for these positive outcomes.

In general, visitors scored very positively on all life quality and wellbeing indicators:
- For life satisfaction, visitors averaged 4.6 on a 5-point scale (high satisfaction)
- For happiness, the average was 4.5 on a 5-point scale (very happy)
- For self-esteem, the score was 3.7 on a 4-point scale (very high self-esteem)
- For sense of control, visitors averaged 3.3 on a 4-point scale (strong sense of control over life)
- For psychological distress, they scored .21 on a 0 to 4-point scale (virtually no distress)
- For physical health, visitors averaged 3 on a 4-point scale (good, but not excellent, health)

Overall, visitors in the study reported a fine quality of life and enjoyed good mental and physical health that did not vary with the numbers of hours they usually spent visiting.

Does Visiting Benefit Some Groups More Than Others?

Considerable social research has documented the positive mental and physical health consequences of doing volunteer work. Few investigators, however, have examined whether volunteer activities benefit some types of people more than others. Many researchers have claimed that volunteerism fills gaps in people’s lives left by being single, widowed, or retired. If this claim were true, then never married, previously married, and retired individuals should spend more time visiting and gain greater satisfaction and wellbeing from their service activities than married and employed persons.

As it turns out, unmarried persons do not spend more hours visiting than married persons. However, visitors who are unemployed do invest significantly more time, an average of 45 minutes more each week than those who are working for pay.

Do those who are unmarried and retired get greater life satisfaction, happiness, self-esteem, sense of control, and physical health from their time spent visiting, while also experiencing lower psychological distress? The answer once again is a surprising “no.” The idea that volunteer work somehow makes up for the lack of marriage or employment roles is not supported. Unmarried and married persons gain similar life quality and wellbeing benefits from their visiting hours, as do retired and employed persons.

Further analysis showed that only one group profited more from Mended Hearts visiting: relatively younger adults, compared to older adults. With greater numbers of hours spent at the hospital or rehab unit, relatively younger adults (79 or younger) had significantly higher self-esteem, a stronger sense of mastery, and less psychological distress than older adults (80 and older) who volunteered the same number of hours. It seems plausible that a busy visiting schedule combined with advanced age takes a toll on individuals’ overall wellbeing.
What Explains These Effects?
As described earlier, the number of hours invested in visiting did *not* predict participants’ overall quality of life or wellbeing. If the time spent doing this volunteer work does not explain visitors’ obviously good quality of life and robust mental and physical health, what might explain these outcomes?

Research on volunteering suggests that the importance people attach to their service activities and the meanings they derive from this work may play a role. And indeed, upon investigation, this is what the survey data showed. In fact, an unfolding cascade of effects was found.

First, the more hours invested in Mended Hearts visiting, the more participants viewed their visitor role as important to them. The graph below shows the average importance attached to the visitor identity by the number of hours individuals usually spent visiting each week.

Believing that one matters to other people in turn fosters a strong sense of having purpose and meaning in one’s life:

Next, the greater the importance attached to the visitor role, the more participants believed they mattered to other people in general. This can be seen in the following graph:

And finally, the more purpose and meaning in life, the greater one’s quality of life and wellbeing. The following three graphs show the association of purpose and meaning with greater life satisfaction, better health, and lower psychological distress, as examples:

An important role leads to a sense of mattering, mattering leads to a sense of purpose and meaning in life, and having a strong sense of purpose and meaning results in positive life quality and wellbeing.
In short, volunteer visiting with patients and their families results in significantly higher quality of life and superior emotional and physical health when individuals view their visitor role as important to them. All else follows from that: An important role leads to a sense of mattering, mattering leads to a sense of purpose and meaning in life, and having a strong sense of purpose and meaning results in positive life quality and wellbeing.

So what sets this cascade of influences in motion? The number of hours a person usually spends in volunteer visiting. The more hours invested, the more important the visitor role seems to the individual, and good consequences unfold from there.

This study is perhaps the first to uncover how and why volunteer work has positive effects on the quality of life and health of volunteers: It’s not the number of hours spent that directly enhances one’s life, but the importance, meaning, and purpose that one extracts from hours invested in helpful work.

Of course, it is plausible that this cascade of effects could be reversed in sequence: Those who have good quality of life and wellbeing may feel their lives are filled with purpose and meaning which also fosters the belief that they matter to other people. Mattering to others makes the visitor role seem very important to fulfill. The more important the visitor role, then the more hours a person will invest in visiting.

Research suggests that effects can work in both directions, from having wellbeing to giving more volunteer hours and from giving more volunteer hours to gaining more positive wellbeing. The key contribution of this study is to suggest that the importance attached to the volunteer role, a sense of mattering to others, and a belief that one’s life has purpose and meaning help to link the hours spent in volunteer activities with individuals’ quality of life, mental health, and physical health.

These study findings may not surprise Mended Hearts visitors who know from personal experience how and why their lives are enhanced by their visiting activities. But these results will offer new information to social scientists and medical practitioners that help to explain the many benefits that are known to flow from doing volunteer work in general.

Peggy A. Thoits, Ph.D., is a member of Chapter 78, Indianapolis/Circle City. She is the Virginia L. Roberts Professor of Sociology at Indiana University, Bloomington. Her research focuses on the distributions of stress in the adult population, the damaging effects of stressful experiences on people’s physical and mental health, and the sources and types of social support that counteract these harmful effects of stress.
For the generationOn Joy Maker Challenge, Serena Catabia with the Rhode Island MLH chapter built a wooden toy chest with the help of her father and grandfather. She and fellow MLH youth members helped paint the chest and fill it with toys for their local pediatric heart clinic.

Participants in the MLH chapter in Richmond, Va., made artwork to help spruce up the office of a cardiology practice that serves pediatric patients.

Work of Heart

MLH kids, tweens and teens step up to help CHD families during a nationwide service campaign.

By Maria Carter

If anyone knows what it’s like to rely on the kindness of strangers, congenital heart disease families do. Whether it’s the nurse who cracks a joke during a tough moment or a nonprofit that brings you a bag full of helpful items during your hospital stay, community support can ease the stress of a medical emergency.

It’s the memory of these acts of kindness that struck a chord with some of Mended Little Heart’s youngest members when they were approached by youth volunteer organization generationOn last fall. MLH agreed to join the organization’s Joy Maker Challenge, a holiday volunteering initiative that connects students in grades K-12 to hands-on service projects from Nov. 10 through Dec. 19.

Overall, 9 MLH chapters from eight states, 72 kids and teens, heeded the call. Their efforts brought in nearly 300 donations for Toys for Tots and benefitted local children’s hospitals, Ronald McDonald House Charities, and more.

‘Season of Service’

“The Joy Maker Challenge is positioned to both inspire kids to step up and volunteer within their school and communities, and also equip them with planning tools, project ideas, and stories of other kids and the work they’re doing in their communities,” says Daniel Horgan, executive director of generationOn.

“Around the holidays, kids, parents and teachers are often looking for ways to give back to the community — it’s what we call the ‘Season of Service,’” he adds.
By the Numbers

Here’s a look at how MLH chapters participated in generationOn’s Joy Maker Challenge.

9 local MLH chapters were involved
8 states were represented
72 kids and teens volunteered
2 official Joy Maker Challenge ambassadors
2 chapters awarded Runners Up finalists
272 toys donated
$500 in grants received

The Joy Maker Challenge is an annual event now going on its 6th year, yet 2014 was MLH’s first time participating. Former MLH National Conference keynote speaker Jennifer Page put the two organizations in touch. Page’s son Max — best known for his role as “mini Darth Vader” in a Super Bowl commercial for Volkswagen — has Tetralogy of Fallot, a congenital heart defect that affects the function of his pulmonary valve. He’s also a celebrity ambassador for generationOn.

“Jennifer’s amazing about figuring out where people fit well together,” says MLH national program director Jodi Lemacks. “She saw that Mended Little Hearts is about kids empowering other kids, families helping families, and that’s what the Joy Maker Challenge is about.”

Doubling the Impact

Hasbro Toys sponsored the challenge: For every act of service registered with generationOn, Hasbro donated a toy or game to Toys for Tots on a national level, up to $1 million dollars’ worth. “Essentially they’re doubling their impact,” Horgan says. “It’s a very cool one-to-one match.”

MLH’s official Joy Maker Challenge Ambassadors — Allison Hageman, 17, of Little Rock, and Serena Catabia, 12, of Rhode Island — each received 100 Hasbro toys to gift to the charity of their choice. Hageman split her donation between Arkansas Children’s Hospital and the Ronald McDonald House, and Catabia gave hers to a pediatric heart clinic in Providence.

For the service component of the challenge, MLH’s youth chose projects in areas they felt most passionate about. “What’s unique about Joy Maker is that kids can do anything,” Horgan says. There are no parameters on the type of volunteer work participants can pursue — it’s up to the students to decide how they want to spend their time and resources, and what community service means to them.

A Theme Emerges

Although MLH chapters chose their projects individually, a theme emerged. While participants representing other organizations served meals at homeless shelters, spruced up public spaces, and spent time at nursing homes, MLH’s youth chose to help children and families facing long hours in doctors’ offices and hospital rooms — an experience they know all too well.

Elizabeth Liddell, 13, and Samuel Walker, 10, in Winston-Salem, N.C., chose to collect food and toiletry items for the Ronald McDonald room at their local children’s hospital. “They remember their own parents staying in that room,” says Valerie King, lead coordinator of the Winston-Salem chapter, speaking of the accommodations funded by the burger chain’s charity so parents of patients can rest under the same roof as their kids.

Liddell and Walker considered service projects such as collecting blankets or doing a Bravery Bag drive but ultimately decided they wanted to give back to the Ronald McDonald House. The thought of all the little things families need but often don’t get when they’re at the hospital was a driving factor. “There was no push from their parents,” King says. “They decided on their own.”

Walker, who is home-schooled, reached out to churches and businesses in his hometown of King, N.C., collecting two red wagons’ worth of non-perishable grocery items.

Liddell went to her school and her parents’ workplaces for the help with the cause. Her school rallied behind her, getting

“There was no push from their parents. They decided on their own.”

— Valerie King, lead coordinator of the Winston-Salem Mended Little Hearts group
“It’s groups like MLH that have organized their national chapters to participate that really have helped us to gain momentum and create that bigger impact in the community.”
— Daniel Horgan, executive director of generationOn

the word out and soliciting donations on Liddell’s behalf. The request spread quickly and supplies poured in. Someone at the school connected with Delta Airlines, which then sent a jumbo-sized box of personal toiletry kits, each packed with a sleep mask, toothbrush and toothpaste — perfect staples for air travel and, more importantly, sleepless hospital stays. By the end of the challenge, Liddell had collected five grocery carts of food and personal items to restock the Ronald McDonald room.

Role Models for Younger Kids
King says Liddell and Walker are role models who come to every MLH activity and talk with the younger kids. “Our 5- and 6-year-olds look up to them,” she says.

MLH chapters elsewhere pursued their own channels of generosity. The Richmond, Va., group wanted to make a local cardiologist’s office more kid-friendly for young patients facing scary appointments, so they created colorful art pieces to spruce up its waiting room and cardiac catheterization lab.

Another group, South Central Illinois, made dozens of no-sew fleece blankets for children in hospitals. Serena Catabia built a wooden toy chest with the help of her father and grandfather; fellow MLH youth members helped paint the chest and fill it with toys for their local pediatric heart clinic.

Breaking Records
Post-campaign, the good will keeps on going. Two MLH groups, Winston-Salem and Rhode Island, were chosen as runners up and granted $250 toward continuing their community service. King says her chapter’s grant will go directly to CHD patients: “Ninety percent of our funds go back to our families, through Bravery Bags, supplies at medical centers, and social events.”

MLH assisted generationOn in achieving record-breaking numbers, too. The organization’s goal was to mobilize 100,000 kids across the country during the 2014 campaign; they ended the campaign with the participation of more than 129,000 kids.

“It’s groups like MLH that have organized their national chapters to participate that really have helped us to gain momentum and create that bigger impact in the community,” Horgan says.

Maria Carter is a health and lifestyle writer living in New York City. She has contributed to more than 40 different publications including Vegetarian Times, the L.A. Times, MensJournal.com, and more. Visit her online at mariacarter.net.
Not long ago, support groups for parents of children with congenital heart defects were few and far between. Leslie Sams found herself “in a whirlwind” of medical information and difficult emotions after the birth of her son, Caleb, now age 5. Caleb has transposition of the great arteries — a rare heart defect requiring immediate medical attention that had not been diagnosed prenatally. “I was looking for support,” Sams says. “There wasn’t a lot in Cincinnati.”

Although MLH spans more than 85 groups in 33 states, too many CHD parents still find themselves in situations that mirror Sams’ experience. MLH leaders hope to reconcile that — soon.

How will this happen? More regional support, for starters. Last August, MLH leaders took a big step by creating a new volunteer position to serve local chapters. They appointed eight assistant regional directors, including Sams (Central region) and Julia Rowbotham (Northeast), each tasked with the shepherding of eight to 18 local groups.

Who’s Your ARD?

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Check out our Regional Map on page 2 to find out who your Assistant Regional Director is.

How Your ARD Can Help

- **Encouragement.** Sams calls herself a “cheerleader” for the coordinators in her region. “The groups I’m working with are already doing great work, so a lot of what I’m doing is just being in their corner” and expressing gratitude for their efforts.

- **Group development.** ARDs assist with the formation of new groups as well as development of already-established groups. One of the groups Sams supports had gone through a dormant phase and was just getting back on track when she became ARD. “I’ve been... encouraging them to get started again,” she says.

- **Meeting attendance.** Families affected by CHD are busy. “We have children with special needs, and many of us work full-time jobs as well,” says Rowbotham, who’s also lead coordinator of the Philadelphia region and mom of Lily, age 8, who has hypoplastic left heart syndrome. Low attendance at support meetings is a common challenge. Rowbotham says that, sometimes, not having a meeting at all is best. Connecting over social media and email and hosting family-friendly events are often better for reaching members.

- **Connecting with national.** ARDs add “another layer of communication for national efforts,” says Sams. “I encourage local leaders to promote national events. It’s also a great opportunity to let national leadership know what’s happening here — some of the local groups are doing awesome things.”

Maria Carter is a health and lifestyle writer living in New York City. She has contributed to more than 40 different publications including Vegetarian Times, the L.A. Times, MensJournal.com and more. Visit her online at mariacarter.net.
Arnold Palmer is one of the world’s greatest professional golfers; Kevin Nealon is one of his generation’s acclaimed actors/comedians. Though seemingly worlds apart, they’ve experienced conditions that raise their chances for developing blood clots and/or having a stroke. The unlikely duo has set out to inspire people to understand the importance of prevention and treatment — and their efforts will earn a donation to Mended Hearts.

They’ve teamed up with Janssen Pharmaceuticals Inc., to raise awareness about deep vein thrombosis, or DVT, which is when a blood clot forms in a deep vein in the body, and atrial fibrillation, or AFib, an irregular heartbeat that puts people with the condition at a five times greater risk for having a blood clot that could cause a stroke. Videos featuring their own personal stories are on www.Drive4Clots.com, and for every view they receive, Janssen will make a donation to Mended Hearts.

‘Being an Athlete Doesn’t Make You Immune’
Palmer is one of up to 900,000 Americans who have experienced a blood clot caused by DVT. As many as 300,000 people die every year from the condition.

“I’m fortunate that my DVT was diagnosed and treated before it led to something even more serious,” Palmer said. “Being an athlete or an active person doesn’t make you immune to blood clots. They can happen to anyone at any time.”

Always quick to make a joke, Kevin Nealon chalked up his first symptoms of non-valvular AFib to a pounding heart that came from trying to impress his future wife.

Fast Heart Beat Was No Joke
“We were on vacation, and I was attempting to ignore the age difference between us by acting energetic — playing volleyball, water skiing, and only resting for short naps,” said Nealon, who’s best known as a cast member of Saturday Night Live from 1986 to 1995. “Suddenly, I couldn’t keep up anymore. My heart was beating so fast that I became concerned and had to see the hotel doctor. I was later diagnosed with AFib, and quickly realized it was no laughing matter.”

Both Palmer and Nealon were told by their doctors that they needed to take a blood thinner to prevent future clots from forming. They also learned that there are treatment options available that don’t require regular blood monitoring or carry any known dietary restrictions.

“Arnold and I worked closely with our doctors to find a treatment that was right for us,” said Nealon. “For people with AFib or DVT who are at risk for blood clots and need to be on blood thinners, talk to your doctors to understand the options and the benefits and risks of treatment.”

Heart Disease Doesn’t Discriminate
“Blood clots do not discriminate based on age, sex, fame or lifestyle,” said Michele Packard-Milam, CAE, executive director of Mended Hearts. “We encourage people to visit the website, learn about DVT and AFib, and help raise money that will make a difference for the millions of Americans living with or who are at risk for blood clots and stroke.”

Visit www.Drive4Clots.com for more information.
Historical Hearts

Mended Hearts Chapter Anniversaries
June – August 2015

45 years
Dayton, OH · Chapter 61 · Central Region

40 years
San Mateo County, CA · Chapter 26 · Western Region

25 years
Joliet, IL · Chapter 129 · Midwest Region

20 years
Calumet/Munster, IN · Chapter 268 · Central Region
Charleston, SC · Chapter 266 · Mid-Atlantic Region

15 years
Montgomery, AL · Chapter 83 · Southern Region

10 years
Barrington, IL · Chapter 337 · Midwest Region

5 years
New Albany, IN · Chapter 366 · Central Region
St. Charles County/St. Peters, MO · Chapter 369 · Midwest Region
Suffern, NY · Chapter 368 · Northeast Region
Wakefield/South County, RI · Chapter 365 · Northeast Region

Mended Little Hearts Anniversaries
June – August 2015

5 years
Mended Little Hearts of Colorado Springs, CO · Southwest Region
Mended Little Hearts of Sacramento, CA · Western Region
Mended Little Hearts of Western, NY · Northeast Region

Speakers Bureau

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

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

To request a speaker for your group, please contact Mended Hearts at 1-888-HEART99 (1-888-432-7899) or at info@mendedhearts.org.
The Secret to Gastonia Chapter’s Success?

Good Old-Fashioned Face-to-Face Interaction

By Kimberly Turner

Mended Hearts Chapter 379 of Gastonia, North Carolina, is not just a chapter, it’s a tight-knit community of friends and neighbors. They conduct their hospital visits in pairs, making sure to vary the combinations of people so that everyone meets and gets to know one another. They focus their newsletter on hometown stories, sharing personal anecdotes from members and articles written by the medical staff at local CaroMont Regional Medical Center. (“Why would I want to go outside the local chapter for our news when we have so many interesting people with stories to tell?” asks Chapter President Jake Gray.) And they hold enough lakeside picnics, golf tournaments, walks with docs, and other fun events that it would be easy to assume that they’re too busy socializing to get much else done — but nothing could be further from the truth.

To call the Gastonia chapter productive would be a massive understatement. In less than four years, the busy young chapter has managed to sign up more than 125 people and gather more than 60 accredited visitors. Even more remarkable, those enthusiastic visitors logged an impressive 1,921 visits in 2014. In a single month (December 2014), they visited 215 patients and their families, including 155 first-time visits and 50 follow-ups, and handed out 91 HeartPacks with information on heart procedures, recovery suggestions, rehab benefits, and caregiver guidelines. And that’s not all: The chapter managed to turn in so many surveys to Mended Hearts national that they were able to earn a four-night hotel stay to the national conference being held from June 24 through June 27 in Orlando, Florida, for one member.

Gastonia gets a lot of love from the community in the form of financial support too, and that allows them to carry out some unique assistance programs. Take, for example, their exceptionally successful scholarship program. In just three years, the scholarship for first-time and continuing nursing students has grown from a fund of $3,500 a year to around $15,000 to $16,000 for 2015. Eight nursing students received scholarships in 2014. Gastonia also coordinates an annual Heart Walk, a Run for the Money race (which raised $5,150 for last year’s scholarship), and a cardiac rehab assistance program that helps patients who would not otherwise be able to afford their deductibles. “We have a lot of contributors,” says Gray, “We’ve gotta spend the money. People give us money and we are always trying to find the very best ways to spend it.”

Chapter 379 is, in short, remarkably inspiring. So how do they do it? The old-fashioned way. The chapter does not have a fancy website, an active online community, or even a social media presence… but then again, they evidently don’t need it. “If I want you to know about something, I’ll call you or email you.” And he does exactly that. Turns out, you don’t have to use social media and technology if you have an army of caring and dedicated men and women on your side.

“We’ve got a great membership,” says Gray. “They are very motivated. We have so many visitors for just one hospital, so each visitor only visits one or two times a month. That way, it’s not a burden on them, but it is enough to keep them engaged.”

— Chapter President Jake Gray
new visitors all the time. We are our own little community.”

CaroMont Regional Medical Center — the hospital that is served by Chapter 379 — makes it easy to recruit those new members and visitors. “The people we visit in the hospital get interested in Mended Hearts. Remember now that we’re not working with a destination hospital; we’re in a community hospital, so most of the patients are from this area in North Carolina,” explains Gray. “So we know that when we visit somebody, we are generally going to see them again. And therefore, it is easier to recruit and engage members than it would be in a hospital that’s a destination where people are coming from far away to have their surgery or whatever. It has worked out very well. It’s a nice thing. The membership, they’re just great. We have people doing some wonderful work.”

CaroMont and its patients are benefiting tremendously from the work of the Gastonia chapter, but that’s only fair because they actually helped to make it a reality. While the majority of Mended Hearts chapters are founded by heart patients or their caregivers, Gastonia’s chapter was the brainchild of the medical center staff. “We’re a unique chapter because the hospital went out seeking a Mended Hearts chapter, rather than the other way around,” recalls Gray. “They initiated the process, and it just grew from there. It was quite a cooperative thing... and still is to this day. They really are 100 percent behind our chapter and our work.”

Gary Mims, cardiac rehabilitation manager at CaroMont understands the chapter’s importance: “The value of Mended Hearts volunteers goes beyond simply providing support to people who have or will be undergoing cardiac procedures. By hearing advice from the perspective of someone who has been there, patients are more likely to take a positive approach to their heart disease, attend cardiac rehabilitation, and begin living a new and healthier lifestyle.”

Jake Gray has been involved with the burgeoning chapter from its very first day. He was recruited by a friend, a CaroMont cardiac nurse, while he was in rehab after undergoing a bypass surgery just a few weeks prior to his seventieth birthday. He agreed to make the first visits, and just three weeks later, his friend/nurse asked him to be president of the new organization. “She’s the kind of gal you can’t say no to,” he laughs. “All of our members just love the cardiac rehab staff to death. I mean, they’re just the greatest.”

These days, the Mended Hearts chapter conducts visits six days a week and does special drop-ins (with special goodie bags for both patients and staff members) on major holidays. Gastonia has recently been able to put all heart patients of any type on their visit list, a move that gives them the opportunity to help many more people with heart disease.

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. She has served as associate editor of Curbed Atlanta, managing editor of Atlanta magazine, and managing editor of multiple titles at Australia’s second-largest magazine publisher. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
Mended *Little* Hearts

Groups on the Move: Little Rock, Arkansas

With solid connections to each other online, a group of parents with children who have CHDs decide to form a MLH group. And two years later, they’re steadily growing.

By Kimberly Turner

Founder and outgoing lead coordinator Dana Brock Hageman — who is now both advocacy and outreach coordinator for MLH of Little Rock and assistant director of the Southern region — organized and ran an online support group for parents of children with congenital heart defects for several months before realizing that they needed more resources. “Mended *Little* Hearts national offered a lot of benefits,” she explains. “They had already done all the base work, so why reinvent the wheel? It was nice having a nationally recognized name and a group with infrastructure that we could turn to when we had questions that we couldn’t answer.”

Hageman credits that pre-charter work and online support group with some of the MLH of Little Rock’s success and rapid growth. “We already had the outreach and contacts with other parents before we even started, so I’d like to say we’ve gotten through our growth phase fairly quickly, but I’m sure there’s more to come. I just really think we’ve been fortunate to have cooperation and coordination from the start.”

A (Mostly) Virtual Network

The virtual genesis of MLH Little Rock is fitting because even today, thanks to the group’s expansive coverage area, much of their work does not occur face-to-face. Most visits happen via phone call or online because their local hospital does not allow in-person visits — at least not yet. Incoming lead coordinator Erica O’Neill says, “That’s one of the things that makes us unique. As of right now, the hospital isn’t on board with us, but we have still been able to succeed and touch so many people’s lives all over the state.”

Hageman elaborates: “It’s against the hospital rules for us to just reach out to parents because they have a child in the hospital. They have to find us — but we are working on that. I meet with a lot of parents, usually after they are out of the hospital and out of that immediately critical stage.”

In addition to meetings every other month, which not every member can get to because of the distance, the group has plenty of other activities throughout the year. They work with the American Heart Association on a Heart Walk and on a sister event called Hearts on Wheels that focuses specifically on congenital heart defects. The Hearts on Wheels tricycle race...
pits cardiologists against the kids. According to Hageman, “It gives the cardiologists a chance to see our children when they’re not in a clinic setting — to see them how they are on a normal day-to-day basis — and it gives us a chance to meet the cardiologists when they’re not wrapped up in white coats. It brings it down to a more personal level.”

**Swapping Stories About the ‘Zipper’**
The group also holds holiday parties and events such as outings to minor league baseball games. O’Neill says the ball game social will be something they do again in 2015. “It was great because it got the dads involved as well,” she says. For the last two years, M.L.H of Little Rock has also hosted a Halloween pumpkin patch/hay ride day. Events like these let kids get together and see that they are not the only one with that big scar they call “The Zipper” or with a story about undergoing a catheter procedure. They also allow parents to ask all those nagging little questions that they wonder about every day. Hageman says, “It’s really easy for a parent in that position to think, ‘I’m going crazy’ or ‘I’m being paranoid’ until you come together with all these other parents who say, ‘No, that’s not paranoid. That’s just your new normal.’”

Hageman understands the concerns and stresses associated with having a child with congenital heart defects all too well. Two of her children were born with pulmonary atresia with intact ventricular septum. Without pulmonary valves, they started turning blue as soon as they were born and were quickly whisked away for surgeries that Hageman was warned that they had only a 50 percent chance of surviving. She was told that her daughter, now 17 years old, had a 40 percent chance of making it to age 5 and that her son, now 7, had a 60 percent chance.

**Rethinking ‘Picture Perfect’**
“I think a lot of parents suffer from basically a form of post-traumatic stress disorder,” she says. “They are thrown from, ‘Okay, we’re going to the hospital to have a baby!’ to all of a sudden, ‘We’re not going home. We’re going to another hospital.’ You’re in this extreme situation where you have to make decisions you’ve never thought about — never knew about — and then when you get home, you expect everything to go back to that perfect picture life, but it’s not there. You don’t go into surgery, go home, and you’re all done. It’s not something that just goes away. It’s life changing. There’s a lot of stress involved in that, and a lot of parents reach out for coping mechanisms that aren’t the best for them because they just don’t have other options, so I think our support group gives them somewhere safe to go and hopefully helps them through that without the other options.”

“I tell parents that there’s hope,” she says. “It’s there. Mine have made it through. All the procedures are improving. All the statistics are improving. I basically just tell them not to give up. I know I can’t tell them that it’s all going to be okay because I’ve seen the situations where it’s not all okay, but I can tell them there’s hope.”

And often, it is the adults who need the most reassurance. “Kids are very resilient,” says Hageman. “Adults are… well, we’re very worry-prone. It’s hard enough worrying about normal risks, but when there are additional risks added on, it takes worry to a whole new level. Especially as they become teenagers, you have to tell them that drinking could be an added danger, drugs could be an added danger, pregnancy could be an added danger, even more so than you would with a normal child. Yet you don’t want to walk around telling them, ‘Your heart could kill you any minute.’ That’s not the message you want to convey.”

“You want to stop all that hurt and all that danger, but you can’t always do it because you can’t lock them in the basement,” she jokes. “It’s not allowed… as much as you might want to.”

As for the kids, Hageman’s 17-year-old may have put it best when she was put on the spot and asked in front of a group of people what it was like to live with congenital heart defects. “Um, I don’t know because I live with them. I’ve never known any other way. I live with them, so I would assume anybody could.”

Kimberly Turner is a writer and editor who has written for dozens of publications in the U.S. and Australia. She has served as associate editor of Curbed Atlanta, managing editor of Atlanta magazine, and managing editor of multiple titles at Australia’s second-largest magazine publisher. Currently, she is editorial director of WellATL, an online health and wellness publication she cofounded.
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Special thanks to the following contributors for their gifts to Mended Hearts and Mended Little Hearts from November 15, 2014 – February 2, 2015

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**Heartbeat**
Spring 2015

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This year’s conference will offer invaluable sessions and breakout seminars. Keynote speakers will lead in heart-related topics for the patient, caregiver and parents of children with CHD. Exhibitors will include sponsors and vendors who will be offering an opportunity to ask questions and gather heart materials. New this year will be a Symposium for an opportunity to join the conference one day to hear the latest heart news.

When planning your trip to Orlando, consider coming in early or extending your stay. Invite your family to join you to enjoy all that Orlando offers!

Online registration is now available at http://mendedhearts.org/conference.htm, or call 1-888-432-7899 for additional information.