Back to Our Roots: Little hearts hold big hopes

Mended Little Hearts’ many volunteers and its staff work together to make the world a better place for children, adults and families affected by congenital heart defects/disease. Today, where people connect more and more online and through technology, Mended Little Hearts works to get back to its simple roots of fostering peer-to-peer connections that change lives. Here, we share with you some of our 2017-8 accomplishments.
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WHO WE ARE

Mission
Mended Little Hearts empowers families affected by congenital heart defects/disease (CHD) through peer-to-peer support, education, awareness, advocacy, and connecting them to needed resources.

Vision
All families and patients affected by CHDs are able to share experiences and resources as members of a nationwide peer-to-peer support network.

“The Importance of Support
When your child is diagnosed with a heart problem, Mended Little Hearts is there. Each year, about 40,000 babies (1 in 110) will be born with a congenital heart defect—the nation’s most common birth defect. Parents are thrust into a world of medical terms, procedures, medications, and equipment that they often have never even heard of—it can be terrifying.

Mended Little Hearts members understand those feelings and know how to help because they have been there themselves. To many, that cherished connection with a Mended Little Hearts volunteer is a lifeline—it lets them know they are not alone and gives them hope for the future.

Looking Ahead
Mened Little Hearts continues to expand its programs and services to reach more families. In this world of technology, much of this expansion has been online to meet people where they are. We fully expect this expansion to continue, and for Mended Little Hearts to continue to be a trusted name in healthcare communities.
Back to Our Roots

My Vision for Mended Little Hearts

Angel Olvera, VP Mended Little Hearts

When I think about the future of Mended Little Hearts, I see great things ahead, but I also know this will only happen when we all work together as a cohesive organization. Therefore, I plan to make sure our future is bright by not only supporting our outstanding programs and services, but also by seeking more opportunities for our chapters and our national organization to work together towards this common vision.

I have four main goals for Mended Little Hearts over the next two years, and I'm confident if we accomplish these goals. We will increase our outreach, improve our services to our communities, hospitals and cardiology practices we serve, and be a stronger, more robust organization.

The goals are:

1. To share our mission, accomplishments and our purpose. Many people who have been touched by Mended Little Hearts understand the power of the peer-to-peer support we provide, so we need to collect and share more data to analytically capture all of the amazing things we do to improve the lives of those affected by congenital heart defects/disease.

2. To create MLH national fundraisers in order to unite CHD families, build MLH awareness and CHD in more communities, and to raise funds for important programs like our Bravery Bag Program, educational conferences, awareness campaigns, and our other services for families.

3. To grow our organization by building partnerships. Mended Little Hearts understands that we are stronger working together. Building partnerships allows us to be better advocates for the families we serve and to provide more support and resources.

4. To build collaboration with groups and the commitment from the National office so that we are ready to tackle all of the important tasks we need to accomplish.

Mended Little Hearts has hundreds of passionate volunteer leaders who donate their time and talents to help others. This dedication and commitment from our volunteers I know that Mended Little Hearts will accomplish these goals and thrive.

“It’s not what we have in life but who we have in our life that matters.”

Margaret Laurence
Bringing People Together

My Vision for Mended Little Hearts

Norm Linsky, Executive Director, Mended Hearts

Since I became Executive Director in 2017, I have had one main goal—to bring people together for the benefit of all. I believe that one of the biggest strengths of Mended Hearts and its vital program, Mended Little Hearts, is that we support patients and families from before a child is born with a heart problem throughout their entire lifetime, and we even have a bereavement program for families whose child has passed. Together, we also support patients, caregivers and families affected by every type of cardiovascular disease. In fact, Mended Hearts and Mended Little Hearts make up the world’s largest cardiovascular disease support organization.

My vision for the future is to continue bringing Mended Hearts and Mended Little Hearts together to create a stronger, more unified organization with a variety of programs and services to meet the needs of our members and our communities. Of course, we will continue to do this with an understanding of the unique needs of people affected by different types of heart disease, including congenital heart disease, and also the unique needs of people from different generations, different access to resources, and different demographics. An example of a program we are currently working on is a transition program for teens and young adults with congenital heart defects because we recognized a gap that needs to be filled to create continuity of care. My vision also includes connecting our local chapters more with the national organization to create a bigger impact overall.

I believe that people working together can do far greater things than working independently. I know that the Mended Little Hearts program will continue to grow and thrive, and I will do everything in my power to help them do just that.

“You just can’t beat the person who never gives up.”

Babe Ruth
OUR PEOPLE

Mended Little Hearts is governed by a volunteer Steering Committee that serves under the leadership of MLH VP, Angel Olvera, who is a member of the Mended Hearts Board and Executive Committee.

Steering Committee

➢ Angel Olvera, MLH VP
➢ Beth Gray, MLH Board Director
➢ Andrea Francis, Advocacy Co-Chair
➢ Dana Hageman, Advocacy Co-Chair
➢ Sharee McCoy, Bereavement Chair
➢ Shannan Pearsall, Social Media Chair
➢ Emily Schaffhausen, Events Chair
➢ Len Schendel, Technology Chair
➢ Michele Bowers, Northeastern Regional Director
➢ Jenna Kidd, Mid-Western Regional Director
➢ Nicole Sanchez, Western Regional Director
➢ Candida Schendel, Southwestern Regional Director

Our Volunteers

Many people believe that Mended Little Hearts has a huge staff, but our national staff for Mended Hearts and Mended Little Hearts together is only 12 people. The reason people believe this is because our volunteers work like staff to make the Mended Little Hearts program outstanding. As of the end of 2017, Mended Little Hearts had 83 chapters. Each chapter is led by a team of volunteers who do everything from one-on-one support to families, to educational and support group meetings, to CHD awareness events, to Bravery Bag and hospital programs, to advocacy, and so much more. We may be biased, but we believe our volunteers are the best anywhere. Many of them have taken a difficult and often painful situation in their lives and used it as an opportunity to give back and help others. They are committed, dedicated, creative, and don’t let anything stop them. We simply would not be the program we are without them.
OUR SERVICES

Since 2004, Mended *Little* Hearts has provided children with congenital heart defects/disease and their families programs and services that directly improve their quality of life.

**Peer-to-Peer Support**

Nothing can replace in-person connections with others traveling on a similar journey. M/LH creates opportunities for families and patients to connect with and support each other in their local communities, share experiences and learn about helpful information and resources. Some of these opportunities include:

- Support group meetings
- Online and social media connections
- Fun activities for families
- Fundraising events
- Service events
- CHD Awareness activities

**Education**

Mended *Little* Hearts educates families through educational programs and educational resources so they have the information they need to make important decisions and care for themselves and their child in the hospital and at home.

Key Mended *Little* Hearts resources are:

- The Mended *Little* HeartGuide digital resource (English & Spanish)
- Webinars
- Annual CHD Symposium
- Health Fairs and Health educational program for local communities

**Hospital Outreach**

Mended *Little* Hearts works with hospitals and healthcare professionals to provide these important programs to support families when they need it the most:
• Accredited Visiting Programs (where available)
• Serving on Family and Patient Councils
• Bravery Bag Programs
  o Bravery Bags provide families in the hospital with toiletries and comfort items, but it is so much more than just a bag—it is a lifeline to many
• Bravery Chest Programs
  o Bravery Chests are chests full of toys for children to choose from after a cardiology appointment
• In-Hospital Peer Support Services
• Angel Box Programs
  o Angel Boxes are boxes full of items for families who have lost children with CHD. They are created by families who have actually lost children and truly understand what is needed.

CHD Awareness Initiatives

Most people are unaware that congenital heart defects (CHDs) are the most common birth defects in the United States. As a result, families often don’t get the vital information and support they need. Mended Little Hearts has national and local CHD Awareness activities.

Some national CHD awareness events are:

- Rock Your Scar Campaign
- Power of Pictures Campaign
- Roar ‘N Run Virtual Charity Race
- Remember Our Hearts Campaign
- Day of Remembrance
- Candlelight Vigil
- Rock the Beat 5K and Fun Run (new in 2018)
- CHD Awareness Week
- Take 5/Give 5 Campaign

Bereavement Services

Mended Little Hearts honors and celebrates the many children and adults with CHD who don’t survive—our CHD Angels. Families who have lost children with CHD need connection, support and other resources maybe more than anyone. Mended Little Hearts works to meet these needs through online and in-person connection and support services and resources for bereaved families.
In addition to our Remember Our Hearts awareness campaign and our signature Angel Box program for families who have lost children to CHD, in 2018 Mended Little Hearts created the first Remember Our Hearts Charm with a card that groups give to families who have lost children either as part of an Angel Box or on its own.

**Online Connections**

Hospital stays and seclusion in the home can leave families and patients who have children with congenital heart disease feeling helpless and alone. Thus, Mended Little Hearts has created a variety of ways to meet people where they are and connect with them online—through our website, through social media, and through digital resources. Our online connections include:

- National and group websites
- Parent matching
- Social media venues: Facebook, Twitter, Instagram, LinkedIn
- National closed Facebook groups
  - MLH CHD Chat for all CHD patients and families
  - Mended Little Hearts Angels for parents and family members who have lost children
  - CHD Chat for Teens for CHD patients ages 18-25 only
  - Online Community Forums

**Advocacy**

Mended Little Hearts, as part of Mended Hearts Patient Advocacy Network (PAN) advocates on issues that help families with CHD, such as newborn screening, CPR in schools, research funding, patient protections and improved surveillance of CHD patients.

Mended Little Hearts believes that advocacy occurs in a variety of settings including a parent advocating for treatment or care of his or her child, Mended Little Hearts members raising awareness of issues CHD families face, public speaking engagements in the media and at events, writing editorials and informative pieces about living with CHD, and, of course, meeting with local and federal policy makers.
OUR IMPACT

Between 2-4 million families are affected by CHD in the United States alone. This creates a huge need for the services that Mended Little Hearts provides—support, education, awareness, hospital programs, and advocacy. Mended Little Hearts’ true impact goes far beyond what is written here because our most important and meaningful impact cannot be captured in reports and numbers. However, we are proud to report some of our accomplishments for 2017-8 with you.

Connections—Hope, Help, Healing

The core service of Mended Little Hearts is to connect people with their peers to give them hope, to help them, and to promote healing. We connect people at a local and national level, online and in person. Mended Little Hearts connects through:

➢ 77 communities served
➢ 8,752 Members
➢ 113 Parent Matches
➢ 1,957 Members MLH CHD Chat Closed Facebook Group
➢ 15 Members CHD Chat for Teens and Young Adults (NEW)
➢ 344 Members Little Angels Closed Facebook Group
➢ 600+ Members in our Online Communities

Education

Throughout the year, Mended Little Hearts works to provide educational opportunities and resources for families in our local communities and nationally. Some of our national educational programs include:

- 2017 CHD Symposium in Houston, Texas hosted by Texas Children’s Hospital
  - 150 Attendees
  - Over 1,000 watching on Facebook Live (on average)
  - Over 10,000 views after the CHD Symposium

- Mended Little HeartGuide and Mended Little HeartGuide Lite
  - The Mended Little HeartGuide is a digital parent resource available in both English and Spanish with downloadable, writable forms. We had over 3,000 people viewing the Mended Little HeartGuide in 2017.
  - The Mended Little HeartGuide Lite is an abbreviated printed version of the Mended Little HeartGuide (in both English and Spanish) available at no cost to hospitals. We gave out over 2,700 from August to December 2017.

- Webinars
Mended Little Hearts hosted two educational webinars in 2017 with almost 400 views. They were on Parent Stress and Family Support and The FUEL Trail: Clinical Trial for Fontan Patients (co-hosted by Sisters by Heart and the Pediatric Heart Network of the National Institutes of Health).

**CHD Awareness**

Another main goal of Mended Little Hearts is to create CHD Awareness so that families learn about congenital heart disease and can get connected to needed support, information and resources. In 2017 and 2018, as usual, Mended Little Hearts rocked CHD Awareness! Here is how:

- 50,032 Followers on our National Facebook Page
- During CHD Awareness Week (Feb. 7-14) we reached over half a million people (505,513) with 103,291 on February 12 and 73,098 on February 13 alone!!
- 84,617 Followers on Facebook locally and nationally combined
- 5,187 Followers on Twitter
- 4,160 Followers on Instagram
- 500+ Connections on LinkedIn
- We created a CHD Toolkit for all chapters with Press Releases, CHD Awareness Facts, Sample Proclamations, CHD Awareness Ideas (Tried & True), Letters to the Editor and more. Most Mended Little Hearts groups had events and activities in their communities to raise awareness.
- The Day of Remembrance on October 25 reached over 48,000 people
- Candlelight Vigil for CHD Angels on February 11 reached over 52,000 people
- We created a new Remember Our Hearts charm and Giving Band for families who have lost children to CHD
- Roar ‘N Run Virtual Charity Race had almost 300 participants and raised over $26,000!
- Rock Your Scar Awareness Campaign reached over 500,000 people with more than 500 participants
Community Outreach

An important role of our volunteer leaders is community outreach. This year, our local groups and national program partnered with many other organizations, both congenital heart defect organizations and others, to reach more people with our mission and with information about congenital heart disease in children and young adults. Our largest such event was Edwards Lifesciences’ Women and Leadership event with over 300 women leaders in attendance. These leaders packed 500 Bravery Bags for children in the hospital across the country. One mom from Philadelphia (across the country) wrote us a note about how much the Bravery Bag meant to her and her family. There were many more smaller events like these where Mended Little Hearts partnered with others to educate and support more people in our communities.

Hospital Programs

Mended Little Hearts partners with hospitals and cardiology practices to support parents, family members and patients. We do this through accredited visiting programs, Bravery Bag Programs, Angel Boxes and other support services.

Bravery Bag Program

Bravery Bags are bags given to families in the hospital after their child has heart surgery or other procedures. They are filled by our local chapters with toiletry items, comfort items, educational items and fun items to not only provide necessities to help them during their hospital stay, but to show them they are not alone and there are others out there who care about them.

- Mended Little Hearts gave out over 5,000 Bravery Bags in 2017 and more than 1,100 Bravery Bag Lites. This represents more than half of children born with critical CHD each year.

Angel Box Program

Mended Little Hearts also supports families who lose children to CHD—our Mended Little Angels. Most chapters give an item to bereaved families, often an Angel Box filled with special items for them. In 2017, our chapters gave out 90 Angel Boxes. Currently, our Angel Boxes include our new Remember Our Hearts Charm.
Accredited Visiting

Mended Little Hearts has an accredited visiting program where leaders go through a training program to become accredited visitors. They then visit families in the hospital (where permitted) by telephone, by text and online before or after their child has a heart procedure. This visit gives families comfort and hope. In 2017, Mended Little Hearts visitors visited 2,198 families and had a total of 2,848 visits.

Affecting Policy for Improved Outcomes

Mended Little Hearts has trained their leaders to be strong advocates and has engaged on topics such as newborn screening, CPR in schools, research funding, patient protections and improved surveillance of CHD patients. During 2017 Mended Little Hearts members advocated in a variety of ways including visits to State and Federal policy makers, speaking engagements at clinical meetings, signing on to letters with other organizations, taking part in nonprofit roundtable discussions and partnering with professional societies.

Mended Little Hearts advocates are a part of coalitions and engage in opportunities to be strong voices for CHD families across the nation. Two of these coalitions are the Congenital Heart Public Health Consortium (CHPHC) and The Patient and Family Engagement Network (PFEN). In 2017 Mended Little Hearts also collaborated with The Speak Now for Kids network to promote access to critical medical coverage for children with complex medical needs.

In addition, Mended Little Hearts also believes that self-advocacy is a vital part of improving outcomes. To improve the lives of families, Mended Little Hearts creates opportunities for CHD patients and families to learn to advocate for themselves both in the hospital and in their lives by educating them on issues CHD patients face like neurodevelopmental issues, psycho-social issues, liver disease, and other non-cardiac issues.
OUR RESOURCES

Mended Little Hearts is a volunteer-led organization. All of our 70 local chapter leaders, our online community leaders, our Regional Directors and our National Steering Committee are volunteers. Mended Little Hearts values each and every donation and sponsorship and carefully determines the best use of the funds received to have the biggest impact. This chart demonstrates where donation and sponsorship dollars were utilized in 2017:

Mended Little Hearts could not serve tens of thousands of families without the generous support of individuals and organizations. In 2017, organizations such as Origami Owl, Lula Roe, Tink & Key, Adam’s Interiors and others hosted fundraisers for Mended Little Hearts national during CHD Awareness Week. Also, our chapters sponsored the Bravery Bag Program and the CHD Symposium. This chart shows where our revenue comes from:
Our Sponsors

We could not do all we do without amazing national sponsors who believe in us and support us. Thank you to these generous companies who sponsor us nationally:

♥ Abbott
♥ Admedus
♥ American Medical ID
♥ Asklepion
♥ Edwards Lifesciences
♥ Medtronic
♥ Prolacta Biosciences
♥ TAI Diagnostics
♥ Texas Children’s Hospital
♥ Women Helping Others
♥ Xeltis

and to all of the other companies and individuals who give so that we can too.
ABOUT MENDED Little HEARTS

From Our Valued Partner
The volunteers who work with Mended Little Hearts are a tremendous asset to our Heart Center. They provide an incredible resource to our patients and their families in so many ways - their visits, their care packages, and their support meetings are invaluable to families who are struggling to understand what it means to care for a child with congenital heart disease. Beyond all of these outward “things” that they provide, they give something much more important - themselves. The journey and the shared experience of having a child with congenital heart disease is something that is impossible for me to give to families, but they can. They understand what it’s like to see your child in pain, to struggle to understand their complex medical problems, and to try and keep your life together while all of this is occurring. They willingly share their experience, provide tips for survival, and most importantly, they listen.

Of almost equal importance, our local chapter has been invaluable in teaching and coaching our leadership team in the Heart Center. We have parent representation on many committees that allow us to better appreciate the perspective of our families and make better decisions about programmatic changes. Their honesty, maturity, and desire to make the Heart Center a better place for all children (not just their own) is selfless and inspiring. We are incredibly grateful for their involvement.

Joshua D. Koch
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