“Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support”
Doctors may have saved my heart, but Mended Hearts has saved my life. Thanks to the incredible vision of Dr. Harken and others, this organization has had such transformative power in my life and in so many other lives. That’s why I’m so delighted at the opportunity to serve as the president of Mended Hearts.

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

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

Our organization is changing and evolving, and we are proud of where we are going. We have stayed true to our roots while we have grown to meet the ever-changing needs of the new heart patient. We’ve made impressive inroads on a project for medication adherence, forging new partnerships with pharmaceutical and medical device companies. They’re helping us to educate patients on the importance of taking their prescribed medications – and asking the doctor questions. I know that our future is bright, and we will continue to provide hope and support to heart patients and families.

With heartfelt love,

Donnette Smith
About Mended Hearts

Mended Hearts is a national and community-based non-profit organization that has been offering the gift of hope to heart disease patients, their families and caregivers since 1951. Mended Hearts is the largest peer-to-peer heart patient support network in the world—our volunteers visit more than 200,000 patients annually. Mended Hearts provides support through ongoing educational, support and advocacy efforts. Mended Hearts and Mended Little Hearts have 300 chapters in North America, serving 460+ hospitals.

Mended Hearts Board of Directors

Executive Committee

❖ Donnette Smith, President of Mended Hearts, Chair of the Board
❖ Millie Henn, Executive Vice-President
❖ Patrick Farrant, Vice-President
❖ Angel Olvera, Vice-President of Mended Little Hearts
❖ Gordon “Gus” Littlefield, Treasurer*

❖ Central Regional Director: Bruce Norris
❖ Mid-Atlantic Regional Director: Bill Carter
❖ Midwest Regional Director: Larry Mantle
❖ Northeast Regional Director: Bob Hoffman
❖ Rocky Mountain Regional Director: Bob Oberfield
❖ Southern Regional Director: Marvin Keyser
❖ Southwest Regional Director: Lynn Berringer
❖ Western Regional Director: Ron Manriquez
❖ Past Presidents’ Council Chair Margaret Elbert
❖ Director, Mended Little Hearts: Beth Gray
❖ Appointed Board Member: Jack Britt
❖ Appointed Board Member: Kathy Boyd David
❖ Appointed Board Member: Tina Sampath

*Deceased

Senior Staff

Norm Linsky, Executive Director
Andrea Baer, Director of Patient Advocacy and Program Management
Marcia Baker, Director of Development, Corporate Partnerships, and Marketing
Rene’ Battles, Director of Operations and Fields Services
Jodi Smith Lemacks, National Program Director, Mended Little Hearts
Mandy Sandkuhler, Manager of Communications and Mended Little Hearts Field Services
Our Support Program

At the heart of Mended Hearts mission is the core belief that peer-to-peer support is vital to individuals who are facing their journey with heart disease. Having the unique ability to say, “I have been where you are,” is crucial to the Mended Hearts organization. Our chapters are run by dedicated peer volunteers and our programs are designed to focus on improving the lives of others.

Mended Hearts visiting is conducted every day, throughout the country, in a variety of ways. Mended Hearts started with face-to-face visiting, mostly in the hospital, but as technology improves, we have focused on creating programs to meet the needs of today’s patient.

In 2017, over 3,000 Mended Hearts Accredited Visitors supported others in hospitals, online in our “Connections in a Heartbeat” community, through emails, and through our telephone visiting programs.

Accredited Visiting Program

All Mended Hearts visitors are trained through the national Accredited Visiting Program. This comprehensive training focuses on how to support others, active listening, HIPAA, and hospital guidelines. So, whether a person is supported in person, online, or by telephone, they can be comforted by the fact that our volunteers meet the standards of excellence that has built our program for over 66 years.

“Individually we are one drop, together we are an ocean” - Unknown
2017 Support Program Reach

143,376 visits to patients and caregivers in person

9997 visits by telephone

7188 visits online and through email
Specialized support programs

❖ In 2017 Mended Heart Visitors were able to reach over 2,000 heart failure and hypocholesteremia patients to provide support via telephone through our alliance partnership with the Patient Access Network (PAN) Foundation. This program is designed to provide the vital peer-to-peer support to individuals who request assistance through their financial support program.

❖ The TAVR (Transcatheter Aortic Valve Replacement) visiting program has enabled Mended Hearts to reach patients who have a TAVR procedure and is designed to meet their unique needs. Mended Hearts is recruiting and training TAVR patients (our initial goal is 100!) to visit other TAVR patients to provide that peer-to-peer support via phone.

Our Chapters

Each year, in local communities, Mended Heart and Mended Little Hearts volunteers work to provide support and outreach in their local communities. We provide education, support and advocacy for patients with heart disease through our monthly support meetings, newsletters, and regional meetings.

209 Chapters
53 Satellite Chapters
83 Mended Little Heart Groups
345 Chapters serving 460 hospitals across the nation
Community Outreach

Mended Hearts chapters engaged in community awareness events, as well as health and resource fairs, in their local communities. Enriching the lives of patients, families, and communities is a priority.

Raising Awareness

Our chapters raised awareness through television interviews and heart walks in their community.
Training and Regional Connections Throughout the Year

National Education & Training Conference

“Let Freedom Ring...Let Your Heart Sing!” 2017 Nashville, TN

Total attendance: 200 volunteer leaders, members and friends

During the 2017 National Education and Training Conference in Nashville, Mended Hearts was honored to award Dr. Arlen Harken, son of our founder, Dwight Harken, the Harken Award for his outstanding service to the cardiovascular community.
2017 Regional Connection Meetings
Kissimmee, FL – 75 attendees
Hartford, CT – 40 attendees
Scottsdale, AZ – 65 attendees
Raleigh, NC – 76 attendees

Six Chapters conducted special valve presentations in 2017:

“Aortic Valve Disease and TAVR – The Latest Treatment Option”

Chapter 161, Hollywood, FL 1/15/17
Chapter 62, San Diego, CA 3/11/17
Chapter 380, Boise, ID 3/23/17
Chapter 28, Richmond, VA 4/4/17
Chapter 13, Albany, NY 4/9/17
Chapter 369, St. Charles County, MO 6/13/17
The Mended *Little* Hearts Program

**Mission**

To empower 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.

**About Mended *Little* Hearts**

Since 2004, Mended *Little* Hearts has worked to improve the lives of families affected by congenital heart defects/disease by providing peer-to-peer support services, educational programs and informational resources, CHD awareness events and campaigns, advocacy and by connecting families with necessary resources.

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.

- 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

*Mended Little Hearts publishes its own Annual Report each year, and it can be found on the website for detailed information about this program.* [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)

*Little hearts hold big hopes.*
Patient Advocacy Network

The Patient Advocacy Network was launched in 2016 to provide a strong patient voice on topics that affect the lives of all individuals with heart disease. This joint program of Mended Hearts and Mended **Little** Hearts is quickly becoming a leading voice in the cardiovascular space. The program has a volunteer advocacy committee that guides the program and sets the advocacy priorities. **The Network grew in 2017 to 400 advocates.**

**2017-2019 Advocacy Priorities**

**Eliminating Barriers to Innovative Cardiovascular Treatments and Devices**

Accessing treatments is vital for all Americans, especially for those with cardiovascular disease. Mended Hearts will advocate to ensure that all patients have access to the best treatments and care available.

**Improved Access to Cardiac Rehab**

Despite its benefits, only 1 in 5 patients enroll in a cardiac rehab program. Barriers to enrollment include the lack of referral, limited or no health care coverage, high out-of-pocket costs, and the scarcity of programs. Mended Hearts will advocate to reduce the barriers of cardiac rehab.

**Medication Adherence and Medication Therapy Management**

It is estimated that half of all patients do not take their medications as prescribed. Mended Hearts is committed to improving medication adherence and addressing adherence through community-based programs.

**Encouraging Innovation in Pediatric Devices for the Treatment of Congenital Heart Disease**

There are multiple barriers to the development of pediatric devices and treatments. Mended **Little** Hearts is committed to eliminating the barriers to the development of new cardiovascular medical devices for pediatric patients.

**Reducing Disparities in Congenital Heart Disease**

Infant mortality due to congenital heart defects are significantly higher in African American and Hispanic populations. Mended **Little** Hearts is committed to advocating on behalf of these patients and their families by raising awareness of the health disparities that exist in congenital heart care and promote policies aimed at reducing them.
Patient Advocacy Network 2017 Accomplishments

In May 2017 the Patient Advocacy Network hosted a Legislative Conference where we expanded training and hosted 100 Congressional Meetings with members from 28 states and the District of Columbia.

Advocates also engaged with their representatives in district in states like GA, CA, and TX.

As of December 2017, the Patient Advocacy Network has trained 200 advocates to share their story effectively and be a voice for others.
The Patient Advocacy Network also actively engaged in over **100 other advocacy opportunities in 2017**. A few ways that our advocates engaged were:

- Submitted comments to CMS, FDA, and Congress.
- Engaged in-person meetings and conferences, op eds, social media, and grassroots advocacy.
- Hosted webinars and took part in Twitter Chats throughout the year.
- Conducted Hill visits and meetings with Congress.
- Shared the patient perspective through State Advocacy engagements in FL, AL, PA, OH and Washington D.C.
- Partnered with other patient organizations on disease-awareness and policy.

Mended Hearts represented the patient voice at a variety of summits and panel discussions with medical professionals, other patient organizations, and industry leaders.

- Infant Health Policy Summit
- Alabama Roundtable on PCSK9 Access
- Spring and Fall IDEA Health Policy Summit
- National Hispanic Medical Association Regional meetings
- Edwards’ Patient Day
- Congenital Heart Legislative Conference
- Congenital Heart Public Health Consortium meeting
- ACC and AHA Scientific Sessions
Mended Hearts was accepted into the Standards of Excellence Certification Program and full membership to the National Health Council in 2017

This stringent certification process was completed in October 2017.

About the National Health Council

Founded in 1920, the National Health Council (NHC) is the only organization that brings together all segments of the health community to provide a united voice for the more than 160 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 125 diverse national health-related organizations and businesses, the NHC’s core membership includes the nation’s leading patient advocacy organizations, which control its governance and policy-making process. Other members include professional and membership associations; nonprofit organizations with an interest in health; and representatives from the pharmaceutical, generic drug, health insurance, device, and biotechnology industries.

Mission

The mission of the National Health Council is to provide a united voice for people with chronic diseases and disabilities and their family caregivers.

Learn more at: http://www.nationalhealthcouncil.org/about-nhc

CDMRP Peer Review

For the fourth year in a row, Mended Hearts advocates were a part of the Congressionally Directed Medical Review Program (CDMRP) through the Peer Reviewed Medical Research Program (PRMRP). The PRMRP, established in fiscal year 1999 (FY99), has supported research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military service members, Veterans, retirees, and their family members. Program oversight is provided by a programmatic panel with joint military service and interagency representation. Mended Hearts and Mended Little Hearts advocates have been the voice of the patient in topic areas of heart disease, congenital heart disease, and women with heart disease.
Fighting for Access: One Hurdle Overcome and Long-term Hope for Others

The Patient Advocacy Network joined forces with the Partnership to Advance Cardiovascular Health (PACH) to work to improve access to innovative treatments for heart patients. Working in 2017 through the states of Alabama, Mississippi, and Florida, advocates engaged in a variety of ways, including social media, to bring attention to this problem and to fight for access to this life-saving medication.

Donnette Smith was a panelist for the Institute for Patient Access when they convened the inaugural Cardiovascular Health Policy Summit in Washington, D.C. Patients, advocates, clinicians, Capitol Hill staff and government representatives used the day to explore how policies impact cardiovascular care across the country. The day-long event was co-hosted by the Partnership to Advance Cardiovascular Health and the Alliance for Patient Access.

“The Mended Hearts Patient Advocacy Network partnered with PACH and Dr. Seth Baum (one of the nation’s leading experts in this field), on an important test case with national implications. PCSK9 inhibitors are an important new class of drugs that dramatically lower elevated LDL’s (“bad cholesterol”) when all other drugs fail. This is literally a life-saving treatment. Blue Cross/Blue Shield of Alabama had denied reimbursement for PCSK9 inhibitors for most patients in that state (including Mended Hearts President Smith). As a test case on behalf of ALL such patients nationally, we mounted an aggressive campaign can get this drug affordably. The campaign in this test case was successful (and Ms. Smith’s LDL’s were dramatically lowered). This win was a start to the quest to assure that patients and doctors can make the best decision for the patient through shared decision making. We believe that this story highlights how patients can be helped through the voices of advocates.

“Just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far-reaching effects” – Dalai Lama
Publication of peer support case study
Andrea Baer and Marcia Baker (Mended Hearts staff) were published in the American Journal of Managed Care. The paper discussed reducing the barriers to medication access and adherence through a community-based peer-to-peer support approach. Two of our chapters were used as case studies to how this approach can be successful.

Andrea and Marcia presented their findings at a meeting in Washington, DC that was hosted by the American Journal of Managed Care and the Patient Access Network (PAN) Foundation.

The Jefferson City and St. Charles County chapters of Mended Hearts attended an event at the Missouri State Capitol to raise awareness of Heart Disease and Diabetes.

Mended Heart advocates teamed up with the Association of Black Cardiologists for their Spirit of the Heart advocacy at 6 regional trainings and shared their patient perspective on why advocacy is important.
Educational Programs

Heartbeat Magazine

Mended Hearts publishes its award-winning magazine six times per year. The magazine is distributed to 20,000 members in print with an additional 15,000 viewers online. Heartbeat highlights innovative treatments, the latest cardiovascular news, personal stories, and highlights our members and chapters. The magazine is free to all members.

HeartBeat Awards in 2017

APEX, Publication Excellence - Magazines, Journals & Tabloids - Design & Layout - Heartbeat Magazine - Jan/Feb 2017


APEX, Grand Award Electronic Media - Mended Hearts GoToGuide on Heart Attacks

AIVA, The Communicator Awards - Award of Distinction - "One Size Fits All..."

Content Marketing Institute, Content Marketing Awards - Finalist: Healthcare/Medical Publication: Heartbeat Magazine 2017

Content Marketing Institute, Content Marketing Awards - Healthcare/Medical Publication: Heartbeat Magazine, Jan/Feb 2017

Content Marketing Institute, Content Marketing Awards - Nonprofit Publication: Heartbeat Magazine, Jan/Feb 2017

Folio, Ozzies - Winner: Best Cover Design for Heartbeat Magazine - Non-profit/Charity - May 2017
HeartGuide and GotoGuides

Mended Hearts provides the **HeartGuide, an educational handbook, to individuals who are facing the journey through heart disease.** This handbook provides important information on heart disease, common tests and therapies, and risk factors. All information is reviewed by our medical advisory board and is written in plain patient language so that it is easy to understand. The guide also contains practical information on topics such as depression, caregiving, and medications.

The HeartGuide is available in both print and online, English and Spanish, as an interactive guide that can be accessed from any mobile device (MyHeartGuide). Chapter volunteers distribute the HeartGuide as a part of their hospital visits, and they are available for distribution at meetings and events. In **2017, Mended Hearts distributed over 100,000 printed copies of the HeartGuide.**

Along with the comprehensive HeartGuide, our **GotoGuides are published on specific topics** to better educate the patient and caregiver on their disease. We have GoToGuides on topics of Valve Disease, AFib, Heart Attack, Chronic Heart Failure, and High Cholesterol and FH. These guides are available online from our website as interactive magazines. They are also available for PDF download.
Online Resources

In 2017, Mended Hearts launched our new, interactive website platform to meet the ever-growing needs of our heart community. This fully-comprehensive resource center is made up of three components:

1. **Your Journey Starts Here: The** Mended Hearts and Mended Little Hearts new website is designed to help guide the user and provide specific information to the visitor. Our extensive resource library and information is enhanced by our new blog, where visitors can read about stories of hope and where we highlight “personal stories” as well as breaking news of the heart world. **Our website was visited over 100,000 times in 2017.**

   The website also includes a comprehensive “members and officers” portal that allows us to share up-to-date information with our 350+ chapters and groups. These areas of the website are secure and contain tools and resources for our chapters and groups. We provide toolkits, fliers, event-planning help, chapter meeting resources, and financial planning information. Mended Hearts believes that providing this information is important for our volunteers who execute the work in the communities each year.

   Mended Hearts also has an extensive library of webinars on our website that individuals can access, for free. **In 2017 we added four new webinars on the following topics: Cardiac Rehab, TAVR, Valve Disease, and Access to Care.**

2. **Connections in a Heartbeat: The** Mended Hearts and Mended Little Hearts discussion forum is an online support network. This portion of our website hosts conversations and is a place where members (and nonmembers) can come together to talk about their journey through heart disease. **In 2017 over 1,000 discussions were posted, and our 600 active members** shared stories, encouraged each other, and helped each other through open heart surgeries and other procedures with support and advice.

3. **National News and Social Media**: National News is our monthly E-newsletter that provides up-to-date information on topics that affect our membership. **This newsletter is emailed monthly to over 21,000 individuals.** Upcoming events are featured in each newsletter, along with programs that Mended Hearts is working on.

   Mended Hearts also provides an E-newsletter template for chapters to utilize with information that is important. These templates can help communicate all the activities and events for the month and reduce the workload of our volunteers in the field.

   Mended Hearts has been working hard to improve our social media footprint. **Our Facebook page is now “liked” by almost 9,000 people, and our Twitter feed is followed by almost 3,000.**
Our Network of Supporters

Mended Hearts wouldn’t be able to provide the quality programming that we do without the support and advice from community leaders. Our medical advisory, Founders Circle, and Corporate Advisory Council members are engaged and work hard to assure that Mended Hearts’ mission can be executed.

Medical Advisory Board

Alden H Harken, MD, FACS
Emeritus, USCF – East Bay, Alameda Health, Oakland, California

Barbara S. Jacobs, MSN, RN-BC
Anne Arundel Medical Center, Annapolis, Maryland

J. Jeffrey Marshall, MD, FACC, MSCAI
Heart Center of Northeast Georgia, Gainesville, Georgia

Srihari “Hari” S. Naidu, MD, FACC, FAHA, FSCAI
Westchester Medical Center, Valhalla, New York

Mark F Sasse, MD
University of Alabama, Birmingham, Alabama

Sarah A. Spinler, PharmD, FCCP, FAHA, FASHP, ACC, BCPS-AQ Cardiology
Philadelphia, Pennsylvania

Founders Circle

Mended Hearts is at a crossroads: From our founding in 1951, we have been dedicated to “inspiring hope & improving quality of life for heart patients and families.” That has translated into millions of bedside visits, thousands of support group meetings, and support throughout the life cycle. We have much to be proud of—and our mission is more important now than ever.

To continue that mission, Mended Hearts recognizes that we must adapt, strengthening what we do well, and revising long-standing practices where needed. Mended Hearts Founders Circle, established in 2017, is an elite group of individuals will be tasked with the goal of strategic advice and management guidance. This Founders Circle is being co-chaired by Tony Hooper and Dr. Alden Harken, son of our founding father, Dr. Dwight E Harken.
Corporate Advisory Council

- Abbott
- Amgen Cardiovascular*
- Astellas Pharma
- AstraZeneca
- Boehringer Ingelheim
- Bristol-Myers Squibb / Pfizer Alliance
- Edwards Lifesciences*
- Gilead Sciences
- Janssen Pharmaceutical Companies of Johnson & Johnson
- Lilly
- Novartis Pharmaceuticals*
- Novo Nordisk
- Sanofi Regeneron Alliance

*Gold level member

Financial Support

Mended Hearts relies on individual donations, corporate donations, fundraising events, and grants to provide the high level of support to hundreds of thousands of patients and caregivers each year. Our chapters are self-supporting and host fundraisers throughout the year to meet the needs of their community.

We appreciate our community of supporters who allow us to continue our mission.

“Coming together is the beginning, keeping together is progress, working together is success” — Henry Ford