Mended Hearts is the largest peer-to-peer support cardiovascular network in the world. As an organization that has been providing support for over 65 years, reaching those patients in new and innovative ways is vital for growth. Mended Hearts would like to share with you the work that we have done in 2016.
Donnette Smith, President of Mended Hearts

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’d be the organization’s president, though I’ve long been an active member. My journey with Mended Hearts began in June, 1988. I’d known that eventually I’d 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’d become part of this organization. Of course, after my surgery, I went back to my career and my family.

Five years later, in 1993, I suffered an aneurysm and was desperate to talk to someone who had pushed through the same condition. By then, our local chapter had disbanded. I resolved to start it again after I recovered. Starting a new chapter took about a year, but we’ve been around since 1994. I’ve been honored to serve at the local and regional level in multiple capacities. Mended Heart is truly the greatest organization I’ve ever been a part of.

And this organization is changing! 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 also hope to enhance our resources for caregivers. The most romantic moment of my life was after one of my heart surgeries. I was still in the ICU, but I couldn’t sleep. The nurse suggested that I take a walk and told me that my husband was in the waiting room. I found him there, asleep on the floor, underneath a makeshift tent he’d made by draping a sheet over a table. He’s been so absolutely devoted, and he’s certainly not alone. Mended Hearts can support our caregivers, the way they’ve supported us.
“Let your voice be heard and may your words uplift, encourage, and spread love.”
- Unknown

OUR MISSION
Our mission is dedicated to “Inspiring hope and improving the quality of life for heart patients and their families through ongoing peer-to-peer support”.

OUR VISION
All families and patients affected by heart disease across the lifespan are able to share experiences and resources as members of a nationwide peer-to-peer support network.
2016 BOARD OF DIRECTORS

▪ Donnette Smith, President of Mended Hearts, Chairman of the Board
▪ Millie Henn, Executive Vice President
▪ Patrick Farrant, Vice President
▪ Randy Gay, Treasurer
▪ Melanie Toth, Mended Little Hearts Vice President
▪ Jana Stewart, Central Region Director
▪ Gerald Kemp, Mid-Atlantic Region Director
▪ Cathy Byington, Midwest Region Director
▪ Priscilla Soucy, Northeast Region Director
▪ Bob Oberfield, Rocky Mountain Region Director
▪ Dr. Fredonia Williams, Southern Region Director
▪ Lynn Berringer, Southwest Region Director
▪ Ron Manriquez, Western Region Director
▪ Megan Setzer, Mended Little Hearts National Director
▪ Tina Sampath, Appointed Board Member
▪ Kathy Boyd-David, Appointed Board Member
▪ Gus Littlefield, Immediate Past President
▪ Margaret Elbert, Past President’s Council

2016 MENDED HEARTS SENIOR STAFF

❖ Norm Linsky, Executive Director
❖ Andrea Baer, Director of Patient Advocacy
❖ Marcia Baker, Director of Corporate Development & Programs
❖ Rene’ Battles, Manager of Field Services
❖ Janette Edwards, Director of Operations
❖ Jodi Lemacks, Mended Little Hearts Program Director

2016 CORPORATE ADVISORY COUNCIL

Abbott                      Edwards Lifesciences
Amgen Cardiovascular       Gilead Sciences
AstraZeneca                Janssen
Astellas Pharma            Novartis Pharmaceuticals
Bristol-Myers Squibb / Pfizer Alliance Novo Nordisk
                                Sanofi Regeneron Alliance
Our Services

Since 1951, Mended Hearts has provided peer-to-peer support to millions of patients and their families. Our mission is to inspire hope and to help patients enjoy fuller, healthier lives following a heart disease diagnosis.

Chapter Programs — Peer Support and Education

Nothing can replace in-person connections with others traveling on a similar journey. Mended Hearts chapter programs allow patients and caregivers to connect with and support each other in their local communities, share experiences and get helpful information and resources. Mended Hearts has 262 chapters across the country serving their local communities in 460 hospitals.

Chapters and Satellites

As Of 6/31/17
209 Chapter
53 Satellites
262 Total

New Chapters
- 399 NW FL, Ft Walton, FL
- 400 Fayetteville, NC
- 402 Florence, SC
- 403 Springfield, MA
- 404 Bremerton, WA
- 405 Port Charlotte, FL
- 406 Sonora, CA
- 407 Savannah, GA
- 408 Hickory, NC
- 409 Grand Junction, CO
- 410 Boca Raton, FL
- 411 Palm Beach Gardens, FL
- 412 Greenville, SC
- 413 Foxborough, MA
- 414 — Colorado Springs, CO

Membership: New & Renewals
- MH Members = 8,609
- MLH Members = 7,158
- Total Members = 15,767
- Overall declining trend
- MH declining/MLH declining*

*Future audiences target:
- Adult CHD survivor, diverse patients and caregivers

*Efforts to reverse those trends are in place.
Our Impact

DIRECT SUPPORT SERVICES IN 2016

• 15,700 Members
• 262 chapters and 80 Mended Little Hearts Groups
• 192,229 visits by Accredited Visitors

Visiting Accomplishments

» Visits increased slightly
  » 182,845 to 192,229
  » Patient Visits: 145,651
  » Family Visits: 26,678
  » Phone visits: 12,762
  » Email visits: 6,428
  » Internet visits: 710

» Six Chapters conducted special valve presentations:
  » “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

Expanded Telephone Visiting

Mended Hearts partnered with Patient Access Network Foundation to provide telephone visiting to underserved heart patients

• 1,200 patients have been supported through this program since August 2016

• Team of visitors provide telephone visiting daily

• HeartGuide, GoTo Guides, and chapter information provided upon request
CHAPTER EDUCATION

A major goal of Mended Hearts is to provide our Chapters with the education and training that they need to execute high impact programs within the local communities. In 2016 Mended Hearts provided:

“On the Road” Educational and Training Conference 2016 was held in 6 locations and attracted over 700 members from across the nation

Visiting Vignettes Newsletter to provide our nationally accredited visitors with education and tools they need for success

Newsletter Templates and Online Support to chapters and groups across the country

Field Accomplishments

- National Education & Training Conferences “On the Road” 2016
  - Scottsdale, Arizona (Rocky Mtn)
  - Irvine/Mission Viejo, California (Western)
  - Chicago, Illinois (Midwest)
  - Raleigh, N. Carolina (Mid-Atlantic)
  - Austin, Texas (Southwest)
  - Huntsville, Alabama (Southern)
  - Total attendance: 600 members

- Regional Cluster Meetings
  - Bellingham, WA – 100 attendees
  - Kissimmee, FL – 80 attendees

Training Accomplishments

- Monthly RD teleconferences
- Semi-annual ARD teleconferences
- Quarterly presidents’ calls
- Training webinars
PATIENT ADVOCACY NETWORK: POWER OF THE PATIENT VOICE

In February 2016, Mended Hearts launched their Patient Advocacy Network Program which bring the voice of the patient into the conversations regarding public health, patient rights and protections, and cardiovascular priorities in policy.

Patient Advocacy Network

- "Connections in a Heartbeat" launched online and in app form: 500 unique users
- New interactive website
- Database program
- 300 advocates: 150 trained to date, online and in person
- Summer Webinar Series

From May 2016-May 2017 our advocates engaged in over 60 opportunities

Patient Advocacy Network

- Advocacy Committee met 12 times
  - Submitted comments to CMS, FDA and CMMI
  - Signed on to 20 letters to policy makers and payors
  - Attended a MEDCAC meeting and provided in person testimony
  - Four grassroots advocacy calls to action
  - Released three issue briefs
  - Expanded to State Advocacy: TX, FL, OH, AL, and CA
SHAPING POLICY, IMPROVING HEALTH
Mended Hearts works in partnership with other organizations to shape policy that positively impacts the lives of those affected by heart disease. Shown below are just a few of the coalitions we worked with in 2016:

National Advocacy Partnerships and Coalitions
Accountable Innovation in Medicare Coalition (AIM)
Adult Congenital Heart Association (ACHA)
Alliance for Aging Research
Alliance for Patient Access (AFPA)
American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR)
Congenital Heart Public Health Consortium (CHPHC)
Heart Failure Society of America (HFSA)
Hypercholesterolemia Foundation (HF Foundation)
National Center for Birth Defects and Developmental Disabilities (NCBDDD)
National Health Council member
National Heart and Stroke Coalition
National Partnership for Women and Family
Patient and Family Engagement Network (PFEN)
Patients Rising
Preventive Cardiovascular Nurses Association (PCNA)
Mended Little Hearts

*Mended Little Hearts* is a program of Mended Hearts that provides support, education and empowerment to patients and families affected by congenital heart disease (CHD). CHDs are the number one birth defect, affecting more than 40,000 births each year. CHD is a life-long journey and patients need specific care and services throughout their life-span.

**Mended Little Hearts Mission:**

To empower families affected by congenital heart disease (CHDs) through peer-to-peer support services, education, connecting families with resources, creating awareness and advocacy.

**Mended Little Hearts 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.

Mended Little Hearts has 80 groups across the nation with peer-to-peer support and educational programming to match the needs of their community.
## OUR RESOURCES

### INCOME AND EXPENSES

#### Statement of Activities: Jan 1–Dec 31, 2016

<table>
<thead>
<tr>
<th>REVENUES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership Dues</td>
<td>$146,290</td>
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<tr>
<td>Grant Income</td>
<td>$1,372,545</td>
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<tr>
<td>Conference Income</td>
<td>$32,561</td>
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<tr>
<td>Other Income</td>
<td>$222,568</td>
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<tr>
<td>Investment Income</td>
<td>$9,085</td>
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<tr>
<td>Bequests</td>
<td>$1,000</td>
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<tr>
<td><strong>TOTAL REVENUES</strong></td>
<td><strong>$1,784,049</strong></td>
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<table>
<thead>
<tr>
<th>EXPENSES</th>
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</thead>
<tbody>
<tr>
<td>Education/Community Services</td>
<td>$1,541,309</td>
</tr>
<tr>
<td><em>Includes: Region Expenses, education materials and activities, field support program, salaries, benefits and payroll taxes, training</em></td>
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<tr>
<td>Program Services</td>
<td>$185,879</td>
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<tr>
<td><em>All MLH Programs including salaries</em></td>
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<tr>
<td>Conference</td>
<td>$138,359</td>
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<tr>
<td>Fundraising</td>
<td>$208,127</td>
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<tr>
<td>Management and General</td>
<td>$169,861</td>
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<tr>
<td><em>Includes: Board of Director expenses, Administrative salaries, benefits, payroll taxes, overhead costs</em></td>
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<tr>
<td><strong>TOTAL EXPENSES:</strong></td>
<td><strong>$2,243,545</strong></td>
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<tr>
<td><strong>EXCESS OF REVENUE OVER EXPENSES:</strong></td>
<td><strong>($459,486)</strong></td>
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</tbody>
</table>
2016 Issues of Note

- Investments in software, databases, website, online communities, online fundraising
- Provides a basis for 2017 and beyond
- Expanded advocacy program
- Projecting impact of projects/revenue expectations
- Staff/Committee ownership of budgets
- Limited spectrum of revenue sources
- Separate fundraising for MH / MLH
- Independence from previous partners
- National/Chapter fundraising
Mended Hearts gratefully acknowledges the financial contributions of individuals, foundations and corporations in 2016. It is through these contributions we are able to provide support and education to thousands of heart patients and caregivers nationwide.

CORPORATE SPONSORS 2016

Abbott  
Amgen Cardiovascular  
AstraZeneca  
Astellas Pharma  
Bristol-Myers Squibb / Pfizer Alliance  
Edwards Lifesciences  
Gilead Sciences  
Janssen  
Medtronic  
Novartis Pharmaceuticals  
Novo Nordisk  
Sanofi Regeneron Alliance

For more information on ways to support Mended Hearts, please Norm Linsky, Executive Director, at 202-607-5448
Mended Hearts
8150 N. Central Expwy, M2248
Dallas, TX 75206
1-888-432-7899 (1-888-HEART99)
www.mendedhearts.org