Advocacy Priorities
In 2016 Mended Hearts and Mended Little Hearts launched a collaborated effort to:

- Create network of highly trained, engaged advocates to share stories efficiently, with high impact
- Explain issues with personal perspectives
- Promote development of/access to new therapies
- Build online support network for heart patients nationwide
Through this engaged network of patients, Mended Hearts can empower patients to be their own voice and be the voice of others.
2016-2017 Advocacy Priorities

• Developed through the voice of the membership

• Designed for high impact to heart patients across the life-span

• Patient centered and peer led
Access to Innovative Cardiovascular Disease Treatments and Devices
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There have been several recent scientific breakthroughs that have lead to the development of new pharmaceutical and device treatments for cardiovascular disease.
Access to Innovative Cardiovascular Disease Treatments and Devices

“Together we can find a path that doesn’t ask us to choose between innovation and affordability.”

- Dept. of Health and Human Services
  Secretary Sylvia Burwell
  - November 2015

- Many factors may limit access
- Maintaining and expanding access = shared responsibility between:
  - Biopharmaceutical/biotechnology industries
  - Government
  - Regulators
  - Payors
Our priority:
Make life-changing innovations accessible and affordable for all cardiovascular patients
It is estimated that at least half of all patients do not take their medication as directed.
Medication Adherence & Medication Therapy Management

Poor medication adherence results in an annual $100 billion in additional medical expenditures
Patients with cardiovascular disease who do not adhere to their prescribed medication regime have a 30 percent increased risk of mortality compared to their adherent peers.
Medication Adherence & Medication Therapy Management

- Medication therapy management
  - Helps patients increase medication adherence
  - Helps reduce adverse effects of medication mismanagement
- Currently provided by Medicare
  - Eligibility limited
Medication Adherence & Medication Therapy Management

- **Our priority:**
  - Expand Medicare eligibility so more patients qualify
  - Improve patient outcomes
  - Increase medication adherence
  - Reduce health care costs
Promote, Ensure Access to, and Expand the Use of Cardiac Rehabilitation
Promote, Ensure Access to, and Expand the Use of Cardiac Rehabilitation

- **Cardiac Rehab**
  - Exercise and education program
  - Helps in multiple ways:
    - Improves health and well-being
    - Patients recover more quickly
    - Return to active lifestyles
    - Reduces risk of future cardiac events
Research shows that cardiac rehab reduces mortality by 50 percent and reduces the likelihood of hospital readmissions by 25 percent.
Despite the program’s benefits, patients often don’t enroll in a cardiac rehab program. It is estimated that among eligible patients, only one in five enroll in a cardiac rehab program.
ADDITIONAL PATIENT INFORMATION

Advocacy Priorities

Promote, Ensure Access to, and Expand the Use of Cardiac Rehabilitation

- Barriers to enrollment:
  - Lack of referrals from physicians
  - Limited/no health care coverage
  - Scarcity of programs in rural and medically underserved areas.

- Our priority:
  - Promote, ensure access to, and expand the use of cardiac rehabilitation
Health Disparities in Congenital Heart Disease (CHD)
Health Disparities in Congenital Heart Disease (CHD)

- Prematurity and birth defects like CHDs major contributors to infant mortality in the U.S.
- Infant mortality due to CHD significantly higher in African-Americans
- Contributing Factors:
  - Health of the mother
  - Management of child's CHD
  - Access to adequate care

Source: CIA Factbook, NCHS/CDC, 2010
Our Priority:

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

- Some devices used in the pediatric population are designed specifically for children
  - However, many are borrowed or adapted adult applications
- Effectiveness and safety of medical devices used in pediatrics unstudied, thus unknown
Encouraging Innovation in Pediatric Devices for the Treatment of Congenital Heart Disease

• Challenges:
  • Small market size
  • Need for multiple pediatric sizes
  • Expense of trials
  • Barriers to enrollment of children in clinical trials
  • Ethical complexities
  • Regulatory approval process
  • Pediatric devices must be especially long-lasting and safe, due to length of use
Encouraging Innovation in Pediatric Devices for the Treatment of Congenital Heart Disease

Mended *Little* Hearts’ Priority:

- Eliminate the barriers to the development of new cardiovascular medical devices for pediatric patients
Access to Innovative Cardiovascular Disease Treatments and Devices

Medication Adherence & Medication Therapy Management

Promote, Ensure Access to, and Expand the Use of Cardiac Rehabilitation
Health Disparities in Congenital Heart Disease (CHD)

Encouraging Innovation in Pediatric Devices for the Treatment of Congenital Heart Disease
Mended Hearts gratefully acknowledges the support of:
Questions?
Thank you!