



**Patient Advocacy  
Training and Capitol  
Hill Day  
Partner Toolkit**

## Welcome Partners

Heart disease affects over 27 million people in the United States, resulting in nearly 600,000 deaths each year. Heart Disease, both congenital and acquired, affects individuals from birth and beyond. In an effort to connect patients and families, unify messaging, and educate those who create laws and regulations on issues that affect patients, Mended Hearts created the Patient Advocacy Network.

As the largest cardiovascular patient peer-to-peer support network in the world, Mended Hearts is poised to become a leader in advocacy and unify our voices to change lives. The goal of the Patient Advocacy Network is to advocate for patient rights and empower patients and families to be powerful advocates for the best care possible.

On May 7-9<sup>th</sup> the Patient Advocacy Network is bringing advocates from across the country to Washington, DC to learn more about our organization's advocacy priorities and to visit their representatives on Capitol Hill. Specifically, advocates will be speaking to their representatives about The ACE Kids Act, funding for researchers (NHLBI, CDC, and FDA), and patient voice (Prescription Drug and Medical Device User Fee Act Re-Authorization). This powerful program will help our advocates to become the voice for change and give them the opportunity to share their story with their representatives.

This event is an opportunity for all heart patients, caregivers and family members around the country to learn about how they can advocate for important cardiac issues in their communities. Although not all of our members will be able to join us in Washington, they will be provided with sample emails and sample phone scripts that they can use to contact their representatives in Washington that day.

In this kit you will find details about our advocacy priorities, sample social media posts and blogs, as well as graphics. We encourage you to use these items as you plan your outreach and educate your audience on our chosen advocacy priorities.

Thank you for your support.



Andrea Baer  
Director of Patient Advocacy  
Mended Hearts



Mended Hearts™



mended hearts little

## Our Message

Our advocates have three items they'll be advocating for when they meet with their representatives on May 8.

1) **The ACE Kids Act** is designed to help the nation's most medically vulnerable children, those with complex medical conditions (a.k.a. medical complexity) who are on Medicaid. The bill would also improve care coordination, helping relieve the burden on the parents, guardians and other family members of these children.

- Roughly 3 million children – 1 in 25 kids – have complex medical conditions; of that population, 2 million rely on Medicaid to access care.
- Children with medical complexity have multi-year, high-acuity conditions often requiring the services of multiple specialists, requiring time intensive coordination of care.
- Their specialized care often requires providers in more than one state.
- Care for children with medical complexity is unique, complex and expensive.
- Children who have complex medical conditions are roughly 6 percent of kids in Medicaid, but account for up to 40 percent of the costs.
- The overall population of children with medical complexity is growing due to important advances in medical care, such as care for premature infants.
- ACE Kids Act would give children and families a centralized point of contact for care coordination, relieving families of the burden of solely coordinating their child's medical care
- Data shows that care coordination decreases hospitalization and improves outcomes
- ACE Kids Act would also streamline care across state lines
- As a whole, the provisions in the ACE Kids Act assure that children with medical complexity in Medicaid will see the right health care providers at the right time, regardless of where a child lives or a provider works

2) **Funding for Research** - As you begin working on appropriations requests for FY2018, we ask that you show your support for continued robust funding for heart disease, stroke, and congenital heart disease-related public health research and surveillance initiatives at the National Institutes of Health and Centers for Disease Control and Prevention.

- NIH—We are advocating for \$34 billion for NIH. The proposed funding level will allow NIH to capitalize on investments to improve health, spur economic growth, spark innovation, and pre-serve U.S. leadership in medical research. Included in this request is a robust funding for congenital heart disease research.
- NHLBI—We support \$3.3 billion for NHLBI. This funding level will sustain current activities and investment in promising critically needed scientific opportunities that will aggressively advance the fight against heart disease.
- NINDS—We recommend \$1.8 billion for NINDS. This funding level will enhance existing initiatives and proactively advance the top priorities in stroke prevention, treatment and recovery research.
- CDC Heart Disease and Stroke Prevention—we are advocating for \$175 million for the CDC's heart disease and stroke prevention programs. This amount is identical to the FY 2017 House Appropriations Committee mark.
- CDC Million Hearts 2022— We are asking for \$5 million for Million Hearts 2022 to capitalize on the solid foundation, best practices, evidence, shared tools, and progress on this public-private initiative to prevent heart attacks and strokes.
- CDC Congenital Heart Failure Program (NCBDDD)—We are advocating for \$7 million for FY2018 to the Centers for Disease Control's National Center of Birth Defect and Developmental Disabilities to support surveillance and awareness activities to address the public health impact of congenital heart disease across the life span.
- DoD, Peer Review Medical Research Program (PRMRP) —We advocate for maintaining the funding levels for the PRMRP. The research funded by the PRMRP helps to drive innovation and cures for the millions of Americans who have heart disease and congenital heart disease.

### 3) Prescription Drug and Medical Device User Fee Act Re-Authorization-

People with chronic and rare diseases and disabilities rely on the FDA to access innovative, safe, and effective treatments. Not only do user fees provide the funding for FDA to quickly review products, but the current user fee agreements provide significant improvements and advancements to the health care community that simply cannot wait. Mended Hearts and Mended *Little* Hearts advocate for re-authorization in a timely fashion.

- The FDA largely relies on user fees authorized by Congress to operate. Without the user fees, most drug, biologic, and device reviewers would be laid off, and the necessary review of innovative therapies would be substantially impaired or halted all together. Further delay, such as a one-year extension of the current agreement, will impact the FDA's ability to carry out its vital mission and delay many of improvements. Quickly reauthorize the Food and Drug Administration (FDA) user fee agreements.

- The current FDA user fee agreements are the culmination of months of negotiation between the FDA and the medical product industry with significant input from the patient advocacy community. We stand behind these agreements and ask that they are reauthorized as quickly as possible.

- Other provisions included in the agreement, such as increasing emphasis on biomarkers and surrogate endpoints, streamlining combination product reviews, studying the feasibility of incorporating real-world evidence (RWE) provided from clinical settings, and improving FDA hiring and retention practices, will lead to a more efficient FDA that is better equipped to review 21st Century treatments in a timely fashion.

The Prescription Drug and Medical Device User Fee Act Re-Authorization also includes several crucial reforms including the further inclusion of patient preference information and patient-reported outcomes in device development and review, as well as the creation of the National Evaluation System for health Technology (NEST).

The collaborative national evaluation system will link and synthesize data from different sources across the medical device landscape, including clinical registries, electronic health records and medical billing claims. A national evaluation system will help improve the quality of evidence that health care providers and patients can use to make better informed treatment decisions and strike the right balance between assuring safety and fostering device innovation and patient access.

## Help Us Get the Word Out

This toolkit contains resources to help you communicate these important advocacy initiatives to your partners and members. It includes suggested tweets and Facebook posts, newsletter content, and graphics to use in your outreach.

Please share these sample tweets and Facebook posts with your members and community on May 7-8. We want the heart community to learn more about these important issues and how they can advocate for them wherever they are.

### Sample Tweets

40% of all U.S. kids rely on Medicaid for their health coverage. Tell gov't to keep medicare strong! #keepkidscovered #Advocacy17

The ACE Kids Act helps kids w/ complex med conditions on #Medicaid ask your gov't rep to keep Medicaid strong #PowerofthePatientVoice

Show your support for con'd funding for heart disease, stroke, & CHD research and surveillance initiatives at @NIH & @CDCgov #Advocacy17

Ppl w/t chronic & rare diseases rely on FDA to access safe/effective treatment. Advocate for #PDUFA

#PDUFA is vital to bringing important Rx to market quickly! Re-Auth this act quickly. #Powerofthepatientvoice

## Sample Facebook Posts

The ACE Kids Act was created to help children with complex medical conditions who are on Medicaid by improving care coordination & relieving some of the burden on parents & caregivers. You can help ensure that these children are protected medically by contacting your federal rep and showing your support for the bill. #Keepkidsprotected #Powerofthepatientvoice

You can make a difference! Help keep federal funding for heart disease, stroke, & CHD-related public health research strong by supporting initiatives at the National Institutes of Health and the CDC and by letting your gov't representatives know this funding matters. Learn more about these initiatives at:  
# PowerofthePatientVoice #Advocacy17

We encourage you to advocate for the Prescription Drug and Medical Device User Fee Act Re-Authorization. People with chronic & rare diseases and disabilities rely on the FDA to access safe & effective treatments. The user fees provide the funding for the FDA to quickly review products & provide advancements to the health care community! #Advocacy17 #PDUFA

## Sample Newsletter Post

Mended Hearts and Mended *Little* Hearts advocates are in Washington D.C May 7-9th to visit their representatives on Capitol Hill and advocate for three important initiatives that affect heart patients. Advocates will speak to representatives about The ACE Kids Act, continued funding for heart, stroke and CHD research at NHLBI, CDC, and the FDA, and the Prescription Drug and Medical Device User Fee Act Re-Authorization. For more information on how you can show your support for these initiatives, go to <http://mendedhearts.org/get-involved/advocacy>

## Sample Graphics

1 in 25 kids have complex medical conditions

The overall population of children with medical complexity is



Children who have complex medical conditions are roughly 6 percent of kids in Medicaid, but account for up to 40 percent of the costs.

## The ACE Kids Act Access and Disparities

