

March 27, 2017

Senator Dick Durbin
711 Hart Senate Office Building
Washington, D.C. 20510

Representative Gus Bilirakis
2112 Rayburn House Office Building
Washington, D.C. 20515

Senator Bob Casey
393 Russell Senate Office Building
Washington, D.C. 20510

Representative Adam Schiff
2372 Rayburn House Office Building
Washington, D.C. 20510

Dear Senators Durbin and Casey and Representatives Bilirakis and Schiff:

As organizations committed to conquering the most common birth defect, we would like to offer our support for the Congenital Heart Futures Reauthorization Act of 2017 (S. 477/ H.R. 1222). Thank you for your leadership in introducing this bipartisan legislation to improve outcomes and quality for the more than 2.4 million people in the United States living with congenital heart disease.

Congenital Heart Disease (CHD) is the most common group of birth defects and the leading cause of birth defect-related infant mortality. Nearly 1 in 100 babies are born with CHD and more than five percent will not live to see their first birthday. Even those who receive successful intervention are not “cured.” Children and adults with CHD require ongoing, costly, specialized cardiac care, and face a lifelong risk of permanent disability and premature death. Healthcare utilization among the CHD population is significantly higher than the general population with medical costs estimated to be 10 to 20 times greater than their unaffected peers. The CDC reports that costs for hospitalizations related to congenital heart defects were more than \$6 billion in 2013.

The bipartisan Congenital Heart Futures Act, originally passed in 2010, called for expanded infrastructure to track the epidemiology of CHD at the Centers for Disease Control and Prevention (CDC) and increased lifelong research at the National Institutes of Health (NIH). Efforts since 2010 at the CDC and NIH have sought to improve our understanding of CHD across the lifespan, the age-specific prevalence, and factors associated with dropping out of appropriate specialty care.

However, urgent action is needed to enable the CDC and NIH to build upon existing programs and focus on successful activities addressing this critical public health need. The Congenital Heart Futures Reauthorization Act of 2017 will build upon current CDC and NIH activities by:

- **Assessing the current research needs and projects related to CHDs across the lifespan at the NIH.** The bill directs the NIH to assess its current research into CHDs so that we can have a better understanding of the state of biomedical research as it relates to CHD.
- **Expanding surveillance for CHDs.** The bill directs the CDC to plan, develop and implement a surveillance program to improve understanding of CHD across the lifespan. This will help us understand the demographics and healthcare utilization of

those living with CHD, over time, leading to evidence-based practices and guidelines for CHD.

- **Raising awareness of CHD through the lifespan.** The bill allows for CDC to establish and implement an awareness and education campaign directed at individuals with CHD across the lifespan. Pediatric, adolescent and adults with CHD and their families need to understand that their conditions require them to seek and maintain lifelong, specialized care.

The Congenital Heart Futures Reauthorization Act of 2017 (S. 477/ H.R. 1222) is essential to better understand CHD across the lifespan, improve outcomes and quality, and reduce costs. Thank you for your continued leadership on this important public health issue.

Sincerely,

Adult Congenital Heart Association
American College of Cardiology
American Heart Association
Asher James Congenital Heart Disease and Thrombosis Foundation
Children's Cardiomyopathy Foundation
Children's Heart Foundation
Congenital Heart Defects Families Association
Ethan Lindberg Foundation Inc.
Kids With Heart National Association for Children's Heart Disorders, Inc.
Mended Little Hearts
Pediatric Congenital Heart Association
Pediatric Congenital Heart Association - Illinois
Pediatric Congenital Heart Association - Michigan
Pediatric Congenital Heart Association - Ohio
Pediatric Congenital Heart Association - Tennessee
Pediatric Congenital Heart Association - Virginia
Pediatric Congenital Heart Association - Washington
Sisters By Heart
The Society of Thoracic Surgeons
Yellow Brick Road: The Holden Flynn Foundation