

March 9, 2016

The Honorable Roy Blunt
Chairman, Appropriations Subcommittee on
Labor, Education, and Health and Human Services
Russell Senate Office Building, Room 260
Washington, DC 20510

The Honorable Patty Murray
Ranking Member, Appropriations Subcommittee on
Labor, Health and Human Services, and Education
Dirksen Senate Office Building, Room 131
Washington, DC 20510

The Honorable Tom Cole
Chairman, Appropriations Subcommittee on
Labor, Education, and Health and Human Services
Rayburn House Office Building, 2358-B
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member, Appropriations Subcommittee on
Labor, Health and Human Services, and Education
Longworth House Office Building, 1016
Washington, DC 20510

Dear Senators Blunt and Murray and Representatives Cole and DeLauro:

As organizations dedicated to supporting public health and biomedical research, as well as comprehensive care for individuals living with congenital heart disease, we are writing to respectfully request that the Subcommittees continue to support congenital heart disease research and surveillance initiatives within the Labor, Education, Health and Human Services appropriations bill for FY2017.

Congenital heart disease is the most common birth defect and the leading cause of birth defect-related infant mortality. Nearly 1 in 100 babies are born with congenital heart disease - five percent of which will not live to see their first birthday. Even for those who receive successful intervention, it is not a cure. Children and adults with congenital heart disease require ongoing, costly, specialized cardiac care and face a lifelong risk of permanent disability and premature death. As a result, healthcare utilization among the congenital heart disease population is significantly higher than the general population. It is estimated that compared to their peers, the medical costs for individuals with congenital heart disease are 10 to 20 times greater. Hospitalization costs for pediatric patients with congenital heart disease alone total more than \$5.6 billion each year, which is 15 percent of all hospitalization costs for patients 20 years of age and younger.

Previous Congressional investment for congenital heart disease activities supported by the Center for Disease Control's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) has funded the development of innovative surveillance strategies among children, adolescents and adults with congenital heart defects, which has led to the standardization of research methods and an increased understanding of the public health burden of this condition. Continued federal investment is necessary to provide rigorous epidemiological and longitudinal public health surveillance and public health research on infants, children, adolescents and adults to better understand congenital heart disease at every age, improve outcomes and reduce costs.

We urge Congress to:

- Provide \$10.0 million in FY2017 to the CDC's NCBDDD to support surveillance and public health research focused on addressing the lifelong needs of the growing population of Americans with congenital heart disease
- Provide \$34.5 billion in FY2017 to the National Institutes of Health to support efforts to develop innovative and cost effective treatment options for those living with congenital heart disease

We thank you and commend you for your leadership in ensuring that our federal commitment to investments that improve our nation's health outcomes for congenital heart disease do not falter.

Sincerely,

335 Heart Foundation, Inc.
Adult Congenital Heart Association
Alliance for Adult Research in Congenital Cardiology
American Academy of Pediatrics
American College of Cardiology
American Heart Association
Children's Cardiomyopathy Foundation
Children's Heart Foundation
Congenital Heart Defect Coalition
Congenital Heart Defects Families Association
Ethan M. Lindberg Foundation
Kids With Heart National Association for Children's Heart Disorders, Inc
Little Hearts, Inc.
Louisiana Pediatric Cardiology Foundation
Mended Little Hearts
National Birth Defects Prevention Network
Parents of CHD Warriors and Angels - A Place for Support
Pediatric Congenital Heart Association
Pediatric Stroke Network, Inc.
Sisters By Heart
The Corbin Story Fund
The Newborn Coalition
The Society of Thoracic Surgeons
Yellow Brick Road: The Holden Flynn Foundation