



Pediatric Congenital
Heart Association

October 27, 2015

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

Representative Adam Schiff
2112 Rayburn House Office Building
Washington, D.C. 20515

Dear Representatives Bilirakis and Schiff:

On behalf of the Pediatric Congenital Heart Association, I would like to offer our strong endorsement and support of the Congenital Heart Futures Act Reauthorization of 2015. Thank you for your leadership in introducing this bipartisan legislation, which builds upon existing programs to track the epidemiology of congenital heart disease (CHD), raises the awareness of CHD, and promotes lifelong CHD research.

CHD is the most common birth defect and the leading cause of birth defect-related infant mortality. Nearly 1 in 100 babies are born with CHD; one of those babies born with CHD is Barrett Chenevert of Minneapolis, Minnesota. Barrett was seemingly healthy at birth. However, less than 24 hours old he became critically ill and was diagnosed with congenital heart disease. His immediate survival was quickly called into question. He was urgently transferred by jet to the closest children's hospital nearly 4 hours away to undergo life-saving surgery on his walnut-sized heart. Barrett is now 18 months old, and the only sign of those early days of crisis is his zipper-like scar. Yet, there is no cure for congenital heart disease. Barrett will require ongoing, specialized, and costly cardiac care and his long-term outcome is unknown. The improved public health research and surveillance called for in the Congenital Heart Futures Act Reauthorization will help us better understand and improve long-term outcomes for Barrett and the more than 40,000 babies born with CHD each year.

The Congenital Heart Futures Act Reauthorization affirms the importance of continued federal investment in rigorous epidemiological and longitudinal public health surveillance research and education and awareness at the Centers for Disease Control and Prevention (CDC) to assess the lifelong needs of individuals with CHD and to raise attention to the public health burden of CHD across the lifespan. In addition, the legislation promotes biomedical research at the National Institutes of Health (NIH) on the diagnosis, treatment, prevention and long-term outcomes in CHD.

We look forward to working with you to advance this legislation in Congress.

Sincerely,

David Kasnic
Executive Director

