

October 27, 2015

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

The Hon. Adam Schiff
2411 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Bilirakis and Congressman Schiff:

On behalf of the millions of individuals with congenital heart defects/disease (CHD), the Adult Congenital Heart Association (ACHA) is pleased to endorse the reauthorization of the Congenital Heart Futures Act. The ACHA is a national not-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart disease (CHD). ACHA serves and supports the more than one million adults with CHD, their families and the medical community to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and promotion of ACHD research.

Congenital heart defects are the most prevalent birth defect, affecting nearly 1 in 100 babies; more than five percent will not live to see their first birthday. Those who receive successful intervention are not cured. In fact, the success of childhood cardiac intervention has created a new chronic disease – Congenital Heart Disease (CHD). Children and adults with CHD require ongoing, costly, specialized cardiac care, and face a lifelong risk of permanent disability and premature death. Thanks to the increase in survival, of the over 2 million people alive today with CHD, more than half are adults.

Your legislation will ensure that the expanded infrastructure to track the epidemiology of CHD at the CDC and increased research on CHD across the lifespan at the NIH will remain in place. These efforts have improved our understanding of CHD across the lifespan, the age-specific prevalence, and factors associated with dropping out of appropriate specialty care. This comprehensive approach will address an important public health issue and improve the quality of life and care for individuals with CHDs. The CDC and NIH will be able to build upon existing successful programs, including:

- Assessing the current research needs and projects related to CHDs across the lifespan at NIH will allow us to better understand the current state of biomedical research and what gaps may exist.
- Expanding the CDC's research into CHDs will facilitate understanding of CHD across the lifespan, including understanding healthcare utilization and demographics, leading to evidence-based practices and guidelines for CHDs.

- The authorization of a CDC awareness, outreach and education campaign is critically important. Few congenital heart survivors are aware of their high risk of additional problems as they age, though they face high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death. Half of all congenital heart survivors have complex problems for which lifelong care from congenital heart specialists is recommended, yet less than 10% of adult congenital heart patients receive recommended cardiac care. The awareness campaign will help identify the people who need to remain in care.

Thank you for introducing this important legislation and your leadership on behalf of the CHD community. We look forward to working with you and your staff to pass this critical legislation.

Sincerely,



Glenn R. Tringali
National Executive Director
Adult Congenital Heart Association