

Opening Statement of Rep. Bilirakis
Subcommittee on Health
Markup on H.R. 1222, H.R. 2410, and H.R. 2430, the FDA
Reauthorization Act of 2017
May 18, 2017

Thank you Mr. Chairman.

My Amendment In the Nature of a Substitute makes minor technical changes based on feedback from HHS.

H.R. 1222, the Congenital Heart Futures Reauthorization Act will ensure continued investment in surveillance research to assess the lifelong needs of individuals with congenital heart defects, or CHD.

These surveillance efforts will help improve our understanding of CHD across the lifespan, from birth to adulthood.

This research will help us learn more about demographic factors such as age, race, gender or ethnicity.

In addition, the legislation emphasizes the need for continued biomedical research at the National Institutes of Health on the diagnosis, treatment, and prevention of CHD.

NIH will further research into the causes of congenital heart defects, including genetic causes, and study long-term outcomes in individuals with CHD of all ages.

NIH may study longitudinal data to identify effective treatments and outcomes, and identify barriers to lifelong care for individuals with congenital heart defects.

I was proud to be one of the original authors of this bill when it was first introduced back in 2009 with my colleague, Congressman Zack Space, a former member of this Committee.

And I am proud to be able to champion this bipartisan reauthorization bill with my colleague, Congressman Adam Schiff.

This bill has the strong support of the

- Adult Congenital Heart Association,
- Pediatric Congenital Heart Association,
- Congenital Heart Defects Families Association,
- American College of Cardiology,
- Children's Heart Foundation,
- American Society of Echocardiography
- The Society of Thoracic Surgeons,
- the American Heart Association,
- and the National Down Syndrome Society.

CHD is the most common birth defect and the leading cause of birth defect-related infant mortality.

It is a true public health issue and, as late-night show host Jimmy Kimmel noted just a few weeks ago, it does not discriminate by race, gender or socio-economic status.

The road ahead may be scary and uncertain for any parent with a newborn who has CHD, but this bill helps give hope to those coping with the diagnosis.

Nearly 1 in 100 babies are born with a CHD and more than five percent will not live to see their first birthday.

Even for those who receive successful intervention, it is not a cure.

Children and adults born with CHD require ongoing, costly, specialized cardiac care, and face a lifelong risk of permanent disability and premature death.

As a result, healthcare utilization among the CHD population is significantly higher than the general population.

It is estimated that compared to their peers, the medical costs for individuals with congenital heart defects are 10 to 20 times greater.

Hospitalization costs for pediatric patients 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.

Despite its prevalence and significance, there are still gaps in research and standards of care for CHD patients.

Originally passed in 2010, the bipartisan Congenital Heart Futures Act called for expanded infrastructure to track the epidemiology of congenital heart defects at CDC and increased lifelong research at the NIH.

Previous Congressional support for the congenital heart defect activities at the CDC's National Center on Birth Defects and Developmental Disabilities has yielded an increased understanding of the public health burden of this condition.

But for the sake of the estimated 40,000 babies who will be born in the next year with CHD, there's more work to be done.

I ask for the adoption of this amendment in the nature of a substitute and for swift passage of the bill.