

## Gus joins Durbin, Cochran, & Space to Introduce The Congenital Heart Futures Act

On Tuesday, Gus joined with Assistant Senate Majority Leader Dick Durbin (D-IL), Senator Thad Cochran (R-MS), and Representative Zack Space (D-OH) to introduce bipartisan legislation that increases awareness, education and research into congenital heart disease — a rapidly growing national health problem.

The Congenital Heart Futures Act aims to prevent premature death and disability and increase the quality of life for the nearly 1.8 million people in the United States living with congenital heart disease.

“This legislation would help provide critical information to physicians and those living with congenital heart disease so they can make more informed decisions about their care,” said Bilirakis. “A child is born with a congenital heart defect every fifteen minutes,” said Durbin. “Despite the prevalence of congenital heart disease, research, data collection, education and awareness are limited. This legislation will expand research and broaden its scope to help those currently living with congenital heart disease and perhaps, one day, find cures.

“This legislation builds on recommendations by the National Heart Lung and Blood Institute to support and augment the research being done on congenital heart disease. The research will translate into better clinical treatments for Americans living with congenital heart disease,” said Cochran.

“For too long, we have allowed congenital heart defects to limit, alter, and end the lives of the Americans they afflict. Today, we take a significant step in the effort to end the horrible grip these conditions hold on far too many,” said Space.

There are over 30 types of congenital heart defects, which occur when the structures of the heart are malformed, missing or in the wrong place during development. Heart defects are the most common and most deadly form of birth defects, affecting nearly 1% of births (approximately 36,000 a year). A child is born with a congenital heart defect every 15 minutes. These defects cause congenital heart disease—cardiovascular problems caused by the birth defect.

In 2004, the National Heart Lung and Blood Institute (NHLBI) convened a working group on congenital heart disease, which recommended developing a research network to conduct clinical research, establishing a national database of patients, and creating an outreach education program on the need for continued cardiac care. Today’s Congenital Heart Futures Act builds upon the NHLBI’s recommendations by:

- Increasing public education and medical community awareness of congenital heart disease through a comprehensive public education and awareness campaign carried out by the Centers for Disease Control and Prevention (CDC);
- Developing a National Congenital Heart Disease Registry at the CDC to track the epidemiology of congenital heart disease;
- Creating an Advisory Committee on Congenital Heart Disease within CDC to provide expert information and recommendations regarding the development and operation of the Registry and other matters;
- Promoting the coordination and expansion of the NHLBI’s congenital heart disease research, including a focus on causation; long term outcomes; diagnosis, treatment and prevention; longitudinal studies; and barriers to care.

While, there is currently no cure for congenital heart disease, modern medicine has made major advances in treating heart defects in newborns. In 1950, a child born with a congenital heart defect only had a 20% chance of surviving, but today that number has increased to 90%. Due to the increase in childhood survival rates, the population of people living with congenital heart disease increases by an estimated 5% every year.

Survivors of successful childhood intervention, however, face life-long risks including heart failure, rhythmic disorders, stroke, renal dysfunction, and neuro-cognitive dysfunction. The estimated life expectancy for those with congenital heart disease is significantly lower than for the general population — age 55 for those with moderately complex heart

defects and 35 to 40 for those with highly complex defects. Less than 10% of adults living with complex congenital heart disease currently receive recommended cardiac care, and many are unaware that they require life-long specialized health surveillance.