

## COLUMN | The Congenital Heart Futures Act

Every fifteen minutes a child is born with a congenital heart defect. These defects are the most common and most deadly form of birth defects, affecting nearly 1% of births or about 36,000 newborns a year. There are over 30 different forms of congenital heart defects, which occur when the structures of the heart are malformed, missing or in the wrong place during development.

Survivors of successful childhood intervention 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.

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 mere 20% chance of survival, 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.

Despite the prevalence of congenital heart disease, research, data collection, education and awareness are limited. We must do all we can to combat this rapidly growing national health problem. That is why I 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.

The Congenital Heart Futures Act seeks to prevent premature death and disability while increasing the quality of life for the nearly 1.8 million people in the United States living with congenital heart disease. Building on recommendations of the National Heart Lung and Blood Institute, the legislation would increase research being done on congenital heart disease and ultimately translate into better clinical treatments for Americans living with heart defects.

My hope is that this legislation will soon be enacted into law to help provide critical information to physicians and those living with congenital heart disease so they can make more informed decisions about their care. For more information on Congenital Heart Disease visit the American Heart Association at [www.americanheart.org](http://www.americanheart.org).

Congressman Gus M. Bilirakis represents Florida's Ninth Congressional District, which includes portions of Pasco, Pinellas, and Hillsborough counties.