BACKGROUND

On February 27, Representatives Gus Bilirakis (R-FL) and Adam Schiff (D-CA) introduced H.R. 1222, the Congenital Heart Futures Reauthorization Act. A companion bill, S. 477, was introduced in the Senate on March 6 by Senators Richard Durbin (D-IL) and Bob Casey (D-PA). The bills seek to expand research for congenital heart defect (CHD) treatments and encourage lifelong, specialized care for patients.

CHDs are problems with the heart’s structure that are present at birth. They are the most common birth defect, impacting about 40,000 babies each year. It is estimated that 2-3 million adults and children are living with CHDs in the US. Approximately half of all children with Down syndrome are born with a CHD. Although common defects can be repaired with a limited risk of death, CHDs in people with Down syndrome early in life have the potential to significantly affect cognitive function and overall health status later in life, and necessitate extensive medical intervention.

First enacted into law in 2010, the Congenital Heart Futures Act has done much to improve the nation’s surveillance, research and education efforts to fight CHD. The law expanded infrastructure to track the epidemiology of CHD at the Centers for Disease Control (CDC) and increased lifelong CHD research at the National Institutes of Health (NIH). Since enactment of the Congenital Heart Futures Act, Congress has appropriated $11 million to the CDC for these activities.

EXPLANATION OF THE CONGENITAL HEART FUTURES REAUTHORIZATION ACT

The Congenital Heart Futures Reauthorization Act would further enhance the CDC’s surveillance of CHD, and promote NIH research, public outreach and education. It would do so by:

- **Assessing the current research needs and projects related to CHD across the lifespan at the NIH** – The bill directs the NIH to assess its current research into CHD so that we can have a better understanding of the state of biomedical research as it relates to CHD.

- **Expanding research into CHD** – The bill directs the CDC to continue to build their public health research and surveillance programs. This would help us understand healthcare utilization and demographics, and lead to evidence-based practices and guidelines for CHD.

- **Raising awareness of CHD through the lifespan** – The bill allows for the CDC to establish and implement a campaign to raise awareness of congenital heart disease. Those who have CHD and their families need to understand their healthcare needs. The campaign would promote the need for pediatric, adolescent and adult individuals with CHD to seek and maintain lifelong, specialized care.

For people with Down syndrome, this legislation has the potential to significantly improve their quality of life. In addition, because CHD is so prevalent in people with Down syndrome, increased federal research focused on diagnosis, treatment, prevention and long-term outcomes of CHD in the Down syndrome population could potentially provide important insights into the cause or causes of the disease and intervention strategies for the broader population.

For more information about the Congenital Heart Futures Reauthorization Act, please contact:

- **Senate**: Senate offices may cosponsor by contacting Jessica McNiece with Senator Richard Durbin at jessica_mcniece@durbin.senate.gov or (202)224-2152.

- **House**: House offices may cosponsor by contacting Shayne Woods with Rep. Gus Bilirakis at Shayne.Woods@mail.house.gov or (202)225-5755.