

**Congress of the United States**  
**Washington, DC 20515**

March XX, 2021

The Honorable Rosa L. DeLauro  
Chair, Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
United States House of Representatives  
Washington, D.C. 20515

The Honorable Tom Cole  
Ranking Member, Subcommittee on Labor,  
Health and Human Services, Education,  
and Related Agencies  
United States House of Representatives  
Washington, D.C. 20515

Dear Chair DeLauro and Ranking Member Cole:

As you begin consideration of the Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill for Fiscal Year 2022, we respectfully request that the Subcommittee continue to support congenital heart disease-related public health research and surveillance initiatives at the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) focused on addressing the lifelong needs of the growing population of Americans with congenital heart defects.

Congenital heart disease (CHD) is the most common birth defect and the leading cause of birth defect-related infant mortality. A baby is born with CHD every 15 minutes. Although we have made significant strides in the treatment of newborns with CHD, 1 in 20 with CHD will not see their first birthday. Even for those who receive an early diagnosis and successful intervention, there is no cure. Children, adolescents, and adults living with CHD require lifelong, costly, specialized cardiac care and face increased risk of disability, co-morbidities, and premature death. Health care utilization among the CHD population is significantly higher than the general population – the \$5.6 billion in annual pediatric CHD hospitalization costs account for 15 percent of all hospitalizations expenditures for patients 20 years of age and younger.

Historically, congressional investments in CHD activities at the CDC's NCBDDD have supported birth defects tracking systems to gather data and inform research on pregnancy exposures, risk factors, and new screening methods. With the passage of the Congenital Heart Futures Act in 2010, NCBDDD has broadened its efforts to conduct surveillance on the growing population of adolescents and adults living with CHD. Federal investments are necessary to build upon efforts to gather and study epidemiological and longitudinal data on CHD patients across the lifespan to minimize disparities, improve health outcomes, and reduce medical costs.

We thank you and commend you for your leadership in ensuring robust, targeted federal commitments to programs and agencies that improve our nation's public health, and health outcomes for many diseases and disorders, including congenital heart disease.

Sincerely,

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Gus M. Bilirakis  
Member of Congress

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Adam B. Schiff  
Member of Congress