

Support Congenital Heart Disease Research

Sign Appropriations Letter

Deadline: March 18th

Dear Colleague:

Please join us in signing the attached letter to Chairman Tom Cole and Ranking Member Rosa DeLauro to encourage the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies' continued federal investment in public health research and surveillance initiatives focused on addressing the lifelong needs of the growing population of Americans with congenital heart disease.

Congenital heart disease (CHD) is the most common birth defect and the leading cause of birth defect-related infant mortality. 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 disease 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 gaps in research and standards of care for CHD patients. Previous Congressional support for the congenital heart disease activities at the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) has yielded an increased understanding of the public health burden of this condition. Continued federal investment is necessary to provide rigorous epidemiological and longitudinal public health surveillance and research on infants, children, adolescents, and adults to better understand congenital heart disease across the lifespan, improve outcomes, and reduce costs.

We ask that you join us in supporting robust congenital heart research by adding your name to the attached letter. If you are interested in signing on, please contact Kristin Seum with Representative Bilirakis at kristin.seum@mail.house.gov or Dao Nguyen with Representative Schiff at dao.nguyen@mail.house.gov. The deadline to sign onto this letter is COB March 18, 2016.

Sincerely,

Representative Gus M. Bilirakis

Representative Adam Schiff

March XX, 2016

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
United States House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
United States House of Representatives
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

As you begin consideration of the Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill for fiscal year 2017, 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. Increased federal investments are necessary to gather epidemiological and longitudinal data on CHD patients across the lifespan to 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,

Representative Gus M. Bilirakis

Representative Adam Schiff