

April XX, 2018

The Honorable Roy Blunt
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
United States Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
United States Senate
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray:

As you begin consideration of the Fiscal Year (FY) 2019 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations bill, we respectfully request that the Subcommittee continue to support congenital heart disease (CHD) research, surveillance, and awareness initiatives at the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD). The critical efforts are focused on helping build the knowledge base to address the lifelong needs of the growing population of Americans with congenital heart defects.

Congenital heart defects are the most common and deadliest birth defect. There are an estimated 2.4 million Americans living with CHD. Every 15 minutes a child is born with a heart defect, and 1 in 20 children with CHD will not see their first birthday. Early detection of CHD can be lifesaving, and significant strides in screening and treatment have been made—90 percent of youth with CHD live into adulthood. However, even for those who receive an early diagnosis and successful surgery, there is no cure. Children, adolescents, and adults living with CHD require lifelong, specialized cardiac care and face increased risk of disability, co-morbidities, and premature death. Hospitalizations for CHD total \$6.1 billion annually.

Historically, congressional investments in CHD activities at the CDC's NCBDDD have improved care and understanding of CHD through data collection and research activities on pregnancy exposures, risk factors, and screening methods. Due to the increase in childhood survival rates, NCBDDD has broadened its efforts to conduct surveillance and improve understandings of the best care for the growing population of adolescents and adults living with CHD. Robust federal investments are necessary to gather epidemiological and longitudinal data on CHD patients across the lifespan to improve health outcomes and reduce medical costs.

Thank you for your continued commitments to programs that improve our nation's public health and outcomes for many diseases and disorders, including congenital heart disease.

Sincerely,

Richard J. Durbin
United States Senator

Charles E. Grassley
United States Senator