

March 10, 2011

The Honorable Tom Harkin
Chairman
Senate Labor-Health and Human Services-
Education Appropriations Subcommittee
U.S. Senate
Washington, DC 20510

The Honorable Dennis Rehberg
Chairman
House Labor-Health and Human Services-
Education Appropriations Subcommittee
U.S. House of Representatives
Washington, DC 20515

The Honorable Richard Shelby
Ranking Member
Senate Labor-Health and Human Services-
Education Appropriations Subcommittee
U.S. Senate
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
House Labor-Health and Human Services-
Education Appropriations Subcommittee
U.S. House of Representatives
Washington, DC 20515

Dear Chairmen Harkin and Rehberg and Ranking Members Shelby and DeLauro:

As organizations dedicated to supporting public health programs, research and comprehensive care for individuals living with congenital heart disease (CHD) we are writing to respectfully request that you provide FY 2012 funding to conduct surveillance of CHD at the Centers for Disease Control and Prevention (CDC) and provide resources for research on CHD at the National Heart, Lung and Blood Institute (NHLBI). The CDC and NHLBI are taking steps to address surveillance and research related to the most common birth defect in the United States and a leading cause of child mortality. However, the success of childhood cardiac intervention has created a new chronic disease – congenital heart disease. Those who receive successful intervention will need life-long specialized cardiac care and face high rates of neuro-cognitive deficits, heart failure, rhythm disorders, stroke, and sudden cardiac death. Thanks to the increase in survival, of the nearly 2 million people alive today with CHD, more than half are adults.

Despite the prevalence and seriousness of the disease, CHD data collection and research are limited. In 2004, the NHLBI convened a working group on CHD, which recommended developing a research network to conduct clinical research and establishing a national database of patients. Thus, the CDC and NHLBI need resources to continue and expand their efforts. Federal support for congenital heart disease surveillance through the CDC and research through the NHLBI will help prevent premature death and disability in this rapidly-growing and severely under-served population.

The National Congenital Heart Disease Surveillance System will collect and analyze nationally-representative, population-based epidemiological and longitudinal data on infants, children, and adults with CHD to improve understanding of CHD incidence, prevalence, and disease burden, as well as assess the public health impact of CHD. The NHLBI will conduct or support research on CHD diagnosis, treatment, prevention and long-term outcomes to address the needs of affected infants, children, teens, adults, and elderly individuals.

We urge Congress to:

- **Provide** \$3.0 million in FY 2012 to the CDC to support data collection to better understand CHD prevalence and assess the public health impact of CHD. This level of funding will support a pilot adult surveillance system (\$1.75 million) and allow for the enhancement of the existing birth defects surveillance system (\$1.25 million).
- **Support** NHLBI's efforts to expand research targeted to the diverse life-long needs of individuals living with CHD.

Should you or your staff have any questions, please do not hesitate to contact Amy Basken, Advocacy Staff, Adult Congenital Heart Association and Children's Heart Foundation, at amy.basken@achaheart.org / (608) 370-3739, or government relations staff at any of our organizations.

We understand that the nation faces unprecedented financial challenges and are requesting only limited funding for resources to ensure our nation makes progress in its effort to address the life-long needs of individuals living with CHD. Thank you for your support of federal programs that will improve the quality of life and reduce long-term costs for CHD survivors.

Sincerely,

Adult Congenital Heart Association
American Academy of Pediatrics
American College of Cardiology
American Heart Association
Children's Heart Foundation
March of Dimes
Mended Little Hearts
The Society for Cardiovascular Angiography and Interventions