FOR THE FIRST TIME IN U.S. HISTORY, CONGRESS ADDRESSES THE NEEDS OF THE CONGENITAL HEART DEFECT POPULATION BY INTRODUCING THE ‘CONGENITAL HEART FUTURES ACT’

There Are Approximately 650,000 Children and 1,300,000 Adults Living in the U.S. with Congenital Heart Defects, a Chronic and Deadly Disease

CHICAGO, Ill. – March 12, 2009 – Senator Richard Durbin (D-IL) and Congressman Zack Space (D-OH) today introduced new legislation that, for the first time in history, will address the needs of those affected by congenital heart defects (CHDs) – America’s most common birth defect that affects approximately one out of 120 babies each year.

“A child is born with a congenital heart defect every fifteen minutes,” says Senator Richard Durbin (D-IL). “Despite the prevalence of congenital heart defects, research, data collection, education and awareness are limited. This legislation will expand research and broaden its scope to help those currently living with congenital heart defects and perhaps, one day, find a cure.”

The Children’s Heart Foundation (CHF) – the country’s leading organization solely dedicated to funding CHD research – is one of five organizations that participated in National Congenital Heart Lobby Day on February 10. The day united organizations that support the National Congenital Heart Coalition (NCHC) in an effort to persuade senators and representatives to fund important initiatives surrounding congenital heart defects (CHDs). The CHF joined the Adult Congenital Heart Association (ACHA), Congenital Heart Information Network (CHIN), It’s My Heart (IMH) and Mended Little Hearts (MLH) in the nation’s capitol to lobby for the ‘Congenital Heart Futures Act,’ legislation calling for federal funding of congenital heart disease research, a national patient registry and education.

“For too long, we have allowed congenital heart defects to limit, alter, and end the lives of the Americans they afflict,” says Representative Zack Space (D-OH). “Today, we take a significant step in the effort to end the horrible grip these conditions hold on far too many.”

The ‘Congenital Heart Futures Act’ will be of great benefit to congenital heart disease patients, who represent nearly one percent of all live births each year. Thanks to medical advances, this population has
increased by an estimated five percent each year. However, adults living with congenital heart disease receive substandard care and face a high risk of premature disability and death and need lifelong health surveillance. An essential goal of the Children’s Heart Foundation is to support national advocacy to improve and prolong the lives of all who are born with heart defects and to prevent congenital heart disease.

“We’re taking a significant step to advocate for the increase public funding of congenital heart defect efforts,” says Bill Foley, Executive Director of The Children’s Heart Foundation. “The legislation will increase research surrounding the cause, diagnosis, treatment, prevention, long-term outcomes and barriers to care for all CHD patients. I am extremely pleased with the outcome of our lobby efforts and we look forward to seeing the ‘Congenital Heart Futures Act’ evolve and truly make a difference in the lives of those with CHDs.”

The legislation is also meant to promote CHD awareness by creating a comprehensive public education and awareness campaign targeted toward the general public as well as the medical community. Finally, it will increase surveillance by encouraging the enhancement and expansion of its infrastructure to track the epidemiology of CHDs into a nationwide registry of actual occurrences.

Important next steps for the Children’s Heart Foundation in concert with the NCHC include securing a number of critical co-sponsors in the House and Senate who will support the passage of this history making legislation. The CHF and coalition members will unite to seek the additional votes necessary to address the needs of congenital heart disease survivors, a severely underserved population.

**About The Children’s Heart Foundation**

Headquartered in Lincolnshire, Illinois, the Children’s Heart Foundation is the country’s leading organization committed to funding research to help find better treatments – and hopefully someday a cure – for children born with congenital heart defects. To date, the Children's Heart Foundation has funded over $3.4 million towards 37 research projects led by the nation’s best and most promising research teams – several of which have gone on to receive funding from the National Institute of Health (NIH) and the American Heart Association (AHA). The Children’s Heart Foundation is the only organization created solely to fund congenital heart defect research. There are currently six chapters nationwide, and each continues to expand. The Foundation is not affiliated with any one medical institution or organization, which ensures that the most promising congenital heart defect research continues to get funded anywhere in the world.

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