

“CONGENITAL HEART FUTURES ACT” INTRODUCED IN U.S. HOUSE AND SENATE

The National Congenital Heart Coalition and the American College of Cardiology Praise Senator Durbin and Representative Space for Addressing the Needs of Congenital Heart Disease Patients

WASHINGTON, D.C. – March 18, 2009 – Senator Richard Durbin (D-IL) and Representative Zack Space (D-OH) yesterday introduced new legislation that, for the first time in history, will address the needs of the millions of children and adults affected by congenital heart defects (CHDs). Congenital heart defects are America’s most common birth defect and affect approximately one out of 120 babies each year. A congenital heart defect is a malformation in the heart which leads to congenital heart disease. The success of childhood cardiac intervention has created a new chronic congenital heart disease population among adults.

“A child is born with a congenital heart defect every fifteen minutes,” said Senator Richard Durbin (D-IL). “Despite the prevalence of congenital heart disease, 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 disease and perhaps, one day, find cures.”

The “Congenital Heart Futures Act” calls for federal funding of congenital heart research, a national congenital heart registry, and education and awareness in congenital heart disease. The proposed legislation will substantially improve the quality of life for all people affected by congenital heart disease as well as future generations.

"This legislation addresses the needs of the millions of children and adults affected by the nation's number one birth defect. We applaud Senator Durbin and Representative Space for their leadership on this critical issue and encourage congressional action for this underserved patient community," said W. Douglas Weaver, M.D., F.A.C.C., President of the American College of Cardiology, which has partnered with the National Congenital Heart Coalition to promote the passage of this legislation.

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

“Due to medical advances, for the first time, there are more adults living with congenital heart disease than children and this is a completely new population of patients,” said Amy Verstappen, President of the Adult Congenital Heart Association. “It is important to treat congenital heart problems as chronic diseases which require increased public awareness and surveillance efforts to ensure that children and adults are educated about the specialized cardiac care they will require throughout life.”

The research and registry called for in the “Congenital Heart Futures Act” will be of great benefit to congenital heart disease patients of all ages, who represent nearly one percent of all live births each year. Thanks to medical advances, this population increases by five percent each year as the large majority of patients now receive successful childhood cardiac intervention. These treatments are not curative and the majority of those living with repaired congenital heart conditions require life-long special cardiac care. Unfortunately, many adults

living with congenital heart disease receive substandard care and face a high risk of premature disability and death. The National Congenital Heart Coalition's goal is to support national policies that will address the needs of the patients in this severely underserved population.

About The National Congenital Heart Coalition (NCHC)

The National Congenital Heart Coalition is a group of seven national congenital heart organizations – Adult Congenital Heart Association (ACHA), The Children's Heart Foundation (CHF), Children's Health Information Network (CHIN), It's My Heart (IMH), Little Hearts, Inc., Mended *Little* Hearts (MLH), and Saving Little Hearts (SLH) – that share a desire to prevent congenital heart disease and improve and prolong the lives of congenital heart survivors. The NCHC supports the passage of the 'Congenital Heart Futures Act'.