



**Pediatric Congenital
Heart Association**

April 14, 2015

Senator Chuck Grassley
135 Hart Senate Office Building
Washington, D.C. 20510

Senator Michael Bennet
458 Russell Senate Office Building
Washington, D.C. 20510

Representative Joe Barton
2107 Rayburn House Office Building
Washington, D.C. 20515

Representative Kathy Castor
205 Cannon House Office Building
Washington, D.C. 20515

Dear Senators Grassley and Bennet and Representatives Barton and Castor:

On behalf of the Pediatric Congenital Heart Association, I would like to offer our strong endorsement and support of the Advancing Care for Exceptional Kids Act (ACE Kids Act) of 2015 (S. 298/H.R. 546). Thank you for your leadership in introducing this bipartisan legislation to improve care for medical complex children with on Medicaid.

Congenital heart disease (CHD) is the most common birth defect with nearly 1 in 100 babies born with CHD. One quarter of the babies born with a heart defect will require an invasive and potentially life saving intervention within their first year of life. Even with successful intervention, it is not a cure. Children with CHD require ongoing, costly and specialized cardiac care. As a result, the medical costs of children with congenital heart disease are an estimated 10 to 20 times greater than that of their peers. Hospitalization costs of pediatric patients total more than \$5.6 billion annually, which represents 15 percent of all hospitalization costs for patients 20 years of age or younger. This represents a significant public health burden, given that one in every three children with CHD are enrolled in Medicaid.

The ACE Kids Act will create better care coordination, improve the standards of care, and reduce medical costs for the 2 million children complex medical conditions, including those with congenital heart disease. This measure will help ensure that every child with a congenital heart defect will be able to see a pediatric cardiologist that is right for their condition – regardless of where the child lives – while creating national standards for data reporting that will help fill our knowledge gaps of the prevalence, impact and public health burden of CHD.

We look forward to working with you to advance this legislation in Congress.

Sincerely,

David Kasnic
Executive Director
Pediatric Congenital Heart Association

