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*The mission of the American College of
Cardiology and the American College
of Cardiology Foundation is to transform
cardiovascular care and improve heart health.*

April 27, 2015

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

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

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

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

Dear Sen. Grassley, Sen. Bennet, Rep. Barton and Rep. Castor:

On behalf of the American College of Cardiology (ACC), I am pleased to offer our strong support for S. 298/H.R. 546, the *Advancing Care for Exceptional (ACE) Kids Act of 2015*. The ACC is a 47,000-member medical society that is the professional home for the entire cardiovascular care team. The mission of the College is to transform cardiovascular care and to improve heart health. The ACC leads in the formation of health policy, standards and guidelines. The College operates national registries to measure and improve care, provides professional medical education, disseminates cardiovascular research and bestows credentials upon cardiovascular specialists who meet stringent qualifications. The ACC also produces the *Journal of the American College of Cardiology*, ranked number one among cardiovascular journals worldwide for its scientific impact.

S. 298/H.R. 546, the *Advancing Care for Exceptional (ACE) Kids Act of 2015*, would extend medical assistance to payment for items and services furnished under a Medicaid Children's Care Coordination (MCCC) Program. ACE is voluntary for states, providers and families. It would improve care for children with medical complexity by facilitating more seamless care for Medicaid children who see multiple providers across state lines. It would also enable the gathering of national level data on rare, complex conditions to determine best practices and drive continued improvement in care. It would require MCCC programs to coordinate, integrate, and provide a full range of services to enrolled children including pediatric care management, care coordination and health promotion. It would also establish a nationally designated children's hospital network to reduce hospitalizations and emergency room visits. These are laudable goals that would truly advance care for our most vulnerable patients, in complete alignment with the mission of the ACC.

According to the [Centers for Disease Control](#), congenital heart defects (CHDs) are the most common type of birth defect. Access to proper care allows babies born with these conditions to live longer and healthier lives. CHDs affect nearly 1% of—or about 40,000—births per year in the United States.

About 25% of CHD cases are critical and require surgery or other procedures within the first year of life. From 1999–2006, there were 41,494 deaths in the United States that were caused by or directly related to CHDs. Nearly half (48%) of these deaths due to CHDs occurred during infancy (younger than 1 year of age).

The nation has a significant population of medically complex children with exceptional health care needs enrolled in Medicaid. Analysis suggests there are some 2 million of these children in Medicaid representing around 6% of children in the program. Despite their small numbers, this 6% represents 40% of the Medicaid spending on children, presenting both a cost challenge to the nation and an opportunity to address possible quality and cost savings in their care.

The American College of Cardiology would like to commend Senator Portman and Senator Bennet for authoring the budget resolution amendment that encourages Congress to focus on medically complex children. The ACC and its Pediatric Council looks forward to working with you to build support for S. 298/H.R. 546 and see that it moves forward in Congress. For more information on Congenital Heart Disease or ACC's priorities, please contact Nick Morse (nmorse@acc.org) or Charles Cascio (ccascio@acc.org)

Thanks very much for your leadership on this issue.

Sincerely,



Kim Allan Williams Sr., MD, FACC, FAHA, FASNC
President