

Adult  
Congenital  
Heart   
Association



American  
Heart  
Association.



Pediatric Congenital  
Heart Association

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

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

Representative Joe Barton  
2107 Rayburn House Office Building  
Washington, DC 20515

Representative Kathy Castor  
2052 Rayburn House Office Building  
Washington, DC 20515

Dear Senators Grassley and Bennet and Representatives Barton and Castor:

On behalf of the millions of volunteers, families, and kids dedicated to improving the health and quality of care for patients with cardiovascular disease, including congenital heart defects, we are writing to offer our support for the Advancing Care for Exceptional Kids Act of 2017, or the ACE Kids Act (S. 428). We urge Congress to pass this bill into law and establish better coordination of care for our medically complex children.

Congenital heart defects are the most common birth defect in the United States. Nearly 40,000 infants are born with some type of congenital heart defect each year. Thanks to advances in research, treatments, and early detection and diagnosis, most infants born with a congenital heart defect now survive and live longer lives. It is estimated that there are at least 2.4 million individuals living in the United States with a congenital heart defect. However, survivors, particularly those with more complex forms of congenital heart defects, are more likely to develop additional heart problems later in life and have co-morbidities that need coordinated care throughout the life-span. Unfortunately, many of these survivors do not receive the care they need.

Therefore, we support the ACE Kids Act and efforts to improve care for children with complex medical conditions, such as congenital heart defects. Specifically, the creation of Enhanced Pediatric Health Homes (EPHH) and nationally designated children's hospital networks would improve coordination of care for children with serious congenital heart defects by linking pediatric resources across multiple providers. These networks would also help to remove barriers to highly specialized care by allowing kids covered by Medicaid and the Children's Health Insurance Program to access the full range of care they need, including providers across state lines.

As a part of the EPHH, care coordination and transition services are vital to the long-term outcomes for children with CHD. Providing children with the right care, from the right providers, at the right time is critical to the long-term success of these children. The fee-for-service health care system has resulted in fragmentation of care for children with a CHD. This legislation creates a state option in Medicaid in

which the payment model would follow the structure of Medicaid Health Homes. States, working with CMS, will be encouraged to develop alternative payment methodologies involving risk sharing and performance-based models. We strongly advocate for patient/family engagement in the development of these models, as well.

The ACE Kids Act would also collect data and develop standards of care to help researchers and providers improve treatments for kids with congenital heart defects. Increased care coordination and data collection are not only critical to improving health outcomes for kids with congenital heart defects but to reducing health care costs, too.

We have made tremendous progress in our understanding and treatment of congenital heart defects, but we have a long way to go. People with congenital heart defects still face life-long health risks, and the ACE Kids Act is an important step towards helping these kids live longer, healthier lives.

We thank you for your support on this important issue and look forward to working together with you to move this legislation through Congress.

Sincerely,

Adult Congenital Heart Association

American Heart Association

Mended *Little* Hearts

Pediatric Congenital Heart Association