



Pediatric Congenital
Heart Association

Pediatric Congenital Heart Association 2017 Policy Priorities

1) Support Congenital Heart Disease Research at the National Institutes of Health (NIH)

- Advocate for adequate funding
- Advocate for multi-centered research across the lifespan specific to congenital heart disease
- Advocate for genomic research on congenital heart defects and other structural birth defects
- Promote research outputs and publications
- Recruit co-sponsors for Congenital Heart Futures Reauthorization Act

2) Support Congenital Heart Disease Research and Surveillance at the Centers for Disease Control and Prevention (CDC)

- Advocate for increased funding
- Advocate for public health research, surveillance and awareness activities that address congenital heart disease across the lifespan
- Promote research outputs and publications
- Recruit co-sponsors for Congenital Heart Futures Reauthorization Act

3) Promote public reporting activities through the Centers for Medicare and Medicaid Services

- Engage CMS in exploring possible levers to promote increased participation in public reporting activities

4) Increased awareness of the public health burden of Congenital Heart Disease

- Educate members of Congress about CHD
- Encourage co-signing of Dear Colleague Letter
- Encourage participation in CHD Caucus
- Recruit co-sponsors for Congenital Heart Futures Reauthorization Act



5) Support access to appropriate and timely specialized care

- Support key coverage provisions that minimize catastrophic medical debt for patients
- Support education and awareness of lifelong need for specialized care, especially during the transition from pediatric to adult care
- Identify Strategic Partners in addressing this issue

6) Identify opportunities to support the CHD community through endorsement of policy not specific to CHD

- Leverage relationships with strategic partners
- Coalition Participation

