



The Children's Cardiomyopathy Foundation (CCF) was established in 2002 to address the pressing need for more research and education on pediatric cardiomyopathy, a chronic and potentially life-threatening disease that affects the heart's ability to pump blood. CCF supports policies and programs that help to reduce the incidence and potentially fatal impact of the disease by working with Members of Congress, federal agencies, and patient advocacy groups to educate stakeholders on the importance of increased research and education on cardiomyopathies affecting children. By leveraging relationships and advocacy efforts, CCF hopes to achieve the following public policy goals for 2019 & 2020:

Goal 1: Sustain and expand pediatric cardiomyopathy research at the federal level.

Goal 2: Promote the development of pediatric cardiomyopathy materials and resources that will educate the public and stakeholders on the symptoms and risk factors associated with the disease.

CCF intends to accomplish these goals by engaging in the following activities:

- **Establish and strengthen relationships with Members of Congress** with a connection to cardiomyopathy or heart disease, as well as engage with staff at relevant federal agencies, such as the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), to educate them on the public health burden of pediatric cardiomyopathy.
- **Urge the National Heart, Lung, and Blood Institute (NHLBI)** to establish a working group on primary, heritable forms of pediatric cardiomyopathy to identify gaps in basic, translational, clinical, and epidemiological research; and to support the expansion of the North America Pediatric Cardiomyopathy Registry (PCMR) through multi-center studies.
- **Encourage the CDC to integrate information** about the symptoms, risk factors, and family health history component of cardiomyopathy into the agency's related initiatives, programs, and materials, and to promote these educational resources to the general public.
- **Secure appropriations report language** in a Congressional funding bill to request surveillance and public health research at the CDC and to encourage the NHLBI to continue supporting the research initiatives of the PCMR and related scientific conferences.
- **Support the inclusion of cardiomyopathy as a designated research topic** under the Congressionally Directed Peer Review Medical Research Program at the Department of Defense.
- **Promote the passage of legislation** that would expand federal funding options for early career and established researchers and/or would establish federal programs aimed at developing educational materials and disseminating them through national channels.
- **Track cardiovascular-related legislation** that was previously enacted, such as the Congenital Hearts Future Act, PREEMIE Reauthorization Act, to ensure that cardiomyopathy receives appropriate representation during implementation.
- **Establish partnerships with similarly-situated stakeholder groups** and organizations to collaboratively raise awareness of the symptoms and risk factors for cardiomyopathy, and in particular to promote Children's Cardiomyopathy Awareness Month in September.