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First Bi-Partisan Legislation on Cardiomyopathy Introduced

Children's Cardiomyopathy Foundation Partners with Representatives Andy Kim and Andy Barr on Cardiomyopathy HEARTS Act

TENAFLY, N.J.—March 10, 2020— The Children's Cardiomyopathy Foundation (CCF) is taking an active role in supporting the Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act (H.R. 6166), which is the first bi-partisan legislation focused on cardiomyopathy, a chronic and potentially life-threatening heart disease. The bill, introduced by Reps. Andy Kim (NJ-03) and Andy Barr (KY-06), calls for the establishment of surveillance research on cardiomyopathy across the lifespan and the development of educational materials targeted to school administrators, educators, and families.

Cardiomyopathy can be difficult to detect because symptoms are not obvious. In some cases, it can be misdiagnosed as the flu or asthma. Without proper treatment, the risk of heart failure and sudden cardiac death increases. Little is known about its prevalence and causes even though the condition can be severe in children. The Cardiomyopathy HEARTS bill will facilitate the collection of data to improve understanding of the prevalence and epidemiology of cardiomyopathy from birth to adulthood.

The Cardiomyopathy HEARTS Act will evaluate current cardiomyopathy research initiatives funded by the National Institutes of Health (NIH) and request the Centers for Disease Control and Prevention (CDC) to collect and analyze data related to the impact of cardiomyopathy at a national level. The bill also requests the CDC to implement an awareness and education campaign that includes developing materials on the symptoms of cardiomyopathy, risk factors for sudden cardiac arrest, and school guidelines on automated external defibrillator (AED) placement, CPR/AED training, and implementing a cardiac emergency response plan. These materials will be disseminated to school administrators, educators, school nurses, coaches, and families through state education agencies and health departments.

Allocating more federal resources to cardiomyopathy continues to be a priority for CCF. In the past, CCF worked with Reps. Frank Pallone (NJ-06), Lois Capps (CA-23), Bill Pascrell (NJ-09), and Senator Robert Menendez (D-NJ) on legislation specific to cardiomyopathy. "This new bill brings cardiomyopathy to the forefront and highlights the research and education components that are needed to help physicians, scientists, and the public better understand the disease," states Lisa Yue, CCF's founding executive director.

"Cardiomyopathy poses a real threat to tens of thousands of families across the United States, and it's a concern that I've heard about from people in my district," said Congressman Kim. "I'm proud to work with Congressman Barr and the advocates at the Children's Cardiomyopathy Foundation on this important topic and bring this issue to light. Together, we can help those suffering from cardiomyopathy and work to save lives."

Congressman Barr expressed a similar sentiment, "Cardiomyopathy is an incurable disease affecting one in every five hundred adults and over 30,000 children across our nation. The Cardiomyopathy HEARTS Act will instruct the CDC to conduct important research, collect data, and bring increased awareness of cardiomyopathy to our communities. I look forward to progressing this legislation and educating my constituents about the risks of cardiomyopathy."

In the coming months, CCF will meet with more members of Congress to increase awareness of pediatric cardiomyopathy and encourage them to co-sponsor the bill. “Our next step is to work with Congressmen Kim and Barr and our community of families to get the necessary House support to get this bill passed,” said Lisa Yue. For more information on cardiomyopathy, visit www.childrenscardiomyopathy.org.

About the Children’s Cardiomyopathy Foundation

The Children’s Cardiomyopathy Foundation (CCF) is a national organization focused on finding causes and cures for pediatric cardiomyopathy. The Foundation was established in 2002 to accelerate research and education, increase public awareness and advocacy, and offer support services to affected families. Since then, CCF has grown into a global community of families, physicians, and scientists, raising more than \$15 million in support of its mission.