



ABOUT THE FOUNDATION AND ITS MISSION

The Children's Cardiomyopathy Foundation (CCF) is a national, non-profit organization focused on pediatric cardiomyopathy – a chronic and life-threatening heart disease that strikes children in the prime of their lives. As the only public interest group for this heart disease in children, CCF is dedicated to accelerating the search for cures while improving diagnosis, treatment and quality of life for those affected by pediatric cardiomyopathy.

CCF was founded in 2002 by a parent who lost two young children to cardiomyopathy. Recognizing the need for better support and more research, CCF was established with the purpose of stimulating and funding promising research on the disease, educating and assisting physicians and patients on the complexities of the disease, and increasing awareness and advocacy related to the needs of affected children and their families.

CCF actively works with federal, private and corporate organizations to advance research and medical knowledge on this heart condition. Guided by a medical advisory board, CCF provides information and support to more than 1,800 physicians and 300 families worldwide. The hope is that one day pediatric cardiomyopathy can be prevented and any affected child can be cured to live a full and productive life.

VITAL FACTS ABOUT PEDIATRIC CARDIOMYOPATHY

1. Pediatric cardiomyopathy is a rare condition in which the heart muscle is enlarged or weakened and the ability to pump blood is affected. It is the leading cause for sudden death and heart transplants in children.
2. Pediatric cardiomyopathy can affect any child regardless of age, gender, race or socio-economic status. It has been estimated that at least 30,000 children in the U.S. are affected, comparable to the number of people affected by cystic fibrosis in the U.S. Every year 1,000 new children in the U.S. are born with cardiomyopathy which is nearly 3 times the number of children in the U.S. born with AIDS.
3. Cardiomyopathy can be acquired (i.e. viral infection, associated with other diseases) or be genetic in nature. With the majority of cases, the exact cause is never known.
4. Symptomatic pediatric cardiomyopathy has one of the highest mortality rates of any childhood disease, even higher than childhood cancer. With some forms of cardiomyopathy up to 40% of affected children do not live beyond 5 years from diagnosis.
5. Unlike other congenital heart conditions, there is no surgical procedure or cure that can repair the damaged heart or stop the progression of the disease. There is also no pre-natal or diagnostic genetic test, leaving affected family members with an uncertain future about the health of their children.
6. While pediatric cardiomyopathy is one of the most difficult heart diseases to treat, there have been little medical advancements in the field. Outcomes for children with cardiomyopathy today are no better than they were three decades ago.