A Brighter Future for Children with Cardiomyopathy

A CAUSE FOR TODAY . . . A CURE FOR TOMORROW

Children's Cardiomyopathy Foundation™

OUR COMMUNITY

Over the years, the Children's Cardiomyopathy Foundation (CCF) has grown to be a **global community** focused on improving the diagnosis, treatment, and quality of life for children affected by cardiomyopathy. CCF provides a **range of services** for the patient, family, medical, and healthcare community.

Patients and Families

- An online discussion forum for families
- A directory of specialists at cardiomyopathy centers of care
- Educational materials for parents, children, and schools
- Informational webinars and family meetings
- Youth programs, family matching, and a parent ambassador program

Medical and Healthcare Providers

- Participation in multi-center research studies
- Opportunities for research collaborations
- Research findings in medical publications and presentations
- Access to international conferences and regional working group meetings
- Patient materials for hospitals throughout North America

Children's Cardiomyopathy Foundation
24 West Railroad Avenue, Suite 408, Tenafly, NJ 07670
Tel 866.808.CURE (2873) • childrenscardiomyopathy.org
ccfheartkids ccfheartkids ccfheartkids

OUR PURPOSE

The Children's Cardiomyopathy Foundation (CCF) is a national nonprofit dedicated to accelerating the **search for causes and cures** for pediatric cardiomyopathy through increased **research**, **education**, **awareness**, and **advocacy**. CCF also provides **support** and **resources** to empower parents in managing their child's condition.

Founded in 2002 by a parent who lost two young children to cardiomyopathy, CCF partners with **healthcare organizations**, **medical centers**, and **government agencies** to raise awareness, advance research, and educate key leaders.

Board of Trustees

MEDICAL ADVISORS

CCF works with a panel of medical experts to coordinate research efforts and develop diagnostic and treatment guidelines for children with cardiomyopathy.

Wendy K. Chung, M.D., Ph.D.
Columbia University Medical Center

Steven D. Colan, M.D.
Boston Children's Hospital

Daphne T. Hsu, M.D.
Children's Hospital at Montefiore

Steven E. Lipshultz, M.D.
University at Buffalo School of
Medicine and Biomedical Sciences

Shelley D. Miyamoto, M.D.
Children's Hospital Colorado

Joseph W. Rossano, M.D.
Children's Hospital of Philadelphia

Jefferey A. Towbin, M.D.
Le Bonheur Children's Hospital

OUR FOCUS

Cardiomyopathy is a chronic disease where the heart muscle becomes abnormally enlarged, thickened, and/or stiffened, affecting the heart's ability to pump blood through the body.

A complex heart disease that is not well understood

- **Less than 25% of diagnosed children have a known cause.**
  It can be inherited or acquired through a viral infection or from chemotherapy.
- **Symptoms and outcomes can vary greatly.**
  It is not clear why affected family members can present differently.
- **Many children remain undiagnosed.**
  It can be difficult to detect because signs are not obvious.
- **There is no current cure.**
  Treatment often involves medication to relieve symptoms and improve the functioning of the heart.

Any child can have cardiomyopathy, regardless of age, race, gender, or socioeconomic status.

A chronic condition that requires specialized medical attention

- **It can progress to heart failure more rapidly in children.**
  A heart transplant may be needed if the heart continues to weaken.
- **In severe cases, it can lead to heart failure and arrhythmia.**
  An implantable defibrillator may be recommended to regulate an abnormal heartbeat.
- **Some children are at a higher risk for a sudden cardiac arrest.**
  A family history of the disease may be unrecognized.
- **Most children are advised to refrain from exercise and sports.**
  Physical activity restrictions may cause psychosocial concerns.

OUR WORK

As a national organization focused on all forms of cardiomyopathies in children, the Children's Cardiomyopathy Foundation has **driven research projects** and encouraged medical centers to work together to **standardize care**.

Along with the **expansion of our family network** and education efforts, we have made great strides in **improving the health outcomes** of children with cardiomyopathy.

Research

Fund research studies and partner with leading institutions, pediatric and youth organizations, and medical and healthcare associations to advance diagnostics and treatments of pediatric cardiomyopathy.

Education

Develop informational materials and support resources that are relevant and accessible to children and their families.

Awareness

Educate the public through awareness campaigns during National Heart Month and Children's Cardiomyopathy Awareness Month.

Advocacy

Lobby state and federal decision-makers to increase surveillance research, identify children at risk for sudden cardiac death, and expand research funding opportunities.

Family Support

Foster an active and supportive network with programs developed to engage families and connect them to medical specialists.

The hope of the Children's Cardiomyopathy Foundation is that every affected child will have a chance to live a full and active life.

Together, we are building a brighter future for children with cardiomyopathy.