

# A Brighter Future for Children with Cardiomyopathy



A CAUSE FOR TODAY ... A CURE FOR TOMORROW



## 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.

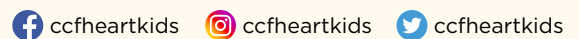
### Patients and Families

- 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**  
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## 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

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## MEDICAL ADVISORS

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

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## 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.**

