



Turning Hope Into Results

While pediatric cardiomyopathy continues to claim lives, there have also been many success stories thanks to the efforts of dedicated doctors and impassioned family members. As new information becomes available and treatments are improved, more diagnosed children are living longer.

Our work at keeping children – and hope – alive takes a great deal of effort and funding. With so much to do still, we need your ongoing support. Please help us to continue healing the hearts of – and supporting – those who need us most.

To learn how you can support CCF's efforts, visit www.childrenscardiomyopathy.org.

CCF takes a strong and pro-active role in bringing experts from the medical and healthcare fields together to advance knowledge of cardiomyopathy and develop better support services and resources for those affected by the disease.

"CCF has been an invaluable resource in helping us diagnose, treat and research this difficult disease."

– Dr. Stephanie Ware, Co-Director of the Diagnostic Cardiomyopathy Clinic at Cincinnati Children's Hospital

"I couldn't begin to imagine where we'd be without CCF; we would really be lost without the information your website and e-community provides."

– Priscilla, mother to 2 yr. old with DCM

"CCF enables us to help many more families live through and beyond pediatric cardiomyopathy with a higher quality of life."

– Dr. Steve Lipshultz, Chairman of Pediatrics at University of Miami School of Medicine



**Children's
Cardiomyopathy
Foundation**

**A Cause for Today...
A Cure for Tomorrow**

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HOPE
is where the
heart is.



When Many Hearts Hold The Same Desires, Great Things Are Possible.

The Children's Cardiomyopathy Foundation (CCF) is a national non-profit organization dedicated to finding causes and cures for pediatric cardiomyopathy through the support of research, education, awareness and advocacy.

CCF started in 2002 with one family's desire to call attention to a poorly understood heart disease and take action on the lack of medical progress and public awareness. Since then, CCF has grown into a community of families, physicians, scientists and pediatric professionals focused on improving diagnosis, treatment and quality of life for children affected by cardiomyopathy.

CCF's hope for the future is that more lives will be saved, and every affected child will have the chance to live a full and active life.

Supporting infants, children and teenagers with cardiomyopathy



Pediatric Cardiomyopathy: An Overlooked Disease

Pediatric cardiomyopathy is a chronic heart disease where the myocardium (heart muscle) becomes abnormally enlarged, thickened and/or stiffened. As a result, the heart cannot contract or relax normally. Eventually, it loses its ability to pump blood effectively.

One of the most difficult heart conditions to treat in children

- Difficult to detect, it often goes undiagnosed until serious symptoms appear.
- It can progress more rapidly and severely in children than in adults.
- Less than 25% of diagnosed cases have a known origin.
- The disease is a challenge to manage because of its variable course and uncertain outcomes.
- There is no FDA approved drug or surgical treatment to eliminate or stop the progression of the disease.

A serious and complex disease that requires more attention

- Over 30,000 children, from newborns to 18 years old, are suffering from some form of cardiomyopathy in the U.S., which is comparable to the number of people living with cystic fibrosis.
- Outcomes for children with cardiomyopathy are no better today than they were thirty years ago.
- Few resources are available to help families manage their children's unique and ongoing needs.
- Given its severity, research on the disease is extremely under-funded by government agencies, pharmaceutical companies and medical institutions.



Offering Help and Hope for the Future

As the first and only national lay group specifically focused on pediatric cardiomyopathy, CCF is actively involved in all aspects of the disease from research and education to patient support, awareness and advocacy. Our work involves:

Catalyzing Research & Promoting Education

- Identify and fund promising research aimed at improving treatment outcomes and finding cures.
- Facilitate dissemination of research findings through peer-review publications and medical meetings.
- Promote the Pediatric Cardiomyopathy DNA and Tissue Repository, established by CCF, as a research resource.
- Sponsor research workshops and scientific conferences in partnership with the National Heart, Lung and Blood Institute and other medical institutions.

Advancing Treatment Models

- Establish comprehensive care programs offering integrated services and expert care management to at-risk and diagnosed children.

Providing Leadership and Advocacy in the Pediatric Community

- Reach out to 2,000 scientists, physicians and clinical professionals with programs focused on improving detection, evaluation, management and research innovation.
- Represent the interests of affected children and their families at the state and federal level.
- Develop disease specific programs and materials in collaboration with various organizations and pediatric experts.

Offering Child and Family Assistance

- Serve as an access point for information, resources, referrals and guidance to over 1,000 families worldwide.
- Distribute easy-to-understand educational materials and newsletters with the latest research updates and advice from pediatric cardiomyopathy specialists.
- Provide networking opportunities such as local support groups, family matching and an online-support community.





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