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# Foundation Fact Sheet

## ABOUT CCF

The **Children's Cardiomyopathy Foundation (CCF)** is a national non-profit focused on pediatric cardiomyopathy, a chronic heart disease that is the leading cause of heart transplants and sudden cardiac deaths in children.

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

## MISSION & VISION

The vision of CCF is to create a future of hope in which pediatric cardiomyopathy is detected earlier, more lives are saved, and all children with the disease can live full and active lives.

CCF's mission is to accelerate the search for causes and cures through increased research, education, awareness and advocacy, and to support families whose children have been affected by the disease.

## KEY ACHIEVEMENTS

CCF takes an active role in advancing knowledge of cardiomyopathy, raising the profile of the disease, and offering better support services and resources for those impacted by the disease.

- Winner of the NJ Biz Education Health Care Hero for an organization and named as a top-rated health organization for three consecutive years by America's leading charity evaluator, Great Nonprofits
- Raised more than \$12 million for pediatric cardiomyopathy research and education
- Funded studies that led to more than 175 publications in leading medical journals and presentations at national medical meetings
- Established the first DNA and tissue repository on pediatric cardiomyopathy
- Formalized a Pediatric Cardiomyopathy Comprehensive Care Program at the Children's Hospital of New York to offer integrated services and expert care management
- Organized and cosponsored with the National Heart, Lung and Blood Institute the first international scientific conference on children with cardiomyopathy
- Collaborated with the American Heart Association, National Society of Genetic Counselors, Pediatric Heart Transplant Foundation and the National Organization for Rare Disease to develop educational materials on the disease
- Introduced the first bill on cardiomyopathy to the U.S. House of Representatives and the Senate
- Distributes a variety of patient education materials to more than 70 hospitals in the U.S. and Canada
- Provides telephone and in-person support groups, regional ambassadors, and an international community forum to help families connect to one another
- Offers an assistance program for low income families with a child undergoing treatment for cardiomyopathy

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

[www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org)