



Foundation Fact Sheet

About CCF

The Children's Cardiomyopathy Foundation (CCF) is a national non-profit focused on pediatric cardiomyopathy, a chronic and potentially life-threatening heart disease.

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 low 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 are affected by the disease.

Key Achievements

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

- Established partnerships with the American Heart Association and American Academy of Pediatrics to offer pediatric cardiomyopathy research grants.
- Funded a number of research and education initiatives, resulting in more than 390 medical publications and presentations on pediatric cardiomyopathy
- Organized the first international scientific conference on pediatric cardiomyopathy with the National Heart, Lung, and Blood Institute as a co-sponsor.
- Supported several multi-center studies with the National Institutes of Health-funded North American Pediatric Cardiomyopathy Registry.
- Secured additional funding for cardiomyopathy research under the Department of Defense Peer Review Medical Research Program.
- Established an Accredited Centers of Care program to identify high-quality cardiac centers that specialize in pediatric cardiomyopathy.
- Provides financial assistance to qualifying families in need of medical and non-medical coverage while their child is undergoing treatment.
- Collaborated with the American Heart Association, National Society of Genetic Counselors, Pediatric Heart Transplant Foundation, and the National Organization for Rare Disorders to develop educational materials on pediatric cardiomyopathy.
- Distributes a variety of patient education materials to 80 hospitals across the U.S. and Canada.
- Launched the inaugural Children's Cardiomyopathy Awareness Month with support from members of Congress and 13 national partners.
- Introduced the first bi-partisan bill on cardiomyopathy in the U.S. House of Representatives.

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Tel: 866.808.CURE • www.childrenscardiomyopathy.org • Email: info@childrenscardiomyopathy.org