



## Family Resources & Services

The Children's Cardiomyopathy Foundation (CCF) has built alliances with more than 70 hospitals in the United States and Canada. CCF offers a variety of informational and support resources to assist patients and their families with their cardiomyopathy diagnosis.

- **CCF Website** – Comprehensive and up-to-date information on pediatric cardiomyopathy written in patient friendly language.
- **Monthly News Updates** – Short updates highlighting new research studies, advocacy initiatives, patient resources, and foundation related events and activities.
- **Patient Education Materials** – Medically reviewed materials offered in print, web or audio-visual format: *A Cardiomyopathy Resource Kit for School Personnel and Parents, Understanding Pediatric Cardiomyopathy, Cardio What? A Kids' Guide to Cardiomyopathy, Secrets of the Heart – Living with Pediatric Cardiomyopathy, Know Your Heart: Genetic Testing for Cardiomyopathy Families, Pediatric Heart Transplants: A Guide for Patients and Families.*
- **Support Chats and Webinars** – Events scheduled periodically on topics ranging from general discussion to presentations on a particular topic related to pediatric cardiomyopathy.
- **CCF Ambassadors** – Parents and young adults with a personal connection to the disease and trained to provide emotional support and information on CCF's resources are available on a one-to-one basis to newly registered family members.
- **CCF Connect Online Community** – A private site that allows families from around the world to share stories, news, and information through an on-line discussion forum. The site also allows registered members to locate specialty centers, access fact sheets, and download other support resources. Professional guests are scheduled periodically to answer questions on topics such as medication, diet, genetic testing, activity restrictions, and psychological concerns.
- **CCF Facebook Groups** – Closed groups specific to families and youth/teens that provide an additional way to connect, ask questions, discuss concerns, and share in the lives of others facing similar situations.
- **CCF Family Assistance Program** – Helps qualifying families in need of financial assistance with cardiomyopathy-related medical and non-medical needs when insurance and other financial resources have been exhausted.

In addition, CCF offers family matching, physician and specialty center listings and research study referrals. For more information, please contact Gina Peattie, CCF's Director of Family Outreach & Support, at 866-808-CURE, ext. 905 or [gpeattie@childrenscardiomyopathy.org](mailto:gpeattie@childrenscardiomyopathy.org).