



Medical Care for Pediatric Cardiomyopathy Patients

Cardiomyopathy can be challenging to manage in a child. Due to the complexity and variability of the disease, it is critical to work with an experienced pediatric cardiologist from a medical center that manages a large number of children with cardiomyopathy. To ensure that your child receives the best medical care, there are several considerations to keep in mind.

- **A pediatric cardiologist with expertise in cardiomyopathy is imperative.** CCF maintains a hospital directory of pediatric cardiomyopathy specialty centers located throughout the United States, Canada, Australia and the United Kingdom. A center profile includes names of pediatric cardiomyopathy specialists, services offered to pediatric cardiomyopathy (PCM) families, the number of PCM patients managed at the center, types of cardiomyopathy treated, and number of surgeries and procedures performed annually.
- **Children are not simply “little adults.”** Working with a pediatric cardiologist is necessary so that special considerations for pediatric patients (under age 18) are taken into account when developing a treatment plan.
- **Knowledge of cardiomyopathy varies among pediatric cardiologists.** Since cardiomyopathy is a relatively rare disease in children, many pediatric cardiologists have only encountered a few medical cases. Your child’s medical provider should have experience treating several pediatric cardiomyopathy patients. CCF’s specialty center directory provides information to help you select a doctor to meet your child’s unique medical needs.
- **Your child’s local care can be coordinated with a PCM specialist.** Families that do not live near a PCM specialty center may decide to travel to a specialty center once or twice a year. In between visits, it is suggested that the child’s local cardiologist work closely with a PCM specialist to ensure optimal care.
- **Your family’s cardiac health history should be shared with your child’s medical team.** It is important to know if there is a history of cardiomyopathy or other cardiac-related issues in your family, so that your child’s medical team can optimize his or her care and determine whether to screen other family members.
- **It is acceptable to get a second opinion.** Because cardiomyopathy is a variable disease and each child presents differently, there is no standardized treatment protocol. Many families find it beneficial to obtain a second opinion to confirm a diagnosis or finalize a treatment plan.

- **CCF's Family Assistance Program can provide additional support.** For some families, a cardiomyopathy diagnosis becomes a financial hardship. CCF offers financial assistance for cardiomyopathy-related medical and non-medical fees to qualifying families. Additional financial aid resources are listed on CCF's website.

For more information on CCF's support services and resources, contact Gina Peattie, Patient Outreach and Support Manager at 866.808.2873 ext. 905 or gpeattie@childrenscardiomyopathy.org.

DISCLAIMER: This fact sheet is meant to provide general information and is not intended to be complete or replace the advice given by a medical professional. Cardiomyopathy is a highly variable disease. The information provided here should not be used for diagnosing or treating cardiomyopathy.