10 Things to Know About Pediatric Cardiomyopathy

1. **Cardiomyopathy is a chronic disease of the heart muscle that affects the heart’s ability to pump blood.** The disease can present in different forms and may, in severe cases, lead to heart failure and/or sudden death.

2. **There are different forms of cardiomyopathy.** The World Health Organization recognizes four forms: dilated (DCM); hypertrophic (HCM); restrictive (RCM); and arrhythmogenic right ventricular (ARVC) cardiomyopathy. Left ventricular non-compaction cardiomyopathy (LVNC) increasingly is being recognized as another form.

3. **Cardiomyopathy is a leading cause of sudden cardiac arrest in young people.** Every year, approximately 7,000 children under the age of 18 in the United States will have a sudden cardiac arrest. SCA is the top cause of death on school property. Only 10.7 percent of students who suffer a cardiac arrest survive.

4. **Cardiomyopathy remains the leading cause of heart transplants in children over one year of age.** Cardiomyopathies result in some of the worst pediatric cardiac outcomes, with nearly 40 percent of children with symptoms receiving a heart transplant or dying.

5. **Cardiomyopathy can affect any child.** Cardiomyopathy can occur in any child regardless of age, race, gender or socioeconomic background.

6. **There is tremendous variation in symptoms among the different types of cardiomyopathy.** Common symptoms include difficulty breathing, fatigue, exercise intolerance, fainting, dizziness or light-headedness, chest pain, heart palpitations, and swelling in the ankles, feet, legs, abdomen and veins in the neck.

7. **Cardiomyopathy can be inherited genetically or acquired through a viral infection or cancer chemotherapy.** Not all is understood about the genetic and molecular mechanism of the disease in children, and up to 75 percent of those diagnosed do not have a known disease cause.

8. **Currently there is no cure.** While there are surgical and medical treatments that may improve quality of life, the damaged heart cannot be repaired in most cases. A heart transplant may be necessary if the heart continues to weaken and medical management is unable to prevent the heart from failing.

9. **Knowing your family cardiac history is essential in preventing premature death.** A discussion of your family’s heart health with a geneticist, cardiologist or pediatrician can help assess your child’s risk for cardiomyopathy.

10. **Many children with cardiomyopathy have activity restrictions and psychosocial issues related to living with a chronic illness.** A diagnosis usually results in more frequent doctor visits, daily cardiac medication and possibly surgical interventions. Other modifications include dietary adjustments, restriction from competitive and contact sports, and school accommodations.

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For more information please visit [www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org) or contact the Children’s Cardiomyopathy Foundation at 866.808.CURE or info@childrenscardiomyopathy.org.