

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.

For more information please visit www.childrenscardiomyopathy.org or contact the Children's Cardiomyopathy Foundation at 866.808.CURE or info@childrenscardiomyopathy.org