

Materials from Children's Cardiomyopathy Foundation Designed to Meet Different Patient Education Needs

By Kella Boyer, Patient Outreach & Support Manager, Children's Cardiomyopathy Foundation

Research has found that there are many benefits to patient education including enhanced patient participation in health-care decision-making, improved commitment to treatment, increased patient satisfaction, better ability to cope with illness, greater quality of life in patients and their families, and decreased anxiety (Yoon et al, 2006). The Children's Cardiomyopathy Foundation (CCF), a national non-profit focused on pediatric cardiomyopathy, understands the importance of patient education following a diagnosis of pediatric cardiomyopathy, a chronic heart condition that affects an estimated 30,000 children. CCF believes strongly that educating patients and their caregivers on the basics of their disease can empower them to more proactively manage their or their loved ones' health and well-being. In order to educate newly diagnosed children and their families, CCF has developed a variety of resources to cover the full range of patient needs. All materials have been

carefully reviewed by CCF's medical advisors and in most cases are offered free of charge.

Cardiomyopathy is a complex disease with many variations in presentation, outcome and cause. The most detailed of CCF's literature, "*Understanding Pediatric Cardiomyopathy*" is a 14-page overview booklet with accompanying inserts on dilated, hypertrophic, and restrictive cardiomyopathy. The easy-to-understand booklet covers common questions of parents and caregivers by addressing topics such as diagnosis, causes, symptoms, treatment options, family screening, effect on daily life, and coping with a chronic disease.

A second resource is a 29-page booklet, titled, "*Cardiowhat? A Kids' Guide to Cardiomyopathy*", which was developed by CCF and the National Society of Genetic Counselors to help children better understand their own and/or their family member's diagnosis of cardiomyopathy. When an ill child lacks disease understanding, the child may wrongfully think the disease or being hospitalized is a punishment (Walker, et. al., 2006). Developed after it was discovered that many parents found it

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difficult to explain the concept of cardiomyopathy to their children, "*Cardiowhat?*" uses simple language, colorful illustrations, and fun activities to teach children the basics of the disease.

Information in audio or video format can help some people learn about a disease more effectively (Roberts, 2008). CCF's third resource, "*Secrets of the Heart - Living with Pediatric Cardiomyopathy*" is a 38-minute DVD that profiles three families with different forms of cardiomyopathy. Their personal stories are interspersed with factual information on the disease contributed by the physicians that care for them. For someone who prefers visual or auditory learning, the DVD is an optimum way to increase knowledge of pediatric cardiomyopathy and learn how other families have successfully handled the challenges of living with this heart disease.

Studies show that patients only remember about half of what they are told during a visit to the doctor (Ley, 1972). Physicians can pass out CCF's materials as a take-home resource to reinforce information about pediatric cardiomyopathy not absorbed during the



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Understanding Pediatric Cardiomyopathy

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visit. In addition to printed resources, CCF has also collaborated with the National Organization for Rare Disorders and the American Heart Association to offer web-based educational materials on pediatric cardiomyopathy.

Patient education is an important part of healthcare that all health care workers should take seriously (Bellamy, 2004). It is CCF's hope that patient education will help improve quality of life and enhance healthcare participation for families affected by pediatric cardiomyopathy. For more information on CCF's other patient services or to receive any of the materials described in this article please contact the Children's Cardiomyopathy Foundation at kboyer@childrenscardiomyopathy.org or visit the website at www.childrenscardiomyopathy.org.

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