



ACHIEVEMENT HIGHLIGHTS

RESEARCH & TREATMENT

- In 2003 CCF partnered with the **North America Pediatric Cardiomyopathy Registry (PCMR)**, the only NIH funded nationwide patient registry for cardiomyopathy, to sponsor **think tank sessions** focused on the clinical aspects of the disease. These sessions have resulted in 3 abstract presentations at the 2004 American Heart Association Scientific Session and publications in leading peer review medical journals such as *Pediatrics*, *Circulation*, and the *Journal of Medical Association*. CCF's partnership with PCMR is the first attempt at developing outcome predictors and treatment protocols using national patient data.
- CCF has established a **national research grants program** to provide seed funding of \$25,000-\$50,000 to investigators studying the causes and therapies for pediatric cardiomyopathy. Since its inception in 2002, CCF has awarded 16 grants totaling \$808,229 to promising investigators at Columbia University, Children's Hospital Boston, University of California San Diego, University of Miami, University of Rochester, Baylor College of Medicine, Toronto Hospital for Sick Children, Medical University of South Carolina, and Children's Hospital of New York, Mount Sinai School of Medicine, Cincinnati Children's Hospital, University of North Carolina, Yale University and University of Washington. CCF's seed funding has helped some of these investigators to secure multi-year, million dollar research grants from the National Institutes of Health.
- CCF has been the sole initiator of a **national biological specimen repository**, a research resource that will allow investigators access to better quality samples from children with this rare disease. Since launching in 2006, the lab has collected over 260 blood and tissue specimens to aid researchers studying pediatric cardiomyopathy. CCF is also working with the North America Pediatric Cardiomyopathy Registry to integrate this repository with their patient registry of clinical data.
- In 2004, CCF awarded \$100,000 to the Children's Hospital of New York to establish a **Comprehensive Pediatric Cardiomyopathy Program**. The specialized program (one of only eight in the entire U.S. and the only one in the tri-state area) makes available in one distinct setting a clinical care center, genetic diagnostic unit and research facility all focused on pediatric cardiomyopathy. This unique program ensures a complete, coordinated and concentrated approach to the disease and serves as a treatment model for other medical centers caring for children with cardiomyopathy.

AWARENESS & EDUCATION

- CCF has collaborated with the **National Organization for Rare Disorders** to develop a disease report on pediatric cardiomyopathy. The NORD report was made available on their website database (100,000 visits/mo), as well as in a printed book sold to physicians and healthcare professionals. CCF has also collaborated with the **American Heart Association** and **National Society of Genetic Counselors** to develop additional patient education materials.
- In Jan 2007, CCF co-sponsored with the National Heart Lung & Blood Institute the **First International Pediatric Cardiomyopathy Scientific Workshop**. Over 35 experts on cardiomyopathy gathered to discuss research direction, priorities, and future projects.

- CCF continues to **build awareness with the medical community** through direct mail, mention in pediatric cardiac newsletters and distribution of materials at medical meetings. To date, CCF has sent out more than 12,000 pieces of patient education materials to pediatric cardiologists and allied health professionals across the U.S. and Canada.
- CCF has received **national and regional media coverage** in Good Housekeeping, New Jersey Bergen Record, New York Times, Peddie Chronicle, The Parent Paper, Sterling Heights Mirror Newspaper, Crain's Investment News, Royal Oak Newspapers. In 2004, President and Founder, Lisa Yue, was selected by Good Housekeeping from hundreds of nominations to be one of five *Heroes for Health*. Lisa Yue was also selected as the 2005 *Golden Heart* recipient by New York-Presbyterian and Weill Cornell Medical Center

PATIENT SUPPORT

- In 2005 CCF launched a **national patient education initiative**, the *Parent Empowerment Program (PEP)*, which provides easy to read printed, audio-visual and electronic materials for affected children and their families. This includes a range of medically reviewed, easy-to-understand materials developed specifically for families with an affected child. These include *Understanding Pediatric Cardiomyopathy* overview booklet, disease specific inserts (Dilated Cardiomyopathy, Hypertrophic Cardiomyopathy, Restrictive Cardiomyopathy), *CardioWhat? A Kids Guide to Cardiomyopathy* booklet, and *Secrets of the Heart – Living with Pediatric Cardiomyopathy* DVD.
- CCF is in various stages of establishing **6 local support groups**. These groups, led by parent volunteers, allow for face-to-face support in association with a leading children's hospital. CCF also maintains a parent listserv and monthly cyberguest program whereby expert guest are invited to answer questions and discuss topics related to living with cardiomyopathy.
- CCF also offers other **family support services** such as peer support, family matching, physician and clinical research referrals, a newsletter, and a website with medical information, patient care tips, research updates and referral links.