



HEART TO HEART

News from the Children's Cardiomyopathy Foundation

December 2014 | Issue 4

CCF Research Grant Recipient Publishes Study Findings

CCF grant recipient, Mark Friedberg, M.D., staff cardiologist at the Toronto Hospital for Sick Children, published his research findings in the September 2014 issue of *Journal of the American Society of Echocardiography*. The article, "Patterns and clinical significance of electro-mechanical dyssynchrony in pediatric dilated cardiomyopathy (DCM)," identifies abnormal muscle contraction in children with dilated cardiomyopathy (DCM) to determine which children with a progressive form will benefit from cardiac resynchronization therapy (CRT), a procedure that uses a pacemaker to stimulate the heart chambers and make them squeeze at the same time.



CRT has been shown to improve life quality and expectancy in adults with heart failure but its effectiveness is not known in children. In the CCF-funded study, Dr. Friedberg used ultrasound techniques on 59 children with DCM to analyze the squeeze and relaxation of different parts of the heart. The study identified a severely affected subgroup of children with classic-pattern dyssynchrony (CPD) and underlying electrical activation delays who would be most responsive to CRT.

[Read article](#)

CCF Awards Pediatric Cardiomyopathy Registry Additional \$447,000



CCF recently awarded \$447,000 to the National Heart, Lung, and Blood Institute (NHLBI) sponsored Pediatric Cardiomyopathy Registry (PCMR), a national clinical patient database, to support multiple research initiatives.

An initial \$75,000 will be allocated to the Genotype-Phenotype Associations in Pediatric Cardiomyopathy study to cover patient recruitment costs to meet the enrollment target of 900 cardiomyopathy children and affected family members. To date, CCF has provided \$225,000 to this national study, which involves 11 medical centers across the U.S. and Canada.

The study is the first large-scale attempt to genetically profile pediatric cardiomyopathy patients and identify genetic variations that affect the development and progression of cardiomyopathy in children.

An additional \$372,000 will be allocated to the PCMR over three years to cover 12 new studies and proposed publications, 6 working group meetings, and a dedicated PCMR research associate. Recently, the PCMR organized a working group retreat in Boston with CCF funding.

CCF Co-Hosts Family Conference

More than 70 families attended the

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2014 Holiday Appeal



'Tis the season for big wishes. Kids with cardiomyopathy wish for a day they can run, climb and jump without worrying about their heart. We hope you will be inspired in this season of giving to support our work in improving outcomes and quality of life for children with cardiomyopathy.

[Give Today](#)

Make a Difference



Get Inspired: Family Fundraisers

Make a difference and host a cardiomyopathy event in your community. Not only will you raise awareness of the disease but you will help support critical research on cardiomyopathy. See what others are doing and get inspired! [Contact CCF's event team](#) today to get started on planning an event.

[Read more & view photos](#)

Advocacy Alert

Take Action and Be Heard!

We continue to advocate in Washington D.C. to raise awareness of cardiomyopathy and enact legislation to protect

family conference "Affairs of the Heart: Understanding Genetic Cardiomyopathy" in Boston last month. CCF co-sponsored the family conference with MyoKardia, the Cardiomyopathy SHARE registry and Brigham and Women's Hospital in Boston.



The meeting offered presentations and break out sessions led by top researchers and clinicians in the field of cardiomyopathy. Speakers included: Dr. Carolyn Ho, Brigham and Women's Hospital; Dr. Neal Lakdawala, Brigham and Women's Hospital; Dr. Betsey Blume, Boston Children's Hospital; Dr. Christine Seidman, Harvard Medical School; and Dr. Dominic Abrams, Boston Children's Hospital. CCF Founding Executive Director, Lisa Yue, co-facilitated a session for parents of children with cardiomyopathy.

During the conference, the Joseph Middlemiss Big Heart Foundation (JMBHF) presented a check for \$15,000 to CCF. JMBHF was established in memory of Joseph Middlemiss, a CCF Heart Kid who lost his life to cardiomyopathy in 2013 at the age of 6.

[View presentations](#)

CCF Receives \$25,400 American Legion Child Welfare Foundation Grant

CCF received a grant from the American Legion Child Welfare Foundation for \$25,400 to develop a 7-minute educational video on cardiomyopathy genetic testing, which will complement CCF's existing family educational materials. The video will answer basic questions such as: What is genetic testing? What are the benefits of having genetic testing? What does the testing process involve? The video's main message is genetic testing can help to identify risks, improve treatment options, and potentially save lives of those undiagnosed individuals at-risk for heart failure and sudden cardiac arrest.

[Read more](#)

CCF in the News for Sudden Cardiac Awareness Month

During Sudden Cardiac Arrest Awareness Month, Founding Executive Director, Lisa Yue, and CCF Medical Advisor, Daphne Hsu, M.D. made the media rounds to increase awareness of pediatric cardiomyopathy. On October 4, they were the weekend feature on NY1 News to talk about the leading cause of sudden death in children, and on October 24, they were guests for an hour long episode of Doctor Radio, a health and medical information channel on SiriusXM Satellite. Also, CCF Teen Ambassador, Matthew Protas, shared his story with the New Jersey Star Ledger for a feature on athletes and cardiomyopathy.

[Watch NY1 News feature](#)
[Listen to SiriusXM episode](#)
[Read Matt Protas' story](#)

Get Ready for National Heart Month



United with us this February to tell America that heart disease affects kids, too, often with worse outcomes. Join other families across the country who are planning a variety of National Heart Month activities.

Ideas include planning a [Big Heart Bake Sale](#), giving out [CCF printable valentines](#) and organizing [school presentations](#) on cardiomyopathy. We also have developed a list of fun awareness activities that compliment the Girl Scout Journey Program.

Contact [Jennifer Hivry](#) for a free bake sale kit with balloons, stickers, posters and handouts. For ideas to involve your Girl Scout troop contact [Gina Peattie](#).

[More Heart Month ideas](#)

CCF Listed as 2014 Top-Rated Nonprofit

Thanks to amazing reviews from CCF parents, CCF has earned a spot on the 2014 Top Rated List. CCF is listed as a final winner on Great Nonprofits leader board which will be distributed to media and corporate foundations, and promoted during #GivingTuesday.



[Read reviews](#)

undiagnosed, at-risk children from sudden cardiac death. We need your help persuading more members of Congress to support the below cardiomyopathy-related legislation. Send emails to your U.S. senators and representatives telling them how important these bills are to you.

[Cardiomyopathy HEARTS Act](#)

[SAFE PLAY Act](#)

[Teaching Children to Save Lives Act](#)

CCF Fundraisers

7th Annual No-Limit Texas Hold 'Em Tournament

Don't miss out on this popular event with entry to the World Series of Poker Main Event as the grand prize! To be held Feb 11, 2015 at the Edison Ballroom in New York City.

[Details](#)

Jewelry from the Heart

The Nolan's Heart of Steel Jewelry Collection was created in honor of Nolan Everett McLaughlin, who was diagnosed with DCM and recently had a heart transplant. A portion of the sales will be donated to CCF.

[Details](#)

Accessories for Every Age

Bravelets is celebrating #GivingTuesday by doubling their donations. When you purchase an item on December 2, CCF will receive \$20 per item sold. Bravelets make a great gift or purchase one for yourself to show off your perseverance and strength.

[Details](#)

Shop Amazon and Give to CCF

Raise funds for CCF while you shop on AmazonSmile this holiday season. Visit Amazon's charitable portal, select CCF as your charity, and CCF will receive 0.5% of the total purchase.

[Details](#)

Family Messageboard

Cardiac Imaging Webinar

Brian Feingold, MD and Timothy Wong, MD Children's Hospital of Pittsburgh Pittsburgh, Penn. December 8 at 6pm EST

[Register for webinar](#)

Webinar Recordings Online

Recorded webinar sessions are available to those unable to attend our June and September webinars.

[View webinar](#)

VANISH Study Recruiting HCM Families

Various sites throughout the U.S. and Canada are seeking qualifying patients. Contact [Stephanie Harris](#) for details on the two-year clinical study.

[Get more information](#)

Family Assistance Program

Qualifying families in need of financial assistance with cardiomyopathy-related medical and non-medical expenses can apply for treatment costs, displacement expenses and fees not covered by health insurance. For assistance, contact [Gina Peattie](#).

[Get more information](#)



Meet Cooper

Cooper is an energetic little boy who loves cars, trucks and trains. He enjoys watching YouTube videos of some of his favorite toys.

[Read More](#)



Meet Luke

Luke is an outgoing teenager who found his niche in drama. He is now a junior year in high school and beginning to think about college.

[Read More](#)



Meet Sedona

Sedona loves art, reading and music. She loves singing "Let It Go" from the movie Frozen and enjoys making up her own songs too.

[Read More](#)



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