



HEART TO HEART

News from the Children's Cardiomyopathy Foundation
December 2015 | Issue 4

Updates from CCF-Funded Pediatric Cardiomyopathy Registry Studies

Findings from studies that the Children's Cardiomyopathy Foundation (CCF) funded with the Pediatric Cardiomyopathy Registry (PCMR) have been accepted for publication in two peer-reviewed cardiology journals. "Lessons Learned from the Pediatric Cardiomyopathy Registry (PCMR) Study Group" was published in the August issue of *Cardiology in the Young*, and "Health-Related Quality of Life and Functional Status are Associated with Cardiac Status and Clinical Outcome in Children: A Report from the Pediatric Cardiomyopathy Registry" was recently accepted by the *Journal of Pediatrics*.

At the American Heart Association Scientific Sessions held in November, two PCMR abstracts were accepted for poster presentations: "Results of Research Genetic Testing in Pediatric Cardiomyopathy Patients Justify Broader Clinical Genetic Testing" and "Impact of Malnourishment or Obesity on Clinical Outcomes in Children with Dilated Cardiomyopathy: A Report from the Pediatric Cardiomyopathy Registry Study Group."

A PCMR working group took place late October 2015 to explore collaborative research opportunities, discuss manuscripts in development and review the status of several ongoing multi-center studies. Additional publications are in the works, including "Genotype-Phenotype Associations in Pediatric Cardiomyopathy," "Clinical Outcomes of Children with Dilated Cardiomyopathy," "Global Burden of Heart Failure in Children," and "Cachexia and Obesity in Pediatric Cardiomyopathy Patients." The PCMR retreat, study analysis and publication work are all sponsored by CCF.

[Lessons Learned from the Pediatric Cardiomyopathy Registry Study Group Abstract](#)

[Results of Research Genetic Testing in Pediatric Cardiomyopathy Patients Abstract](#)

[Association of Growth Patterns and Clinical Outcomes in Children With Dilated Cardiomyopathy Abstract](#)

Cardiomyopathy HEARTS Bill Reintroduced

In November, representative Frank Pallone (D-NJ6) reintroduced the Cardiomyopathy Health Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act, legislation to raise awareness of cardiomyopathy and to help identify undiagnosed children at risk of sudden cardiac arrest.

The bill ([H.R. 4015](#)) requires the development of materials and resources on cardiomyopathy and the dissemination of these materials to schools and child care centers nationwide. The Children's Cardiomyopathy Foundation (CCF) worked with Rep. Pallone's office when it was first introduced in 2011 and continues to work in partnership with the Congressman to move this legislation forward.

[Read the press release](#)
[Support the Cardiomyopathy HEARTS Act](#)

Inaugural Cardiomyopathy Awareness Walk Unites Families Across U.S.

The Children's
Cardiomyopathy Foundation's

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2015 Annual Appeal



Let's go the distance to end cardiomyopathy for our heart kids.

Our annual appeal campaign has started, and we need you to be on our team. Please remember CCF in this season of giving and help us get to the finish line for a cure.

[Donate today](#)

Advocacy Alert

Take Action and Be Heard!

Raise awareness of cardiomyopathy and support legislation that will protect at-risk children from sudden cardiac death. We need your help to persuade more members of Congress to support cardiomyopathy-related legislation. You can email your senators and representative to tell them how important this issue is to you.

[Support the SAFE PLAY Act](#)
[Support the CM HEARTS Act](#)

CCF Events

(CCF) first Walk for a Cure, held during Children's Cardiomyopathy Awareness Month, was an exhilarating success with 28 walk teams participating across the U.S. and helping to raise close to \$40,000. The New Jersey walk held on September 27 at the South Mountain Recreation Complex in West Orange, N.J. gathered more than 110 CCF families and friends from the tristate area to raise awareness of pediatric cardiomyopathy. Before the sendoff by CCF Founder Lisa Yue and Walk Ambassadors Gianna and Sophia Olup, CCF parent Maureen Egan was given a spirit award for her enthusiastic 25-member team walking in honor of Lena Strong.



In addition to the Walk in New Jersey, awareness walks were held at beaches, local parks and neighborhood sidewalks in Indiana, Florida, Texas, Maryland, Alabama, Illinois, Ohio, Wisconsin, Louisiana, and Michigan.

[View Walk photos](#)

Bake For A Cure During National Heart Month



During National Heart Month this February, the Children's Cardiomyopathy Foundation (CCF) is encouraging families to host a Big Heart Bake Sale to raise awareness and funds for pediatric cardiomyopathy research. Bake sales are a fun way to get family, friends and neighbors involved in a meaningful cause. Over the years, CCF families have showcased their creativity, hosting a red heart themed baking party and attaching CCF valentines to treat bags for a heartfelt touch.

To help you get started in your community, CCF is offering a free bake sale kit with balloons, stickers, posters, and handouts. Contact [Jennifer Hivry](#) to learn more about how to make your bake sale a sweet success.

[Host a Big Heart Bake sale](#)
[Print CCF valentines](#)

CCF Co-Sponsors Cardiomyopathy Family Conference

The Children's Cardiomyopathy Foundation (CCF) is co-sponsoring a third Affairs of the Heart family conference with the Sarcomeric Human Cardiomyopathy Registry (SHaRe). The conference will take place in Stanford, Calif. on February 20, 2016 at the Stanford



Alumni Center. In collaboration with the Stanford Center for Inherited Cardiovascular Disease, the conference will consist of presentations and breakout sessions led by top cardiomyopathy researchers and clinicians from Stanford University Medical Center. This conference is offered free-of-charge to families affected by heritable genetic cardiomyopathies.

CCF sponsored the first SHaRe family conference in November 2014 at Brigham & Women's Hospital in Boston, Mass. and the second conference in Ann Arbor, Mich. in October 2015.

#MyCampAED Winner Announced



Camp Amnicon in South Range, Wis. is the winner of this year's #MyCampAED Scavenger Hunt and received a Philips HeartStart Onsite automatic external defibrillator (AED) donated by One Beat CPR. "We are super excited to receive the donated AED," says Hannah Damon, Camp

Amnicon associate director. "Having an AED at our facility means we can better serve our guests and visitors. It brings peace of mind that in the event of an emergency we are better able to respond."

CCF has partnered with the [American Camp Association](#) and [One Beat CPR](#) for three consecutive years on this awareness program. The #MyCampAED Scavenger Hunt was created by CCF to highlight the importance of AED accessibility during a cardiac emergency at camps across the nation.

NIGHT FOR A CURE

CHILDREN'S CARDIOMYOPATHY FOUNDATION

A Night for a Cure
February 10, 2016
New York, NY

In celebration of National Heart Month, join us for a lively evening with friends, cocktails and delectable fare at the art-deco inspired Edison Ballroom in New York City. Don't miss this popular annual event.

[Details](#)

Tricky Tray to Benefit CCF
May 11
Paramus, NJ

The Twins' Mothers of Bergen County will host their 56th annual charity event to benefit CCF. More than 200 local sponsors will donate items to make this one of the largest tricky tray events in Northern New Jersey, which is open to the public.

[Details](#)

Mama In The Now Fundraiser
Mama in the Now blogger and CCF parent, Tove Maren Stakkestad, is selling "Be Where You Are" inspirational t-shirts and bumper stickers to benefit CCF through December 22. Makes a meaningful holiday gift for someone special, or treat yourself.

[Details](#)



Order Your Team CCF T-Shirt!

Join the spirit squad today by purchasing a Team CCF t-shirt. The red collegiate-style t-shirts, available in adult and child sizes, make a fun holiday gift. They are great to wear on their own or for a community awareness event.

[Details](#)

Shop Amazon and Support CCF
Support CCF this holiday season by using AmazonSmile to make all your online gift purchases. Visit Amazon's charitable portal, select "Children's Cardiomyopathy Foundation," and CCF will receive 0.5% of your total purchase.

[Details](#)

Family Messageboard

CCF Connect Cyberguests

Implantable Cardiac Defibrillators and Pacemakers
Matthew Williams, M.D.
Rady's Children's Hospital
San Diego, Calif.
December 7-11

Genetics and Cardiomyopathy
Stephanie Ware, M.D., PhD.
Indiana University School of Medicine
January 25-29

To Join CCF Connect, contact [Shari Maurer](#).

CCF Awarded 2015 Top-Rated Nonprofit

Thanks to several amazing reviews from CCF parents, CCF has earned a spot on Great Nonprofits 2015 Top Rated List.

The GreatNonprofits Top-Rated Awards is the only People's Choice Award in the Nonprofit Sector. The GreatNonprofits seal is the second most trusted rating seal, after the Better Business Bureau, according to a study by Software Advice.



[Read reviews](#)

Ambassador Program

Learn how you can help CCF to spread awareness, advocate for change and give support to new cardiomyopathy families.

[Learn more](#)

Youth Heart Buddy Program

This program connects CCF's pre-teen and teen members while providing support and friendship as they approach adulthood.

[Learn more](#)

Family Assistance Program

Qualifying families in need of financial assistance can apply for aid on cardiomyopathy-related medical and non-medical expenses related to treatment, displacement and uncovered health insurance fees. For assistance, contact [Gina Peattie](#).

[Learn More](#)



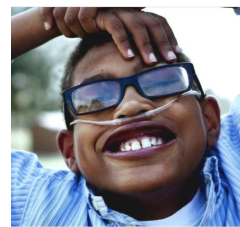
Meet Jacob

Jacob's favorite color is green, and he loves to play Minecraft, build Legos and play with his dog Daisy.
[Read more](#)



Meet Sara

Sara loves art and music, and her dream job is to be a graphic artist. She is currently learning to play the guitar.
[Read more](#)



Meet Jay

Jay loved movies, video games and dancing. Every day he was full of smiles.
[Read more](#)



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