



HEART TO HEART

News from the Children's Cardiomyopathy Foundation
September 2015 | Issue 3

Children's Cardiomyopathy Awareness Month and Walk For A Cure Set for September

Initiative Urges Families to #KnowYourHeart and Learn Risk
Factors



Children's
Cardiomyopathy
Awareness Month™

Twelve national organizations are joining CCF this September in raising awareness of pediatric cardiomyopathy. The Children's Cardiomyopathy Awareness Month was

launched last year to educate the public about the signs, symptoms and risk factors for cardiomyopathy and to encourage families to learn about their cardiac health history.

CCF is celebrating the month with 30 days of activities, which include circulating facts on the disease, sharing stories about cardiomyopathy families, planning community events, and generating media coverage. Awareness month partners include the [American Academy of Pediatrics](#), [American College of Cardiology](#), [American Heart Association](#), [Centers for Disease Control and Prevention](#), [National Association of School Nurses](#), [National Athletic Trainers' Association](#), [National Organization for Rare Disorders](#), [Parent Heart Watch](#), [Sarcomeric Human Cardiomyopathy Registry \(ShaRe\)](#), [School-Based Health Alliance](#), [The Society of Thoracic Surgeons](#), and [Sudden Cardiac Arrest Foundation](#).

This year CCF is adding a Walk for a Cure to bring the message to more communities. 21 walk teams have registered in New Jersey and across the country. Walk for a Cure will take place on September 27 in West Orange, N.J., and the family day will include music, activities and food. Gianna and Sophia Olup, two sisters diagnosed with left ventricular non-compaction cardiomyopathy, will serve as Walk ambassadors at the ceremonial ribbon cutting.

[Participate in Awareness Month](#)
[Register for Walk For A Cure](#)

AED Hunt on the Hill with Rep. Capps

CCF is working with Representative Lois Capps (CA-26) to host the second annual AED Hunt on the Hill during Children's

Cardiomyopathy Awareness Month. The event, to be held on September 17 in the Capitol complex, will invite members of Congress and congressional staff members to learn about the importance of emergency preparedness and early defibrillation in an adverse cardiac event.

The AED Hunt on the Hill follows the success of CCF's #MyCampAED scavenger hunt, which ran all summer long in partnership with the American Camp Association and One Beat CPR + AED.

[Download AED hunt sheet](#)

Findings Published from CCF-Funded Pediatric Cardiomyopathy Registry Studies

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Make a Difference



On September 27, families across the U.S. will unite to raise awareness of pediatric cardiomyopathy.

Join Team CCF and make a difference in your community. Come walk with us in New Jersey, plan a walk in your hometown, or support CCF as a virtual walker.
#ItTakesATeam

[Register for walk](#)

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 SAFE PLAY Act](#)

Help CCF Win Award



CCF has been named a top-rated health organization for four consecutive years by leading charity evaluator Great Nonprofits. We need your help to get top-rated for

New findings from CCF-funded Pediatric Cardiomyopathy Registry studies have been published in two peer-reviewed cardiology journals.

"Cardiomyopathy Phenotypes and Outcomes for Children with Left Ventricular Myocardial Non-Compaction: Results from the Pediatric Cardiomyopathy Registry" and "Prevalence, Predictors, and Outcomes of Cardiorenal Syndrome in Children with Dilated Cardiomyopathy" were published in the July issues of the *Journal of Cardiac Failure* and *Pediatric Nephrology* respectively.

The first study reviewed clinical data from children with left ventricular non-compaction cardiomyopathy to determine the risk of death and transplant among different phenotypic groups. The results will help guide treatment plans and inform cardiologists on when patients should be listed for transplantation based on certain clinical indicators.

The second study looked at the risk factors for cardiorenal syndrome in children diagnosed with dilated cardiomyopathy (DCM). The study found that children with DCM, especially those with impaired left ventricular function, should be monitored for renal disease. This sub-group also may be associated with higher mortality.

[Journal of Cardiac Failure Abstract](#)
[Pediatric Nephrology Abstract](#)

CCF Founder Named Associate Editor of *Progress in Pediatric Cardiology*

CCF Founding Executive Director, Lisa Yue, has been named as an associate editor for advocacy and family support of *Progress in Pediatric Cardiology*, an international peer-reviewed journal of scientific research, reviews and experienced opinion important to the understanding and management of cardiovascular diseases in children.



"I appreciate that the journal recognizes the importance of family support and advocacy in the overall management of patients with cardiac disease," said, Lisa. "I look forward to working with the editorial board to promote the journal as a leading cardiology journal."

As a member of the editorial board, Lisa will guest edit special journal issues, help develop a team of ad-hoc guest editors and peer reviewers, assist with commissioning of reviews and commentaries, and encourage submission of original articles.

Cardiac Safety Language Included in Every Child Achieves Act

CCF partnered with Senator Robert Menendez to include cardiomyopathy specific language in the Every Child Achieves Act of 2015 (S. 1177). The bill, which passed the Senate in July, is a bipartisan educational policy reform bill that would replace the No Child Left Behind Act of 2001. The bill would end the federal government's mandate on national school standards and let states develop their own accountability systems.

If passed into law, the bill would allow states to use federal funds for a series of activities that include disseminating materials on cardiac conditions such as cardiomyopathy and developing emergency action plans for student athletes.

The language secured in the bill complements the Supporting Athletes, Families, and Educators to Protect the Lives of Athletic Youth (SAFE PLAY) Act, which CCF helped reintroduce in the House and Senate earlier this year. The SAFE PLAY Act includes provisions to protect student athletes from sudden cardiac arrest which can occur with children at-risk of cardiomyopathy.

[Learn more](#)

CCF Holds 13th Annual Golf Classic

Tri-state Event Raises Awareness and Funds for Pediatric Cardiomyopathy Research and Education

The 13th Annual CCF Golf Classic, held on July 20, was a sold-out success with 224 attendees and 64 sponsors. Held at the historic Montclair Golf Club in New Jersey, the event raised more than \$370,000 for pediatric cardiomyopathy research and education. [Read more](#)



[View event program](#)
[View event photos](#)

CCF Co-Sponsors Cardiomyopathy Family Conference

CCF is sponsoring a second family conference with the Sarcomeric Human

2015! Simply select "Children's Cardiomyopathy Foundation" at [Great Nonprofits](#) and write a positive review about CCF so we can receive this award again.

[Submit a review](#)

CCF Events

Big Hearts Fill Our Soles Walk

September 13
Highland, Ind.

Come walk with family and friends in Indiana during Awareness Month in honor of Gianna Knight who is living with HCM.

[Details](#)

Trivia Night

October 23
O'Fallon, Mo.

It will be a battle of great minds as CCF member Jennifer Vinyard hosts this community event in honor of her 13-year-old daughter, Sara, who has HCM.

[Details](#)

Chad's Race for a Cure

October 24
New York, N.Y.

Chad was diagnosed with HCM and had a defibrillator and pacemaker implanted as a result. Under his physicians' guidance, Chad will participate in New York's Urbanathlon, a 10-mile obstacle course, to raise funds for CCF.

[Details](#)

Shop Amazon and Support CCF

Need back to school items or Halloween costumes? Support CCF by using AmazonSmile to make all your online purchases. Visit Amazon's charitable portal, select "Children's Cardiomyopathy Foundation" and CCF will receive 0.5% of your total purchase.

[Details](#)

Family Messageboard

Participate in Quality of Life Study

CCF is funding a research study to learn how to improve the quality of life for children with cardiomyopathy and their families. We invite children ages 8-18 and their parents or caregivers to complete a short online survey about the impact of cardiomyopathy on different aspects of their daily life.

[Learn more](#)

Preparing for Transplant Webinar

Joseph Rossano, MD
Children's Hospital of Philadelphia
Philadelphia, Penn.
September 15 at 6pm EST

[Register for webinar](#)

Webinar Recordings Online

Recordings are available online for past webinar sessions.

[View webinars](#)

Back to School Resource Kit

CCF's school packet, [Ensuring a Good Learning Environment - A Cardiomyopathy School Resource Kit](#), helps to educate school staff about the disease and guide parents in obtaining the appropriate school accommodations and modifications for their child.

[Order resource kit](#)

Ambassador Program

Learn how you can help CCF to spread awareness, advocate for

Cardiomyopathy Registry (SHaRe) in Ann Arbor, Mich. Affairs of the Heart: Living with Genetic Cardiomyopathy will take place October 3 and is offered free of charge to patients and families. CCF sponsored the first SHaRe family conference in November 2014 at Brigham & Women's Hospital in Boston, Mass.

The meeting will consist of presentations and breakout sessions led by top cardiomyopathy researchers and clinicians from University of Michigan Health System and Detroit Medical Center.

[Learn more](#)

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](#)



Meet Noah

Noah enjoys playing with legos and loves talking about his school day.

[Read more](#)



Meet Hana

Hana is a strong, independent child who can be both sweet and sassy.

[Read more](#)



Meet Zara

Zara loves sushi and is always sneaking sips of her mom's tea.

[Read more](#)



Children's Cardiomyopathy Foundation
Toll free 866.808.CURE
info@childrenscardiomyopathy.org
childrenscardiomyopathy.org



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