



HEART TO HEART

News from the Children's Cardiomyopathy Foundation

September 2014 | Issue 3

CCF Launches Awareness Month This September

Initiative Urges Families to #KnowYourHeart and Learn Risk Factors

When heart disease is mentioned, adults usually come to mind but heart disease affects children, too, often with more devastating outcomes. In fact, cardiomyopathy is the leading cause of sudden cardiac arrest (SCA) and heart transplants among young people.



Children's
Cardiomyopathy
Awareness Month™

This September CCF, along with 13 partners, is launching the first Children's Cardiomyopathy Awareness Month to raise awareness of pediatric cardiomyopathy and help identify more undiagnosed children at-risk of SCA. There will be 30 days of fun educational activities, which include circulating cardiomyopathy facts, warning signs and risk factors; sharing cardiomyopathy family stories; issuing a call to action to support life-saving cardiomyopathy legislation and urging the public to #KnowYourHeart to understand their cardiac family history.

Partners joining in the month-long awareness initiative include the [American Academy of Pediatrics](#), [American College of Cardiology](#), [American Heart Association](#), [American Public Health Association](#), [CHAD Foundation](#), [Eric Paredes Save A Life Foundation](#), [National Association of School Nurses](#), [National Athletic Trainers' Association](#), [National Organization for Rare Diseases](#), [Parent Heart Watch](#), [Sarcomeric Human Cardiomyopathy Registry \(ShaRe\)](#), [School-Based Health Alliance](#) and [The Society of Thoracic Surgeons](#).

[Learn more about awareness month](#)
[View September activity calendar](#)

CCF Rolls out AED Hunt on the Hill with Representative Lois Capps

CCF is working with representative Lois Capps (CA-26) to launch an AED Hunt on the Hill Day during Children's Cardiomyopathy Awareness Month in September. The event, which will be held on September 17 in the Capitol complex, will invite members of Congress and congressional staff members to take their picture with an automatic external defibrillator (AED) and tweet/post on social media sites.



The AED Hunt on the Hill will call attention to the importance of emergency preparedness and early defibrillation in an adverse cardiac event. Recently, U.S. Capitol police officers performed CPR and used an AED to revive a man who collapsed outside of the Hart Senate Office Building. Their prompt actions saved the man's life.

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.

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Help CCF Win Award



CCF has been named a top-rated health organization for three consecutive years by leading charity evaluator Great Nonprofits. We need your help to get top-rated for 2014! Simply select "Children's Cardiomyopathy Foundation" at [Great Nonprofits](#) and write a positive review about CCF so we can continue to receive this award.

[Submit a review](#)

Support the Cause



Get Inspired with Family Fundraisers!

You can make a difference by hosting a cardiomyopathy event in your community. Not only do you raise awareness of the disease but you can 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!

CCF Wins NJBIZ Healthcare Hero Award



The Children's Cardiomyopathy Foundation was selected as the winning organization in the Education Hero category at the NJBIZ 8th annual Healthcare Heroes Awards Ceremony. Held in Somerset Park on June 24, the morning event recognized individuals and organizations making significant contributions to the quality of healthcare in New Jersey.

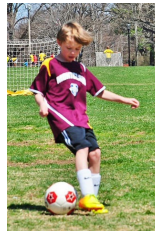
More than 400 medical and healthcare professionals attended the event. NJBIZ, New Jersey's only weekly business journal, along with sponsors Horizon Blue Cross Blue Shield, Comcast Business and Hackensack University Health Network, gave out ten awards honoring the best in New Jersey for hospital, nurse, physician, healthcare professional, volunteer, women's health and wellness, workplace wellness, innovation and healthcare education.

[NJBIZ Healthcare Heroes supplement](#)

CCF Unites with Legislators on SAFE PLAY Act

Comprehensive Bill Introduced to Protect Young Athletes from Sudden Cardiac Death

CCF has partnered with Senator Robert Menendez (D-NJ), Representatives Lois Capps (D-CA) and Bill Pascrell (D-NJ), and the National Athletic Trainers' Association on a new comprehensive bill that includes provisions to protect student athletes from sudden cardiac arrest (SCA). The Supporting Athletes, Families, and Educators to Protect the Lives of Athletic Youth (SAFE PLAY) Act will bring awareness to youth athlete safety and encourage the development of best practices to prevent, document and address youth athlete cardiac emergencies and injuries.



Each year, more than seven million high school students participate in school sports. In some instances, a student athlete will make headlines for collapsing on the field from a cardiac arrest. Often the cause can be attributed to cardiomyopathy, the leading cause of SCA among young people and the top cause of death on school property.

To protect children from sudden cardiac death, the SAFE PLAY Act will provide educational resources to increase awareness of cardiomyopathy and other high-risk childhood cardiac conditions, as well as provide grants for cardiac training and equipment in public schools and set guidelines for emergency action plans for athletics. In the months ahead, CCF will be working to get other legislators to sign on in support of the bill.

[Read Rep. Capps' press release](#)

[Ask your representative to cosponsor](#)

CCF Research Grant Recipient Publishes Study Findings



CCF grant recipient, Daniela Cihakova, M.D., Ph.D., Director of the Immune Disorders Laboratory at Johns Hopkins University in Baltimore, M.D. published her findings in the June 2014 issue of *Journal of Experimental Medicine*. The article titled "Cardiac fibroblasts mediate IL-17A-driven inflammatory dilated cardiomyopathy" covers outcomes from her 2012 CCF funded study, "Drivers of Pediatric Cardiomyopathy," and investigates how mediators of inflammation, called cytokines, lead to dilated cardiomyopathy. Specifically, it was discovered that an immune cell product called cytokine IL-17A plays an important role in the development of inflammatory dilated cardiomyopathy.

Dr. Cihakova and her research team determined that IL-17A can cause myocarditis to progress to dilated cardiomyopathy through its direct action or signaling on specific cells in the heart. The study examines the relationship and interaction of IL-17A, cardiac fibroblasts and heart-infiltrating myeloid cells in the development of dilated cardiomyopathy. Dr. Cihakova has been investigating molecular and cellular processes of autoimmune diseases since 1998, and has focused specifically on autoimmune myocarditis and dilated cardiomyopathy since 2003.

[Download article](#)

CCF Holds Twelfth Annual Golf Classic

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

The 12th Annual CCF Golf Classic, held on July 21, was a sold-out success with 240 attendees and 61 sponsors. Held at the historic and

raise awareness of cardiomyopathy and support legislation that will protect undiagnosed, at-risk children from sudden cardiac death. We need your help in persuading more members of Congress to cosponsor cardiomyopathy-related legislation. You can 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 Events

Rylan Bros Carnival for Pediatric Cardiomyopathy

On September 20, a street in Naperville, Ill., will be turned into a vintage style carnival with games, live music, food, raffles and an auction provided by local vendors. Heather Ory organized the community event in honor of her son, Rylan Lombardo, diagnosed with HCM at 5 weeks old.

[Details](#)

Heart Jewelry Sale

Jennifer Engel Designs created the Nolan's Heart of Steel Collection in honor of brave little Nolan Everett McLaughlin, who was diagnosed with DCM and recently had a heart transplant. A portion of the proceeds will go to CCF.

[Details](#)

Mama in the Now

Shop through the Mama in the Now website for great gift items from Gymboree, Lego and Mabel's Labels. A percentage of September sales will go directly to CCF.

[Shop Mama in the Now](#)

Give to CCF with Style

Choose from a variety of fashionable accessories while supporting CCF through Bravelets. \$10 will be donated to CCF for every piece purchased. Bravelets make a great gift or purchase one for yourself as a reminder of your perseverance and strength.

[Shop Bravelets](#)

Shop Amazon and Support CCF

Help CCF while you shop when you use AmazonSmile. Visit Amazon's charitable portal, select CCF as your charity, and CCF will receive 0.5% of the total purchase.

[Shop Amazon](#)

Family Messageboard

CCF Webinar

Pediatric Cardiomyopathy 101
John Lynn Jefferies, MD
Cincinnati Children's Hospital
Medical Center
Cincinnati, Ohio
September 9 at 6pm EST

[Register for webinar](#)

CCF Co-Sponsored Family Conference on Cardiomyopathy

Affairs of the Heart: Understanding Genetic Cardiomyopathy Conference
Brigham and Women's Hospital
Boston, Mass.
November 1, 8:30am - 3:00pm

[Register for conference](#)

[Ambassador Program](#)

distinguished Montclair Golf Club in New Jersey, the event raised more than \$364,000 for pediatric cardiomyopathy research and education.

The day was blessed with perfect golfing weather-sunshine and clear blue skies. 53 foursomes competed for the lowest par score on Montclair's greens. Betting holes and contest holes spaced throughout the courses added excitement to the game. [Read more](#)

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



Help CCF to spread awareness, advocate for change and give support to new families.

[Get more information](#)

Youth Heart Buddy Program
CCF's Heart Buddy Program connects pre-teens and teens (ages 12-25) with each other.

[Get more information](#)



Meet Lucy

Lucy's favorite song was Let Me Call You Sweetheart and she loved Elmo and stacking toys. Her favorite word was "No."
[Read more](#)



Meet Silas

Silas is a rambunctious little boy who loves trucks and helicopters. He cherishes his blankie and family dog, Mikey, who he calls "My-EEE."
[Read more](#)



Meet Evangeline

Evangeline loves spicy jalapeno chips, ketchup, and pepperoni. She loves Mater the Tow Truck and roller coasters.
[Read more](#)



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