Children's Cardiomyopathy Foundation

A Cause for Today...
A Cure for Tomorrow

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HEART TO HEART

News from the Children's Cardiomyopathy Foundation
June 2015 | Issue 2

CCF Celebrates National CPR and AED Awareness Week with #MyCampAED Launch

CCF, in partnership with the American Camp Association (ACA) and One Beat CPR, celebrates National CPR and AED Awareness Week (June 1-7) with the launch of the Third Annual #mycampAED Scavenger Hunt. The fun social media program encourages parents and campers to take photos of AEDs at camp and post them online with #mycampAED. The awareness program puts the focus on identifying automated external defibrillators (AEDs) at camps across the nation and stresses the importance of knowing its location and knowing what to do in a cardiac emergency. A Philips HeartStart Onsite AED provided by One Beat will be awarded to a randomly selected camp in need of an AED.

Download AED Scavenger Hunt sheet
Download AED Scavenger Hunt map

CCF Funds New Cardiomyopathy Quality of Life Research Study

CCF is working with Dr. Kristi Glotzbach, a pediatric cardiologist at the Montefiore Children's Hospital in New York, on a new research study. Dr. Glotzbach and her colleagues are interested in learning from patients and families what it is like to live with cardiomyopathy. The study is recruiting parents, caregivers and diagnosed children ages 8-18 through social media and CCF's family network to complete a short online survey. Frequent research updates will be posted on the study Facebook page, along with new links to research in the field.

Every year approximately 1,300 children are diagnosed with cardiomyopathy, yet there are very few pediatric studies focused on the impact of the disease on patient and family quality of life. The CCF-funded study, Improving the Lives of Children and Families Living with Cardiomyopathy, will look at how medications, procedures and frequent trips to the doctor may affect everyday life with families living with cardiomyopathy. Findings will help medical professionals to better understand key concerns and address the emotional health, neurodevelopment and psychosocial functioning in cardiomyopathy patients and their families.

View study site

State of Virginia Commends CCF's Work

In recognition of CCF's efforts during Children's Cardiomyopathy Awareness Month, Virginia Delegate Patrick Hope introduced a state resolution (HJ888) commending the Children's Cardiomyopathy Foundation for its advocacy and education on issues affecting children with cardiomyopathy. The bill was passed in the Virginia House and Senate during National Heart Month in February.

The bill recognizes cardiomyopathy as a potentially life-threatening disease and the number one cause of sudden cardiac arrest in the young. The Children's Cardiomyopathy Awareness Month is held every September and focuses on raising awareness of pediatric cardiomyopathy and educating the public on the risk of sudden cardiac arrest when not properly identified.

In This Issue

2015 Spring Appeal

Cardiomyopathy places an unimaginable burden on families both emotionally and financially. We need your help to continue assisting families facing financial hardship while their child undergoes treatment for cardiomyopathy. Please give from the heart and donate to CCF's Family Assistance Program.

Give Today

Make a Difference

Get Inspired: Family Fundraisers

Make a difference and host a cardiomyopathy event in your community. See what others are doing and get inspired! Contact CCF's event team today to get started on planning an event.

Learn More

Advocacy Alert

Take Action and Be Heard!

CCF continues to advocate in Washington to enact legislation to protect at-risk children from sudden cardiac death. We need your help in

View the resolution

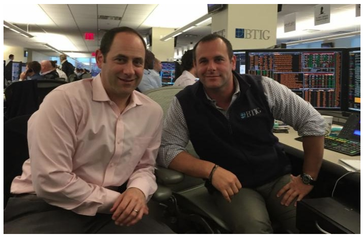
Update from CCF Funded Working Group Meeting

The Pediatric Cardiomyopathy Registry (PCMR) Study Group held a two-day working group meeting at the New England Research Institute in May. Funded by CCF, the meeting's purpose was to discuss preliminary findings from several multi-center studies, provide updates on study publications and writing groups, and discuss future PCMR studies.

Sixteen study investigators representing 12 PCMR research sites attended the meeting in Boston. Participants discussed current study publications, including the second issue of ***Progress in Pediatric Cardiology***, which covers proceedings from CCF's Third International Scientific Conference. The group also reviewed patient enrollment strategies and protocols on two main studies supported by CCF: Genotype-Phenotype Associations in Pediatric Cardiomyopathy and Cardiac Biomarkers in Pediatric Cardiomyopathy.

In addition to planning for the next set of PCMR research publications and the National Heart, Lung, and Blood Institute grant renewal, the group also discussed ideas for new studies focused on identifying genes and gene expression as predictors of outcome, developing randomized clinical trials to investigate new therapies, and incorporating 'quality of life' outcomes into future PCMR studies.

CCF Nominated for BTIG Charity Day



Thanks to BTIG Managing Director Ilan Adika, CCF was nominated for the second year to receive proceeds from BTIG Charity Day. More than 50 celebrity partners participated in the April 28 fundraiser organized by the global financial services firm. BTIG raised $13,500 for CCF through trading day commissions.

"As a BTIG employee, I am proud to nominate CCF and have the Foundation chosen as a beneficiary," says Ilan. "There's no charity more worthy than CCF and I am proud to be a supporter of the important work they do."

BTIG Charity Day is a global initiative that began in 2003 and has since donated over US $30 million to hundreds of charities, many of them supporting children in need around the world.

View BTIG Charity Day site

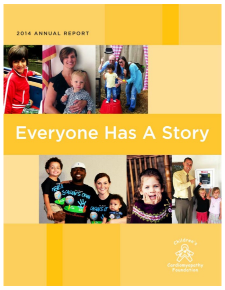
Tee Up for a Cure: CCF's 13th Annual Golf Classic

CCF's Annual Golf Classic is still going strong, and the popular event will be held at the historic Montclair Golf Club in northern New Jersey.

The all-day event will take place Monday, July 20 and start off with a BBQ lunch and then golf on Montclair's challenging 32-hole course. The evening portion will include cocktails and dinner, a silent auction and presentation of the golf awards. Last year, more than 240 attended to raise $364,000 for pediatric cardiomyopathy research and education.

View event page
Register to attend

CCF's Annual Report Now Online



The 2014 Annual Report, "Everyone Has a Story" is now downloadable from CCF's website. 2014 was an eventful year for CCF with many achievements. Two highlights include CCF's Third International Scientific Conference that brought together more than 60 leading researchers and clinicians to determine the future direction of pediatric cardiomyopathy research, and the launch of the Children's Cardiomyopathy Awareness Month with thirteen national partners to educate the public about the signs and risk factors associated with cardiomyopathy.

Download annual report

persuading more members of Congress to support cardiomyopathy-related legislation. Send an email to your U.S. senators and representative telling them how important this bill is to you.

SAFE PLAY Act

CCF Fundraisers

CCF's 13th Annual Golf Classic
July 20, 2015
Montclair Golf Club, N.J.
Tee-off for a cure at the popular fun-filled golf event. This is a sold out event every year so reserve your playing spot and sponsorship package today.

Details

6th Annual Casen's Crew for Children's Cardiomyopathy
August 22, 2015
Maxwell Golf Course, Tx.
The 6th Annual Casen's Crew fundraiser features both a 5K run/walk and golf tournament. Casen's Crew honors Casen Riley, who lost his battle with HCM at 6 months old.

Details

Walk for a Cure
September 27, 2015
South Mountain Recreation Complex, N.J.
Join Team CCF for our First Annual Walk for a Cure during Cardiomyopathy Awareness Month. Come walk with us or organize one in your hometown to raise awareness of pediatric cardiomyopathy.

Details

Jameson's Heartraiser
August 15, 2015
Wilmington, Del.
This second annual summer concert fundraiser, hosted by Michael & Erin Noonan, will honor their son, Jameson, who was diagnosed with HCM as an infant. The event will include live bands, water slides and face painting.

Details

Shop Amazon and Support CCF
Get a gift for Father's day and support CCF using AmazonSmile. Visit Amazon's charitable portal, select CCF as your charity, and CCF will receive 0.5% of the total purchase.

Details

Family Messageboard

CCF Connect Cyberguest
Gastrointestinal Issues Associated with Cardiomyopathy
Jenifer R. Lightdale, MD, MPH
University of Massachusetts Memorial Children's Medical Center
July 6-July 13

Join CCF Connect

Ambassador Program
Get involved and help CCF to spread awareness, advocate for change and give support to new families.

Get more information

Heart Buddy Program
CCF's Heart Buddy Program connects CCF's pre-teen and teen members to provide support and friendship as they approach adulthood.

Get more information

Meet Sawyer

Sawyer is from Virginia and is a happy 2 year old boy who is always on the go and enjoys playing outside.
Read More

Meet Katie

Katie is a 7 year old from New York. She loves to dance and draw with her favorite colors of pink and purple.
Read More

Meet Carter

Carter is 10 and a prankster who likes making people laugh in his hometown in Texas.
Read More

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