



HEART TO HEART

News from the Children's Cardiomyopathy Foundation
March 2015 | Issue 1

CCF Announces 2015 Research Grant Recipients

CCF will award \$323,118 to seven new researchers for 2015. This represents the largest grant cycle amount CCF has given since the program's inception ten years ago. Grant awardees include: Richard Czosek, M.D., Cincinnati Children's Hospital; Sharlene Day, M.D., University of Michigan; Mario Delmar, M.D., Ph.D., New York University School of Medicine; Kristi Glotzbach, M.D., Albert Einstein College of Medicine; Lars Grosse-Wortmann, M.D., The Hospital for Sick Children; Robert Henning, M.D., James A. Haley Veterans' Hospital; and Abdur Razzaque, Ph.D., University of Wisconsin.

The seven selected studies cover a broad range of research topics focused on dilated cardiomyopathy, hypertrophic cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy. Topics range from identifying new therapies targeted to the underlying disease process and detecting at-risk individuals who require earlier medical intervention, to the impact on emotional health, neurodevelopment and psychosocial functioning in patients and their families. The funded studies include: Automated ECG Screening of Hypertrophic Cardiomyopathy, Disease Pathways for MYBPC3 Mutations in Hypertrophic Cardiomyopathy, Visual Proteomics for Personalized Assessment of Risk in ARVC Families, Influence of Pediatric Cardiomyopathy on Health Related Quality of Life, Evolution of Late Gadolinium Enhancement and Myocardial Hypertrophy in Childhood Hypertrophic Cardiomyopathy, Human Cord Mesenchymal Stem Cells Decrease Cardiomyopathy Fibrosis, and Mechanism of RAF1 Mediated Pediatric Hypertrophic Cardiomyopathy.

CCF's research grant program has steadily grown from six grant applications received in 2004 to 50 letters of intent received this year. With reduced funding from the National Institutes of Health (NIH), CCF's grant program has become an increasingly important funding source for pilot studies in the field.

[View 2015 research abstracts](#)

Safe Play Act Reintroduced to Protect At Risk Youth Athletes

CCF has again partnered with Senator Robert Menendez (D-NJ), Representatives Lois Capps (CA-24) and Bill Pascrell (NJ-09), and the National Athletic Trainers' Association on a federal bill (S.436/H.R.829) that includes important provisions for protecting student athletes from sudden cardiac arrest, which is commonly associated with cardiomyopathy. The reintroduction of 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 both youth athlete cardiac emergencies and injuries. The bill specifically asks for the development and distribution of educational materials on cardiomyopathy, grants to be provided for cardiac training and equipment in public schools, and guidelines to be set for emergency action plans for athletics. CCF is currently reaching out to other members of congress to obtain legislative support for this comprehensive bill to protect youth athletes.

[Read press release](#)
[Support the bill](#)

CCF Unites Hearts Across America During National Heart Month

Hundreds of families and friends joined CCF during

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Make a Difference



Get Inspired: Family Fundraisers

Make a difference and host a cardiomyopathy event in your community. You can help raise awareness of the disease and support critical research on pediatric cardiomyopathy. 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 D.C. and enact legislation to protect at-risk children from sudden cardiac death. We need your help persuading more members of Congress to support the below 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

Prairie Farms: Our Caps, Your Cause
Purchase milk from Prairie Farms and turn your caps into a CCF donation! Our Caps, Your Cause program allows buyers to redeem a code beneath the cap. Five cents will be given to CCF for every code redeemed.

[Details](#)

National Heart Month in reminding America that heart disease affects children too, often with worse outcomes than adults. CCF's 50-state awareness challenge, Uniting Hearts Across America, brought much needed attention to pediatric cardiomyopathy while honoring cardiomyopathy children from all 50 states. Fundraisers took place across the U.S. raising more than \$277,000, and CCF received more than 50 new likes to our Facebook page and nearly 500 page shares and tweets. CCF will lead efforts this September to support Children's Cardiomyopathy Awareness Month.



Summer Camp AED Winner Announced



After a summer-long search for automatic external defibrillators, CCF announced the winner of the second annual #MyCampAED Scavenger Hunt. The winning camp, Angeles Crest Christian Camp, was presented with a Philips HeartStart Onsite automated external defibrillator

(AED) donated by One Beat CPR to use at their year-round camp in Fullerton, Calif. CCF partnered with the American Camp Association on the awareness campaign to highlight the importance of having AEDs at camp and for campers and counselors to know their location and how to use them.

"Our camp is now a safer place for children and youth," says David Crouse, Angeles Crest Christian Camp executive director. "Our camp is open year round and having an AED on site helps to safeguard our participants during a cardiac emergency. We are very grateful to CCF and One Beat CPR for this award."

[Read more](#)

[View scavenger hunt photos](#)

CCF's Annual Poker Event Sets Stage for National Heart Month

CCF hosted the Seventh Annual All-In For A Cure No-Limit Texas Hold 'Em Tournament on February 11 at the Edison Ballroom in New York City. Presenting sponsor Brookfield Asset Management joined 300 guests and 52 additional sponsors to raise a remarkable \$274,000 - a 23 percent increase in proceeds from last year. Since its inception, the popular event has raised more than \$1.5 million for pediatric cardiomyopathy research and education during National Heart Month.



Guests enjoyed a lively evening of cocktails, food and charity poker at the elegant, art deco styled Edison Ballroom. Betsy Lucas from Sterne Agee took home the grand prize, a \$10,000 entry to the 2015 World Series of Poker Main Event in Las Vegas. She is the first woman champion in CCF's poker history.

[View event program](#)

[View event photos](#)

Shop AVON for CCF

Jennifer Vinyard teamed up with AVON to offer fabulous products to raise funds for CCF. If you are in the St. Louis, Mo. metro area, consider a gift for a friend or treat yourself! The promotion will run April 1-15. Contact Carol Helton for details.

[Details](#)

MacPack - Run with the Pack!

Jennifer McFarland Kern, along with her husband and two children, will participate in running events this month to raise funds for CCF in tribute to Mac, Jennifer's first husband, who lost his life to DCM.

[Details](#)

Origami Owl Fundraiser

Origami Owl custom-inscribed jewelry will donate a portion of sales to CCF through March 7 on behalf of Team Lucy when you use the event code 6896 at checkout.

[Details](#)

Give to CCF with Style

Ten dollars will be donated to CCF for every Bravelets accessory piece purchased. Bravelets make a great gift, or purchase one for yourself as a symbol of your perseverance and strength.

[Details](#)

Shop Amazon and Support CCF

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

[Details](#)

Family Messageboard

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.

[More information](#)

Webinar Recordings Online

Recordings are available online for past webinar sessions.

[More information](#)

Heart Buddy Program

CCF's Heart Buddy Program connects pre-teens and teens with each other and is designed to provide support and friendship among CCF youth members as they approach adulthood.

[More information](#)

Family Assistance Program

Qualifying families can apply for cardiomyopathy-related medical expenses not covered by insurance and non-medical fees related to displacement. For assistance, contact Shari Maurer.

[More information](#)



Meet Miles

Miles is a great drummer and a fan of motorcross and bikes. He loves singing with his Grandma.

[Read More](#)



Meet Savannah

Savannah enjoys meeting new friends, loves car rides jamming to her favorite music.

[Read More](#)



Meet Camden

Camden is a happy baby who loves playing music, dancing and anything to do with cars.

[Read More](#)



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