



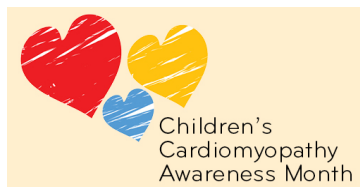
HEART TO HEART

News from the Children's Cardiomyopathy Foundation
September 2016 | Issue 3

September is Children's Cardiomyopathy Awareness Month

Initiative Encourages Families to Start a Heart-Health Conversation

The National Alliance for Youth Sports (NAYS) joins the Children's Cardiomyopathy Foundation (CCF) roster of 13 national organizations supporting Children's Cardiomyopathy Awareness Month in September. The month-long initiative features 30 days of fun and educational activities to increase awareness of the signs, symptoms and risk factors for cardiomyopathy and encourage families to start a conversation about their cardiac health history.



The National Alliance for Youth Sports (NAYS) will publish a two-part series on cardiomyopathy on [Sporting Kids Live](#), a site for parents and coaches featuring stories on athletic safety and wellness. Other partners, including the American Academy of Pediatrics, National Organization for Rare Disorders, and Centers for Disease Control and Prevention, will highlight Awareness Month on their blogs, newsletters and social media sites. A webinar, An Overview of Pediatric Cardiomyopathy, is being offered on September 22 in partnership with the National Association of School Nurses.

To commemorate Awareness Month, the Second Annual [Walk for a Cure](#), will be held on September 18 in West Orange, New Jersey. CCF Heartkid Lena Gonzalez will serve as Walk Ambassador. Lena was diagnosed with left ventricular non-compaction cardiomyopathy (LVNC) after suffering a sudden cardiac arrest at 3 months old. The family day, sponsored in part by Novartis, will include a 1.7 mile walk around the reservoir, music, arts and crafts, and other fun activities.

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

CCF Cosponsors American Academy of Pediatrics Meeting

During Children's Cardiomyopathy Awareness Month, CCF will co-sponsor the American Academy of Pediatrics (AAP) [Specialty Review in Pediatric Cardiology](#) held in Chicago. The course, planned for September 19-23, will reach pediatric cardiologists in training, established pediatric cardiologists seeking updates and pediatricians interested in pediatric cardiology. This intensive board review, hosted by the AAP Section on Cardiology and Cardiac Surgery, is led by a distinguished faculty of clinician-educators and will cover both basic science and clinical application. The three-day meeting will feature talks on congenital heart disease, myocarditis and cardiomyopathies, arrhythmias and sudden death, heart failure, and post heart transplant management.

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Know the Facts



View CCF's new infographic sheet and get the facts on pediatric cardiomyopathy. Share these statistics with friends and family during Awareness Month.

[View fact sheet](#)

Help CCF Win Award



CCF was named a top-rated health organization for five consecutive years by leading charity evaluator Great Nonprofits. We need your help to get top-rated again for 2016. Submit a review about how CCF has helped your family.

[Submit a review](#)

CCF Fundraisers

Raising Funds for a Different Tomorrow
October 29
Punta Gorda, Fla.

Diagnosed with dilated cardiomyopathy (DCM) at 22 years old, Kyle Bowe is

Updates on Published Studies from CCF-Funded Investigators

Findings from two CCF-funded studies were published in two peer-reviewed cardiology journals, and one CCF-funded study will be presented at the upcoming American Heart Association Scientific Session in November.

["Electrocardiography Screening for Hypertrophic Cardiomyopathy"](#) authored by Campbell M, Zhou X and Czosek RJ et al. and ["Developmental SHP2 Dysfunction Underlies Cardiac Hypertrophy in Noonan Syndrome with Multiple Lentiginosities"](#) by Lauriol J, Cabrera JR and Kontaridis MI et al. were published in the June issues of *Clinical Electrophysiology* and *Journal of Clinical Investigation* respectively.

"Spectrum of Gene Mutations in Pediatric Hypertrophic Cardiomyopathy" by Barach PR, Cox GF, Lipshultz SE et al. will be on display at the science and technology hall as part of the Heart Failure: Type of Heart Disease Abstract Poster Session on Tuesday November 15 at the American Heart Association Scientific Session. Only 10 percent of study submissions to the AHA are accepted for presentation at their annual meeting.

Progress in Pediatric Cardiology Special Issue on Cardiomyopathy

Proceedings from CCF's Third International Conference on Cardiomyopathy in Children have been featured in three dedicated issues of *Progress in Pediatric Cardiology*. Part three of the series was published in March 2016. Steven E. Lipshultz, M.D.; James D. Wilkinson, M.D.; Steven D. Colan, M.D.; and Jeffrey A. Towbin, M.D., authors of the three-part series, hope that the published proceedings will contribute to shaping future research priorities on pediatric cardiomyopathy.

CCF Holds 14th Annual Golf Classic

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

The 14th Annual CCF Golf Classic, held on July 18, was a great success with 200 attendees and 55 sponsors. Held at the historic Montclair Golf Club in New Jersey, the event raised more than \$325,000 for pediatric cardiomyopathy research and education.



In the evening, golfers enjoyed a lively cocktail hour with a silent auction and jazz provided by Scott Adamchek, a high school student who developed his musical interests after he was diagnosed with hypertrophic cardiomyopathy. During dinner, golf prizes were awarded, and Lindsay Davis, former Miss Ohio, spoke about her experience with cardiomyopathy. [Read more](#)

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

CCF Connect Online Community Launched

CCF has launched a new online community, CCF Connect, to engage more members and offer additional family resources. The private online community, which will replace the existing Google email forum.

The new site will enable members to engage in discussions on pediatric cardiomyopathy and participate in "Meet the Expert" Q&A sessions. Members will also be able to view CCF's activity calendar and research study recruitments, as well as access informative fact sheets, Q&A transcripts, medical center profiles, heart camp listings, and other family support resources. The community site will have downloadable community outreach and fundraising documents for those interested in planning an awareness event.

The new online community is open to diagnosed individuals, family members, medical and healthcare professionals and those interested in learning more about pediatric cardiomyopathy

[Join CCF Connect](#)

competing in his first National Physique Committee bodybuilding show to support CCF.

Details

Nathan Sprague Heart Fundraiser

Brenda Sprague is hosting an online shopping fundraiser now through September 26 offering fashionable and functional items from Thirty-One Gifts.

Details

Use Goodsearch to Raise Funds for CCF

Raise funds for CCF while using goodsearch.com for your internet searches. Simply select "Children's Cardiomyopathy Foundation" as your nonprofit of choice.

Details

Shop Amazon to Support CCF's Programs

Need back to school items or Halloween costumes? Visit AmazonSmile and select "Children's Cardiomyopathy Foundation." CCF will receive 0.5% of your total purchase.

Details

Family Messageboard

Overview of Pediatric Cardiomyopathy Webinar

September 22 at 3 p.m. EST
Elfriede Pahl, M.D.
Children's Hospital of Chicago

This webinar is ideal for newly diagnosed families and those who want to learn more about the disease. The overview will cover disease types, causes, signs and symptoms, and treatment.

Register for webinar

Local Support Group

Sept 15 at 5 p.m. EST
Texas Children's Hospital
Houston, Texas

Cardiomyopathy Caregiver Support Group meetings are held the first and third Thursday of each month from 5 p.m to 6 p.m.

Learn more

Back to School Resource Kit

CCF's school packet was developed to educate school staff about the disease and guide parents on appropriate school accommodations and modifications for their child. Printed copies can be ordered through CCF.

View resource kit

WALK CURE

IT TAKES A TEAM TO DEFEAT CARDIOMYOPATHY

[View Video](#)

[Register Today](#)

Join Team CCF this Sunday in New Jersey.
It Takes a Team to Defeat Cardiomyopathy.



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