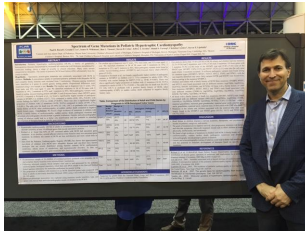


HEART TO HEART

News from the Children's Cardiomyopathy Foundation
December 2016 | Issue 4

Pediatric Cardiomyopathy Research Update

The Pediatric Cardiomyopathy Registry (PCMR) team continues to make substantial progress on the research and public advocacy front. Several peer review papers and editorials in lead scientific journals have been published in 2016. This work has been led by Paul Barach, M.D., M.P.H., the inaugural Children's Cardiomyopathy and Kyle John Rymiszewski Foundations Senior Scholar in Pediatric Cardiomyopathy.



Barach has delivered five invited talks and keynote presentations on PCMR findings in the U.S. and internationally. Under Dr. Steve Lipshultz's guidance, Barach presented the findings of a CCF funded study "Spectrum of Gene Mutations in Pediatric Hypertrophic Cardiomyopathy" at the [American Heart Association Scientific Sessions](#) in New Orleans this November. The scientific report described the genotype-phenotype associations in children with hypertrophic cardiomyopathy.

"Improving Communication with Families of Patients Undergoing Pediatric Cardiac Surgery" was published in the November issue of *Progress in Pediatric Cardiology*. Three editorials were accepted or published in the *Journal of Pediatrics*, *Progress in Pediatric Cardiology*, and the *Journal of the American College of Cardiology*

The PCMR team also received a green light from Springer Publishing, a leading publisher of health care books, to develop a textbook on prevention, treatment, and epidemiology of pediatric safety including cardiomyopathy. The book is expected to be in print in 2017.

[Improving Communication with Families of Patients Undergoing Pediatric Cardiac Surgery](#)

[The Benefits and Hazards of Publicly Reporting Quality Outcomes](#)

[Readmitting Children with Heart Failure: the Importance of Communication, Coordination, and Continuity of Care](#)

Scientific Conference Planned for 2017

Plans are underway for the Children's Cardiomyopathy Foundation (CCF) 4th International Scientific Conference on Pediatric Cardiomyopathy, which will be held May 18-19, 2017 at the Bethesda North Marriott in Maryland. Hosted by CCF and co-chaired by CCF Medical Advisor Steven Lipshultz, M.D. of Wayne State University School of Medicine and Pediatric Cardiomyopathy Registry Administrative Director James Wilkinson, M.D., M.P.H. of Children's Hospital of Michigan, the conference will provide a forum for sharing recent advances in pediatric cardiomyopathy medicine and management, and for determining research priorities and direction.

The two-day conference, open to medical and healthcare professionals, will feature presentations and panel discussions from 40 leading experts on pediatric cardiomyopathy, heart failure, and transplantation. Planned sessions include: New Heart Failure Targets, Optimizing Donor Quality for Pediatric Heart Transplantation, Current Controversies in Diagnosis and Management, Cutting-Edge Studies on the Pathophysiologic Understanding of the Disease, State of the Art Current Knowledge, Update on Ventricular Assist Devices, Gene-Directed Therapies, Translationally-Derived Diagnostic Markers and New Targeted Therapies, Pediatric Cardiomyopathy Registry Biomarker and Genetics Studies, and Clinical Microsystems Centered

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New York City Event



Celebrate National Heart Month at CCF's 9th annual charity poker event. The lively and popular event will take place Wednesday, February 8, 2017 at the art deco-inspired Edison Ballroom in New York City.

[Register for event](#)

Top Rated for 2016



Thanks to the many wonderful reviews from parents and supporters, CCF has earned a spot on the 2016 Top Rated List. This is the 5th consecutive year CCF has received this award by leading charity evaluator Great Nonprofits.

[Read reviews](#)

Facts About PCM



View CCF's new infographic sheet and get the facts on pediatric cardiomyopathy (PCM). Share these important statistics with friends and family.

[View fact sheet](#)

Conference proceedings will once again be featured in the peer-review journal *Progress in Pediatric Cardiology*. Past articles from CCF's previously funded conferences were among the most downloaded, accessed, and cited in the journey's history.

[Download conference agenda](#)
[Register for conference](#)

CCF's Walk for a Cure Celebrates Awareness Month



Friends and families celebrated Children's Cardiomyopathy Awareness Month with walks in New Jersey, Ohio, Pennsylvania and Virginia. On September 18, more than 120 walkers united for the [2nd Annual Walk for a Cure](#) held at the South Mountain Recreation

Complex in West Orange, N.J. It was a day of family fun with music, food, and kid activities. The event kicked off with inspiring words from CCF Founder Lisa Yue and ribbon cutting by 1.5-year-old walk ambassador, Lena Gonzalez. The event was supported by Novartis, BJ's Wholesale Club, Costco, Toys "R" Us, and Whole Foods.

[View event photos](#)

Bake for a Cure for National Heart Month

Big Heart Bake Sales are a fun way to bring people together and raise awareness of cardiomyopathy in the community. With the holidays in full swing and National Heart Month approaching in February, it is the perfect time to plan a bake sale or start baking in preparation for National Heart Month. Extra batches of cookies can be kept in the freezer for up to three months if properly stored. CCF is offering a free bake sale kit with balloons, stickers, ribbon, baking bags, and valentines to tie to bake sale goodie bags.



[Host a Big Heart Bake Sale](#)
[Print CCF valentines](#)

California Camp #MyCampAED Winner



[Camp Fire San Diego](#) this year's winner of the #MyCampAED Scavenger Hunt and will be awarded an automatic external defibrillator (AED). For the fourth year, CCF has partnered with the [American Camp Association](#) and [One Beat CPR + AED](#) on this summer awareness

program. The initiative highlights the importance of AED accessibility in a cardiac emergency. Campers across the U.S. participated by locating their camp AED and posting photos of its location on social media.

Julie Petty, Camp Fire's executive director, expressed her appreciation, "Safety is an important component to running a successful camp, and this generous donation of an AED to our facility means we can better serve our youth and guests."

Chad's Race for a Cure

January 14, 2017
Washington, D.C.

Chad, who was diagnosed with hypertrophic cardiomyopathy in 1999, will participate in the Goruck Light Challenge, a team obstacle course with military fitness exercises, to benefit CCF.

[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](#)

Holiday Shopping on Amazon

Support CCF during the holidays by making your gift purchases through Amazon Smilie. CCF will receive .5% of your purchase when you select "Children's Cardiomyopathy Foundation."

[Details](#)

Family Messageboard

Ambassador Program

CCF is looking for enthusiastic volunteers to assist with outreach, family support, advocacy, and awareness projects.

[Learn more](#)

Educational Webinars

CCF offers informational webinars led by medical experts on topics such as cardiomyopathy 101, coping with loss, and preparing for a heart transplant. Join the CCF Connect Community to view past webinars.

[Learn more](#)

Youth Heart Buddy Program

This program connects pre-teens and teens while providing support and friendship as they approach adulthood.

[Learn more](#)

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.

[Learn more](#)



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