



HEART TO HEART

News from the Children's Cardiomyopathy Foundation
March 2016 | Issue 1

CCF Announces 2016 Grant Recipients

CCF awarded \$199,552 to four new investigators to study various forms of cardiomyopathy affecting children. Grant awardees include: Juan Alejos, M.D. and Patricia Lester, M.D. of University of California; Angeliki Asimaki, Ph.D. of Beth Israel Deaconess Medical Center; Bahig M. Shehata, M.D. of Emory University School of Medicine; and Noah Weisleder, Ph.D. of Ohio State University.

Selected from more than 39 letters of intent by CCF's medical advisors, the four research studies are focused improving diagnosis and enhancing treatment, and range from basic science and genetics to clinical and behavior health. The four funded studies are: Integrated Family-Centered Behavioral Health Screening & Preventive Intervention for Pediatric Cardiomyopathy, The Role of GSK3 β in the Pathogenesis of Arrhythmogenic Cardiomyopathy, Genetic Analysis to Identify Inheritance Patterns in Histiocytoid Cardiomyopathy, and Targeting Membrane Repair to Treat Pediatric Dilated Cardiomyopathy

Since its inception, CCF's Research Grant Program has funded more than 45 studies on pediatric cardiomyopathy across the U.S. and Canada and resulted in over 79 medical articles and conference presentations.

[View 2016 research abstracts](#)

CCF Founder Publishes in Peer-Reviewed Journal

An article by CCF founding executive director Lisa Yue, "From Partnership to Progress in the Field of Pediatric Cardiomyopathy," has been published in *Progress in Pediatric Cardiology*, an international peer-reviewed journal of scientific research, reviews and experienced opinion. The article gives an overview of the progress in research, education and patient support related to pediatric cardiomyopathy in the past decade and highlights CCF's role in advancing medical care, increasing public awareness, and broadening representation in the public health and legislative arena. The article is now published online, and the printed version will be available in March as part of a special issue focused on pediatric cardiomyopathy.



[Read the article](#)

CCF/Kyle John Rymiszewski Research Scholar Named

Recognizing the need to foster the next generation of researchers in the field, CCF joined forces with the Kyle John Rymiszewski Foundation to establish a pediatric cardiomyopathy research scholar program. Paul Barach, M.D., MPH. has been named the 2016 cardiomyopathy research scholar and will be starting his new position

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Spring Appeal

[DONATE NOW](#)

Cardiomyopathy is can be life altering for the family. The financial burden placed on families can be as difficult as the emotional strain following diagnosis. Give to CCF's [Financial Assistance Program](#) so that we can continue to help cardiomyopathy families be in the best position to care for their sick child. A little can go a long way for a family facing financial hardships.

[Learn more](#)

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!

in mid March. This will be in addition to his role as a clinical professor at Wayne State University School of Medicine.

The scholarship is funded in part by the Kyle John Rymiszewski Foundation to honor Kyle Rymiszewski, a Michigan teenager who died from hypertrophic cardiomyopathy. "I'm excited Dr. Barach will be the first recipient of this scholarship in Kyle's memory. He will bring a new perspective to the PCMR research team and can spearhead more qualitative studies on the disease," said Kyle's mom, Aimée Cowher.

Dr. Barach is a Harvard-trained cardiac anesthesiologist and intensive care expert with formal training as a health services researcher. He was formerly the associate professor at University of Miami and medical director of quality and safety at Jackson Memorial Hospital in Miami. Dr. Barach has edited several medical textbooks and published over 400 medical articles.

Dr. Barach will work with Drs. Jay Wilkinson and Steve Lipshultz at the Pediatric Cardiomyopathy Registry Administrative Coordinating Center located at the Children's Research Center of Michigan. Dr. Barach will collaboratively design and conduct research on pediatric cardiomyopathy.

CCF Celebrates Heart Month with a Night For A Cure



42 corporate sponsors more than 220 guests united for CCF's Night for a Cure to celebrate National Heart Month. The event held on February 10 at the Edison Ballroom in New York City raised more than \$202,000 for pediatric cardiomyopathy research and education.

Last year's winner, Betsy Lucas played her way to the final table, but was beat out by

Michael Huthwaite from RW Baird who took home the grand prize, a \$10,000 entry to the 2016 World Series of Poker Main Event in Las Vegas.

[View event program](#)

[View event photos](#)

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

The President's FY 2017 Budget was released in February and specifically mentions cardiomyopathy and the Children's Cardiomyopathy Foundation. This was the result of CCF's advocacy efforts in Washington D.C. to get the National Institutes of Health and the Centers for Disease Control and Prevention to direct more resources to the disease.

In the report, the CDC states specific activities they have engaged in to address pediatric cardiomyopathy, including partnering with CCF during Children's Cardiomyopathy Awareness Month, establishing a Sudden Death in the Young registry to capture sudden deaths due to cardiomyopathy, and developing a dedicated webpage highlighting trends in cardiomyopathy rates among children.

[Read report](#)

Cardiomyopathy Family Conference Held at Stanford

CCF was a co-sponsor at the third Sarcomeric Human Cardiomyopathy Registry (SHaRe) family conference in Stanford, Cali. The February 20 meeting, Affairs of the Heart: Living with Inherited Cardiomyopathy, was a collaboration with the Stanford Center for Inherited Cardiovascular Disease and featured physicians from Stanford University with an expertise in hypertrophic cardiomyopathy and dilated cardiomyopathy. More than 200 families attended and heard CCF board member, Raymond Yue, speak about CCF's patient support and advocacy efforts.



[View video and slides](#)

Emergency Wallet Cards

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

14th Annual Golf for a Cure

July 18, 2016

Montclair Golf Club, NJ

Join us for this popular and fun-filled golf outing and tee-off for a cure! The popular event sells out quickly so reserve your playing spot and sponsorship package early.

[Details](#)

New Jersey Tricky Tray

May 11

Paramus, NJ

The Twins' Mothers of Bergen County will host their 56th annual charity event to benefit CCF. More than 200 local sponsors will donate items to make this one of the largest tricky tray events in Northern New Jersey, which is open to the public.

[Details](#)

NJ High School Film Festival

The 3rd Annual NJ High School Film Festival will be donating the net proceeds of their film festival to CCF. High School students in the tri-state area are encouraged to enter their video/film submissions from March 1-April 29 and attend the screening May 19 at Cresskill High School in New Jersey.

[Details:](#)

Order Your Team CCF T-Shirt

Join the spirit squad today by purchasing a Team CCF t-shirt. The red collegiate-style t-shirts, available in adult and child sizes, make a fun holiday gift. They are great to wear on their own or for a community awareness event.

[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

Coping with Loss Webinar

Donna Schuurman, MD

Senior Director of Advocacy & Training

Dougy Center for Grieving Children & Families

April 5 at 6pm EST

[Register for webinar](#)

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](#)

CCF partnered with the New York Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC) to develop an emergency card for pediatric cardiomyopathy patients. These cards can be printed, filled out and carried by the patient in a wallet/backpack in the case of a cardiac emergency.

[Download emergency card](#)

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.

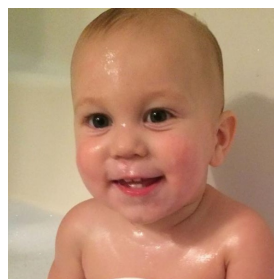
[Read More](#)



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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