



HEART TO HEART

Latest News from the Children's Cardiomyopathy Foundation

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Third International Scientific Conference on Cardiomyopathy

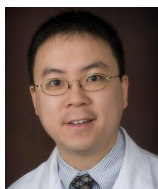
The Third International Scientific Conference on Cardiomyopathy in Children took place on May 15-16 in Bethesda, Md. and brought together more than 60 leading researchers and clinicians to exchange ideas and discuss research direction on cardiomyopathies in children.



Hosted and funded by CCF and co-chaired by Steven Lipshultz, M.D. of Wayne State University School of Medicine and James Wilkinson, M.D., MPH of Children's Hospital of Michigan, the conference covered a wide range of topics on cardiomyopathy, heart failure and heart transplantation in children.

[Read More](#)

CCF and AHA Joint Research Award Recipient



Tim Wong, M.D., director of the [University of Pittsburgh Medical Center's Hypertrophic Cardiomyopathy Center](#) is the latest recipient of the Children's Cardiomyopathy Foundation and American Heart Association Pediatric Cardiomyopathy Joint Research Award. Dr. Wong will receive \$308,000 over four years for his study, "Cardiovascular Magnetic Resonance Assessment of Diffuse Myocardial Fibrosis in Hypertrophic Cardiomyopathy."

The research will examine cardiac magnetic resonance imaging (MRI) heart scans in several hundred individuals with hypertrophic cardiomyopathy (HCM) to determine why some individuals develop less or more scar tissue (fibrosis) leading to heart rhythm disorders, heart failure and sudden cardiac death.

New MRI methods now provide a noninvasive way of imaging diffuse fibrosis in the heart, which is more accurate than studying scar tissue under a microscope. Studying the entire range of fibrosis in HCM disease progression will improve our understanding of the underlying pathways of the disease, identify new treatment targets and allow measurement of their response to therapy.

[Read more](#)

New Publication from CCF-Supported Pediatric Cardiomyopathy Registry

The Pediatric Cardiomyopathy Registry (PCMR) has published findings from another CCF-funded ancillary study providing guidelines on renal and cardiac transplantation and post-transplant care. While better methods of matching donors to recipients and newer immunosuppressive drugs have improved the

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CCF Appeal



Make One More Research Study Possible

Research on pediatric cardiomyopathy continues to be extremely under-funded even though the years of potential life lost in a child with heart disease is 2-7 times that of an adult.

Please give today. Every study we fund brings us one step closer to real cures.

[Give Today](#)

CCF Action Alert



Get Inspired: Family Fundraisers

You can make a difference by hosting a CCF event. Every dollar raised goes toward research and education focused on pediatric cardiomyopathy. It also is a great way to raise awareness of the disease in your community. See what others are doing and get inspired! [Contact CCF's event team](#) today to get started on planning a fantastic fundraiser.

[Read more & view photos](#)

Advocacy Alert

Take Action and Be Heard!

overall survival rate of transplant recipients, challenges still exist in the long-term management and quality of life of transplant recipients.

The multi-center study, "Issues in Solid-Organ Transplantation in Children: Translational Research from Bench to Bedside" published in the May issue of *Clinics*, reviews the challenges of post-transplant care such as donor tissue rejection, side effects of immunosuppressive drugs, infections, malignancy, toxicity, blood cell disorders and, in some cases, recurrence of the primary disease.

The publication covers the mechanism of cardiac transplant rejection, the role of tissue biopsy and biomarkers in detecting graft rejection and the role of genetic analyses. The article also identifies future translational research directions aimed at identifying higher risk children for transplantation and improving post-transplant success.

[Download Clinics article](#)

CCF Receives Seal of Approval For Best Charities



CCF has been certified as among the best charities in America by Independent Charities of America after a very rigorous review of CCF's public accountability, programs and cost effectiveness. Of the 1,000,000 charities operating in the United States, fewer than 2,000 have been awarded this Best in America seal.

Since earning this certification, the Children's Medical & Research Charities of America (CMRCA) has recognized CCF's leadership in the field. The CMRCA is a federation of America's finest national organizations working to save lives of children in the U.S. and abroad. CCF also is an approved organization of the Combined Federal Campaign (CFC), the largest workplace charity campaign. If you are a federal, state/municipal or corporate employee whose employer uses CFC for donation distribution, please consider contributing to the Children's Cardiomyopathy Foundation through CFC Number 20736.

CCF Teams Up with the American Camp Association for AED Scavenger Hunt

CCF is partnering with the [American Camp Association](#) and [One Beat CPR +AED](#) on a summer-long hunt to find automated external defibrillators (AEDs) in camps across the nation. Campers and staff are encouraged to join this national

initiative to call attention to the importance of quickly locating an AED during a cardiac emergency when seconds count. The hunt involves locating a camp AED, taking a selfie and posting the picture with details on the AED location to social media outlets.

[Read more](#)

[Download AED Scavenger Hunt Map](#)



New Spanish Materials Available on PCM



To meet the needs of the growing Spanish population, CCF has translated into Spanish its organizational pamphlet and Understanding Pediatric Cardiomyopathy booklet with DCM, HCM, RCM and LVNC inserts. The Spanish materials are now available for download off CCF's website, along with CCF's other English educational resources for cardiomyopathy families. All CCF educational materials have been reviewed by a physician with expertise in cardiomyopathy and are available at no charge to families and hospitals.

[Download Spanish materials](#)

[View other education materials](#)

CCF's 2013 Annual Report Now Online

The 2013 Annual Report, "Seeking Answers, Finding Hope" is now downloadable to showcase CCF's 2013 accomplishments. During the year, CCF funded three new research grants and provided additional support to the Pediatric Cardiomyopathy Registry. We also raised our voices in Washington to lobby for increased research funding and educational awareness programs. Throughout 2013, CCF strengthened its patient support services and resources and was named a top-rated health organization for the third consecutive year.



We continue to advocate in Washington D.C. to raise awareness of cardiomyopathy and enact legislation that will protect undiagnosed, at-risk children from sudden cardiac death. We need you to raise your voice and persuade more members of Congress to support cardiomyopathy-related legislation. You can send emails to your U.S. senators and representative telling them how important these bills are to you.

[Cardiomyopathy HEARTS Act - Take Action!](#)

[Teaching Children to Save Lives Act - Take Action!](#)

CCF Events

CCF's 12th Annual Golf Classic July 21, 2014

Montclair Golf Club, N.J.

Join us for this popular and fun-filled golf event and tee-off for a cure! This is a sold out event every year so reserve your playing spot early.

[Details](#)

Family Fun Day For CCF

Erin Noonan, along with family and friends, will be throwing a summer fundraiser in honor of her son Jameson. The August 9 event is will be held in Delaware and includes a live band, a comedy show, water slides and face painting.

[Details](#)

Remembering Jaiden

On September 13, Hilda Hill will be celebrating her birthday. with a "pretty in pink" themed gathering is in honor of Hilda's granddaughter. Jaiden lost her battle with DCM at 11 months old. In lieu of gifts, guests are being asked to make a donation to CCF in memory of Jaiden.

[Donate today](#)

Shop Amazon and Support CCF

Help CCF while you shop when you use 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 Webinar

Living With Chronic Illness
Anne Farrar-Anton, MD
Joseph M. Sanzari Children's Hospital, Hackensack, NJ
June 17 at 6pm EST

[Register for webinar](#)

Cardiac Camp Directory

CCF maintains a list of heart-safe summer camps throughout the U.S. Many camps are low/no-cost or offer scholarships for eligible campers.

[Request cardiac camp list](#)

Ambassador Program

Help CCF to spread awareness, advocate for change and give support to new families.

[Get more information](#)

Youth Heart Buddy Program

CCF's Heart Buddy Program connects pre-teens and teens (ages 12-25) with each other.



Meet Anna

Anna's favorite foods are broccoli and strawberries. She loves singing Christmas songs year round. Anna is waiting for a new heart. [Read more](#)



Meet Judah

Judah loved bubbles and books like Yo Gabba Gabba and Monsters, Inc. Diagnosed with DCM at a week old, we lost Judah before he received a new heart. [Read more](#)



Meet Nathan

Nathan's favorite team is the Auburn Tigers. He also enjoys fishing and playing with his brother. An echocardiogram confirmed Nathan had HCM. [Read more](#)



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