



HEART TO HEART

News from the Children's Cardiomyopathy Foundation

March 2014 | Issue 3

Additional Research Study Funded by CCF

CCF recently awarded funding to Daniel Bernstein, M.D. of Stanford University for his study, "iPSC-Derived Cardiomyocytes in Left Ventricular Non-Compaction Cardiomyopathy (LVNC)." The \$50,000 grant represents the fourth research study that CCF is funding this year, bringing the total amount awarded in 2014 to \$200,000.

LVNC is a cause of heart failure that is increasingly being recognized in patients of all ages, but especially in children where it accounts for almost 10 percent of cases. LVNC has been associated with mutations in a wide variety of genes, but the mechanisms that link a specific gene mutation to alterations in the heart seen in LVNC are largely unknown.

Dr. Bernstein's research will use a novel technology, induced pluripotent stem cells-derived cardiomyocytes, as a model system to study the mechanisms of structural and functional changes in LVNC and the role of altered mitochondrial function, the energy-generating source in heart muscle cells, found to be abnormal in heart failure patients.

[View 2014 research abstracts](#)

CCF Founder Appears on TODAY Show

CCF's founding executive director, Lisa Yue, was selected for TODAY's "Everyone Has a Story" segment with Kathie Lee and Hoda. Lisa, her husband, Eddie Yu, and four children shared their story of losing two children to cardiomyopathy and how it inspired them to start CCF.



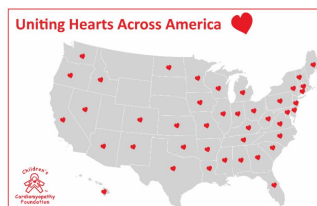
The segment, which aired on February 6, was a timely opportunity to increase awareness of pediatric cardiomyopathy during National Heart Month. Following the show, many new families contacted CCF, and the show's Facebook page received numerous messages from people expressing their gratitude for calling attention to the disease. Many cardiomyopathy families also shared their personal story of living with cardiomyopathy.

[View TODAY Show segment](#)

Uniting Heart Across America

National Heart Month Awareness Initiatives a Success!

During National Heart Month hundreds of families and friends joined CCF in telling America that heart disease isn't just about adults; it affects kids too, often with worse outcomes. The campaign, *Uniting Hearts Across America*, brought much needed attention to pediatric cardiomyopathy, and it was fun way to honor cardiomyopathy kids across America. Many from around the country



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Spring 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.

To date, CCF has funded more than 45 studies on pediatric cardiomyopathy, resulting in more than 165 medical publications and presentations. However, more worthwhile studies could be funded with a larger research budget.

This Spring Appeal, our goal is to raise \$50,000 to fund one additional research study. We need your help to make this possible. Every study we fund brings us one step closer to real cures.

[Give Today](#)

Making a Difference



[Get Inspired: Family Fundraisers](#)

participated in CCF's 50-State Challenge sharing facts about the disease, planning Big Heart bake sales and giving out CCF awareness valentines. Before long, our CCF state map was filled with hearts for every awareness effort.

[Read more & view CCF heart map](#)

CCF's Presence in D.C. Grows Safeguarding Students During Athletics

Lisa Yue, CCF's founding executive director, was in Washington, D.C. last week at the Youth Sports Safety Alliance meeting to talk about the importance of protecting student athletes from sudden cardiac death.



CCF is working with Senator Robert Menendez (D-NJ) and the National Athletic Trainers' Association on a set of initiatives that will help keep children safe while participating in athletic activities. The Senator introduced a resolution the first week of March on athletic safety that outlines priorities for a comprehensive legislation that will be introduced next month. This new bill will include provisions for identifying children with life-threatening heart conditions.

[Read Senator Menendez' resolution](#)

CCF Poker Tournament Wins Big

CCF's Sixth Annual All-In For A Cure No-Limit Texas Hold 'Em Tournament was once again well-attended. Held February 12 at Providence in New York City, the charity poker event raised more than \$241,000 for pediatric cardiomyopathy research and education.



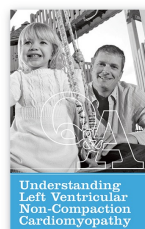
More than 265 guests and 42 corporate sponsors came together for a lively cocktail hour before hitting the tables. Ian Sandler of the Carlyle Group was thrilled to win the grand prize -- a \$10,000 entry to the 2014 World Series of Poker Main Event in Las Vegas.

[View event page](#)

[View event photos](#)

New LVNC Resource Available

A new insert on left ventricular non-compaction cardiomyopathy (LVNC) is now available as part of CCF's *Understanding Pediatric Cardiomyopathy* educational series. The insert provides an overview of LVNC, including information on causes, symptoms, diagnosis, treatment and prognosis.



Other inserts available in the *Understanding Pediatric Cardiomyopathy* series include dilated, hypertrophic and restrictive cardiomyopathy. All CCF educational materials are available at no charge and have been reviewed by a pediatric cardiologist with expertise in cardiomyopathy.

[View CCF's Educational Materials](#)

New Research Publication from CCF-Funded Multi-Center Study Pediatric Cardiomyopathy Registry Study Provides Insight on DCM Echocardiographic Function

The Pediatric Cardiomyopathy Registry (PCMR) has published another article based on findings from a nationwide study on dilated cardiomyopathy in children. "Recovery of Echocardiographic Function in Children with Idiopathic Dilated Cardiomyopathy: Results from the Pediatric Cardiomyopathy Registry" was published in February in the *Journal of American College of Cardiology*. CCF is acknowledged as a funder in the article.

The study analyzed extensive patient data from various medical centers to determine the incidence of and predictors for recovery of normal echocardiographic function among children with idiopathic dilated cardiomyopathy (DCM). Children under the age of eighteen who had both depressed left ventricular (LV) heart function and LV dilation were studied. The study concluded that children with DCM can recover normal heart size and function despite marked LV dilation and depressed function initially, especially those younger and with less LV dilation at diagnosis. Predictors for recovery, such as gene associations, serum markers, and the impact of medical therapy or ventricular assist devices, are important areas to investigate next.

The National Heart, Lung and Blood Institute Pediatric Cardiomyopathy Registry (PCMR) was established to describe the epidemiologic features and clinical course of selected cardiomyopathies in patients aged 18 years or younger and to promote the development of etiology specific treatments. CCF has been funding auxiliary studies since 2003, and 26 publications and medical presentations have resulted from CCF's partnership with the PCMR.

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!

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!](#)

Upcoming & Ongoing 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](#)

Heart Jewelry Sale

Jennifer Engel Designs created the Nolan's Heart of Steel Collection in honor of brave little Nolan Everett McLaughlin, who was diagnosed with DCM and recently had a heart transplant. A portion of the proceeds will go to CCF.

[Details](#)

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](#)

Cowboy Up 4 Cardiomyopathy

Saddle up for the first rodeo to support CCF. To be held May 3 in Louisiana, the event is hosted by Khloe Madison (age 12, HCM) and her family.

[Details](#)

Family Messageboard

CCF Connect: Cyberguests

Cardiovascular Genetics and Genetic Testing Related to Cardiomyopathy

Amy E. Roberts, MD
Boston Children's Hospital
April 14 - April 21

[Join CCF Connect](#)

[Ambassador Program](#)

[View publication abstract](#)

Rural AED Program Funding Increases

Working with the American Heart Association as a member of The Ad Hoc Coalition to Save Lives through Public Access to Defibrillation, CCF supports the Health Resources and Services Administration's (HRSA) Rural and Community Access to Emergency Devices Program.

Recently, the program received an appropriation of \$3.364 million in the Consolidated Appropriations Act (Public Law 113-76) that was signed into law in January. This 43 percent increase in funding will provide more federal grants to rural communities for the purchase of automated emergency defibrillators (AEDs). It also trains lay rescuers and first responders in their use and maintenance.

[Read coalition letter of support](#)

CCF Heart Kids



Meet Simon Fitch-Jenett

Simon loves drumming, cooking, trains and dinosaurs. Simon was diagnosed with acute congestive heart failure at 4 months old and diagnosed with DCM.

[Read more](#)



Meet Tara Carlson

Tara enjoys singing and dancing to every activity. She is the queen of tea parties, which she hosts daily in her room for guests. At 8 days old Tara was diagnosed with DCM.

[Read more](#)



Meet Claire Fowler

Claire wants to be an actress when she grows up. Claire was diagnosed with RCM at age 4 and received a heart transplant after surviving a cardiac arrest.

[Read more](#)

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

[Get more information](#)

Youth Connect Blog

CCF's Youth Connect Facebook group features weekly blog entries by young members. This is a private moderated Facebook group page only open to youths ages 12-25.

[Join CCF's Youth Connect](#)



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