



HEART TO HEART

News from the Children's Cardiomyopathy Foundation
June 2016 | Issue 2

CCF-Funded Investigator Publishes in *Nature Communications Journal*

Mario Delmar M.D., Ph.D., professor of cardiology at New York University School of Medicine and a 2015 CCF-funded investigator, published his preliminary findings in [Nature Communications](#). Dr. Delmar's research study, "Visual Proteomics for Personalized Assessment of Risk in ARVC Families," aims to improve the detection of individuals with arrhythmogenic right ventricular cardiomyopathy (ARVC) who are at higher risk of sudden death and therefore need immediate medical intervention.

His paper, "Nanoscale Visualization of Functional Adhesion/Excitability Nodes at the Intercalated Disc," explains the molecular visualization technology Dr. Delmar and his research team is using to study stem cells of patients with ARVC. Visual proteomics is a super resolution imaging technology that is used to view cell proteins in three dimension at a resolution of about 40 million times smaller than a pin head. Dr. Delmar is using this technology to find if minute changes in molecule position, regardless of genetic information, can be a sign for higher risk for sudden cardiac arrest.

"The paper shows the conceptual and methodological framework that we are now using to advance our studies of patients with ARVC," says Dr. Delmar. "CCF's support has been vital to our take-off on this investigation, and results from these experiments are in separate papers now under review with [European Heart Journal](#)."

[View abstract](#)

Spotlight on CCF-Funded Researcher: Sharlene Day, M.D.



Sharlene Day, M.D. is the director of the Hypertrophic Cardiomyopathy (HCM) Clinic at the University of Michigan Cardiovascular Center and 2015 CCF- Funded Investigator.

Dr. Day received her MD degree from New York University School of Medicine. She completed her internal medicine residency and cardiovascular medicine fellowship at the University of Michigan.

Dr. Day started her own research laboratory in 2006 and is currently funded by the National Heart, Lung, and Blood Institute. Her research interests are in the regulation of protein turnover and degradation, cardiovascular biology, and heart failure. She is particularly interested in the relationship between normal and mutant sarcomere proteins that are responsible for hypertrophic cardiomyopathy.

Dr. Day recognizes the detrimental physical and mental consequences of restricting kids with cardiomyopathy from playing sports. "This motivates me to understand whether these restrictions are universally warranted and whether sports participation truly increases one's risk of having a cardiac arrest or experiencing faster progression of their condition," said Day. She is co-leading a study called "Lifestyle and Exercise in Hypertrophic Cardiomyopathy that

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Find Your Camp AED



Join CCF, One Beat CPR and the American Camp Association for the 4th Annual #MyCampAED Scavenger Hunt. Post a photo of your family or child next to a camp AED on social media with the hashtag #mycampAED and include the camp name, state and AED location.

The national awareness initiative will run until end of August at camps across the U.S. The hunt encourages campers and camp staff to locate their camp automated external defibrillator (AED) and know how to use it in a cardiac emergency. One Beat CPR will award a Philips HeartStart Onsite AED to a selected camp in need.

[Read More](#)

will examine long term outcomes and quality of life in pediatric and adult patients based on their level of exercise and sports participation.

Dr. Day believes we are entering a new era in cardiomyopathy research helping move the field from observation to intervention. Her CCF research study, "Disease Pathways for MYBPC3 Mutations in Hypertrophic Cardiomyopathy," investigates new therapies for HCM that target the underlying disease process, rather than treating symptoms and complications as they arise.

Former Miss Ohio to Speak at CCF Annual Golf Event

CCF is honored to have special guest speaker, Lindsay Davis, speak at CCF's 14th Annual Golf for a Cure outing on July 18 at Montclair Golf Club in New Jersey. Lindsay is a model and beauty queen who was crowned Miss Ohio U.S. International in 2010 and Miss Ohio United States in 2011. Lindsay trained as a ballerina until age 17 when she was diagnosed with hypertrophic cardiomyopathy (HCM).



Because of her diagnosis, she has made it her mission to raise awareness of cardiomyopathy. In 2013 she helped introduce and pass "Lindsay's Law," a bill in Ohio that addresses and prevents sudden cardiac arrest among young athletes. The legislation calls for coaches to go through online training to recognize and address symptoms of sudden cardiac arrest. Lindsay speaks nationally about cardiomyopathy and has written about the disease for Sports Illustrated and USA Today.

[Register for event](#)

View CCF's Genetic Testing Video



Genetic testing is an important component of the cardiomyopathy evaluation process. A new educational resource "Know Your Heart: Genetic Testing for Cardiomyopathy Families" provides families with a basic overview of the genetic testing process.

The short video, produced by CCF and funded by a grant from the American Legion Child Welfare Foundation, features two families living with cardiomyopathy and includes commentary from pediatric cardiologists, a geneticist and a genetic counselor. A range of topics are covered, including what genetic testing is, when it should be considered, how the process works, and why it can be beneficial to families.

CCF Reaches Out to the Medical Community



CCF continues to connect with the medical community to share information on pediatric cardiomyopathy and CCF's programs at various medical meetings across the U.S. and Canada. In the past 6 months, CCF has had a presence at several cardiomyopathy and pediatric heart failure meetings.

In June, CCF co-sponsored the fourth SHaRe family conference, Affairs of the Heart: Living with Hypertrophic and Dilated Cardiomyopathy, in New Haven, Conn. Held at the Yale New Haven Hospital Heart and Vascular Center, CCF's Manager of Patient Outreach and Support, Gina Peattie, spoke about CCF's patient support and advocacy work to more than 100 families in attendance.

Shari Maurer, CCF's patient support and outreach coordinator, represented CCF at the 12th International Conference on Pediatric

Advocacy Alert

Take Action and be Heard!

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 representatives telling them how important this bill is to you.

[SAFE PLAY Act](#)

Annual Report 2015



CCF's 2015 Annual Report is now available on CCF's website. It takes a team of families, supporters and physicians to defeat a complicated disease like cardiomyopathy.

View the report to see how far the Foundation has come in the areas of research, education, family and patient support, and awareness and advocacy.

[View Annual Report](#)

Make a Difference



You can make a sweet difference throughout the year by organizing a bake sale in your community. Contact [CCF's event team](#) today to receive your complimentary Bake for a Cure fundraising kit.

[Start Baking](#)

CCF Fundraisers

Annual Golf for a Cure
July 18
Montclair Golf Club, N.J.

Tee off for a cure, and join us for this fun-filled golf outing at the Montclair Golf Club. The popular event sells out quickly so reserve your playing spot now.

[Details](#)

Kasi Webb Inaugural Golf

Mechanical Support Systems & Pediatric Cardiopulmonary Perfusion at Columbia University Medical Center in May and introduced CCF's family and medical resources to attending cardiac professionals.

In September, the Foundation will be a sponsor at the upcoming Pediatric Heart Failure Summit at Sick Kids Hospital in Toronto. CCF also was a sponsor at the Innovations in Pediatric Heart Failure conference in December 2015, which was organized by Rady Children's Hospital San Diego.

New Jersey Tricky Tray Event Benefits CCF

The Twins' Mothers Club of Bergen County in New Jersey hosted their 56th annual charity dinner and tricky tray night on May 11. The Queen of Hearts-themed event featured fantastic items donated from more than 200 local businesses, making the event one of the largest raffles in Northern New Jersey. President Amanda Lupino presented a check to CCF for \$6,000 to support the development of additional educational materials on pediatric cardiomyopathy.



Lisa Yue Named Lady GODIVA Finalist

CCF Founder and Executive Director, Lisa Yue has been named as a finalist in the 2017 Lady GODIVA program, which celebrates women with attributes of selflessness, generosity and leadership. Inspired by Lisa's dedication to helping children with cardiomyopathy even after losing her two young boys to the disease, GODIVA selected Lisa as an extraordinary woman making a difference in the world. Lisa is in the running to win a \$10,000 grant for the Foundation.



Meet Savannah

Savannah is a happy girl who enjoys car rides with her family and jamming to music.
[Read More](#)



Meet Camden

Camden is an adorable baby who loves cars and wants to drive everything he sees.
[Read More](#)



Meet Aria

Aria takes tap and ballet classes and hopes to be Miss America when she grows up.
[Read More](#)

Tournament

June 21
Clarksville, Ga.

This memorial outing celebrates the life of Kasi Webb who passed away six years ago due to cardiomyopathy. Friends and families have selected CCF to receive the event proceeds.

[Details](#)

Family Messageboard

AED Rebate Offer

One Beat CPR + AED is offering a rebate on two AED models. Receive a \$50 rebate for the HeartStart OnSite AED and a \$75 rebate for the HeartStart FRx AED.

[Learn more](#)

Family Gathering Guide

This new resource provides instructions and resources for planning a local CCF family gathering.

[Learn more](#)

Family Assistance Program

Qualifying families can apply for financial aid on cardiomyopathy related non-medical and medical expenses.

[Learn More](#)



Children's Cardiomyopathy Foundation
Toll free 866.808.CURE
info@childrenscardiomyopathy.org
childrenscardiomyopathy.org



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