

HEART TO HEART

News from the Children's Cardiomyopathy Foundation - July 2017



CCF's Federal Advocacy Efforts

CCF has been working with Federal agencies to create new funding options for researchers studying pediatric cardiomyopathy. As a result of CCF's advocacy efforts, the U.S. Department of Defense is now accepting research applications on pediatric cardiomyopathy through their Peer Review Medical Research Program (PRMRP).

Other advocacy priorities include obtaining congressional support of cardiomyopathy-specific language in the FY18 appropriations

bill and working with legislators to introduce a bipartisan bill on cardiomyopathy in the House and Senate.

PRMRP Funding



Reaching Out to Patients and Physicians

CCF continues to sponsor regional family meetings with the Sarcomeric Human Cardiomyopathy Registry (SHaRe). Last month CCF participated at the SHaRe conference at University of Michigan Medical Center in Ann Arbor, Mich. and will be involved at the Duke University Hospital conference to be held in Durham, N.C. on September 23.



CCF is also sponsoring a lecture on cardiomyopathy at the Midwest Pediatric Cardiology Society annual meeting in St. Louis, Mo. CCF Medical Advisor, Jeffrey Towbin, M.D., of Le Bonheur Children's

Hospital, will speak at the September conference.

Register for SHaRe Meeting

Ellis Ann Cosby Foundation Event Benefits CCF

The Ellis Ann Cosby Foundation organized their inaugural fundraiser in Dothan, Ala., raising \$13,000 for CCF. The party, held at KBC, a popular eatery specializing in Southern cuisine, included a silent auction of donated items from 70 local businesses.



David and Megan Cosby started the foundation as a tribute to their daughter, Ellis Ann, who they lost to cardiomyopathy at just 6 months old. The Foundation's goal is to raise awareness of pediatric cardiomyopathy, and to help grieving parents who have experienced the loss of an infant.

[Read More](#)



Children's Cardiomyopathy Foundation

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