

HEART TO HEART

News from the Children's Cardiomyopathy Foundation - September 2017



Children's Cardiomyopathy Awareness Month

Children's Cardiomyopathy Awareness Month Initiates Heart-Healthy Conversations

Eleven national organizations join CCF this September in raising awareness of pediatric cardiomyopathy. The month-long initiative features 30 days of educational activities to increase awareness of the signs, symptoms, and risk factors for cardiomyopathy. A highlight of the month's activities is a webinar with renowned cardiomyopathy specialist Jeffrey Towbin, M.D. of Le Bonheur Children's Hospital. It will be held on September 21 at 6 p.m. EST.

Cardiomyopathy is a leading cause of sudden cardiac arrest (SCA) in the young, and often those undiagnosed and unaware of a family history of heart disease are at a higher risk for SCA. During Awareness Month, families are encouraged to start a conversation about their cardiac health history.

Awareness month partners include the [American Academy of Pediatrics](#), [American Heart Association](#), [Centers for Disease Control and Prevention](#), [Eric Paredes Save a Life](#), [National Alliance of Youth Sports](#), [National Association of School Nurses](#), [National Athletic Trainers' Association](#), [National Organization for Rare Disorders](#), [Parent Heart Watch](#), [Sarcomeric Human Cardiomyopathy Registry \(ShaRe\)](#), and [Sudden Cardiac Arrest Foundation](#). Partners will highlight Awareness Month on their blogs, newsletters, and social media sites.

To commemorate Awareness Month, the Third Annual Walk for a Cure will be held on September 17 in West Orange, N.J. Hometown walks are also scheduled across the country in Pennsylvania, Florida, Virginia, Delaware, and Michigan.

[View Awareness Month activities](#)
[Register for Walk for a Cure](#)



CCF-Funded Studies to be Featured at AHA Scientific Sessions

The National Heart, Lung, and Blood Institute (NHLBI) and Children's Cardiomyopathy Foundation (CCF)-funded Pediatric Cardiomyopathy Registry (PCMR) will present four research abstracts at the [American Heart Association \(AHA\) Scientific Sessions](#). The Scientific Sessions, to be held in Anaheim, Calif. on November 11-15, is the top cardiovascular meeting for basic, translational, clinical, and population science. The AHA receives more than 10,000 abstracts every year and only accepts 30% for presentation. The abstracts featured at the poster sessions include: "Cardiac biomarkers are associated with death and listing for heart transplantation in pediatric patients with newly diagnosed dilated cardiomyopathy: A multi-center study from the pediatric cardiomyopathy registry;" "Are echocardiogram and magnetic resonance imaging comparable in measuring maximal septal thickness in children with hypertrophic cardiomyopathy?;" "Fibrosis and hypertrophy assessed by magnetic resonance imaging and serum biomarkers in pediatric hypertrophic cardiomyopathy: A report from the pediatric cardiomyopathy registry group;" and "Exome sequencing in a pediatric cardiomyopathy cohort: Findings from the pediatric cardiomyopathy registry." Since 2003, CCF has taken an active role in supporting PCMR's multi-center studies and have funded several working groups and ancillary studies.

PROGRESS IN PEDIATRIC CARDIOLOGY

Publications from CCF's 4th International Scientific Conference

Conference proceedings from CCF's 4th International Scientific Conference held in May have been published in the September issue of *Progress in Pediatric Cardiology*. This is the first of three issues to be dedicated to pediatric cardiomyopathy. In the September issue, six papers authored by select meeting attendees will run, including: "[Continuous donor perfusion for heart preservation](#);" "[Induced pluripotent stem cell-derived cardiomyocytes: A platform for testing for drug cardiotoxicity](#);" "[Non-cardiac targets to treat heart failure in children: Anemia, exercise, and nutrition](#);" "[Noncompaction cardiomyopathy and heterotaxy syndrome](#);" "[Serum biomarkers for primary graft failure in pediatric heart transplantation](#);" and "[The echocardiographic risk assessment of donor hearts for consideration of transplantation](#)." Additional articles from the conference will be published in December and March 2018.



Children's Cardiomyopathy Foundation

Toll free 866.808.CURE

info@childrenscardiomyopathy.org

childrenscardiomyopathy.org



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