

## HEART TO HEART

News from the Children's Cardiomyopathy Foundation - October 2017



### AED Hunt on the Hill

CCF worked with Representative Phil Roe (TN-01) to host the AED Hunt on the Hill in Washington D.C. on September 27. The educational event held at the Capitol during Children's Cardiomyopathy Awareness Month focused on cardiomyopathy, the risk of sudden cardiac arrest, and the importance of early defibrillation during a cardiac emergency.

Sudden cardiac arrest (SCA) claims more than 350,000 lives in the United States annually, and cardiomyopathy is a leading cause of SCA. At the event, a representative from George Washington University's Lifesavers Program gave cardiopulmonary resuscitation (CPR) and automatic external defibrillator (AED) demonstrations, and members of Congress and congressional staff took photographs with an AED for a social media awareness campaign.

[Read more](#)

[View event photos](#)



### Cardiomyopathy HEARTS Act Reintroduced

For the past few months, the Children's Cardiomyopathy Foundation (CCF) has been working closely with Congressman Frank Pallone's (NJ-06) office on new legislation to raise awareness of cardiomyopathy and direct more federal resources to the disease. The Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act (H.R. 8330) was introduced last week during Children's Cardiomyopathy Awareness Month. The bill will assess the research needs of cardiomyopathy across the lifespan, establish cardiomyopathy surveillance research, and create educational resources to disseminate to school administrators, educators, and families.

On October 2, Rep. Frank Pallone, Jr. and State Assemblyman Patrick Diegnan, Jr. (D-Middlesex) held a press event at Metuchen High School to announce the introduction of the bill to New Jersey school administrators, teachers, and students. Lisa Yue, CCF founding executive director, spoke about the importance of the legislation and how it can help to prevent sudden cardiac death from undetected heart conditions such as cardiomyopathy.

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## CCF Delivers Family Care Bags to Several Hospitals

CCF launched a Family Care Bag program to help support families coping with an extended hospital stay due to their child's cardiomyopathy treatment. The bags include basic necessities and kids activity items donated by Google, colorful S'well water bottles, and information about cardiomyopathy and CCF's support resources.

Nancy Hwang, mom to 3-year-old Nina diagnosed with cardiomyopathy, organized a community volunteer day at Google to assemble the care bags for CCF. The bags, intended to make families more comfortable while their child receives treatment, were hand delivered by CCF ambassadors to several medical centers across the U.S., including Children's Hospital of Philadelphia; Montefiore Medical Center in the Bronx, N.Y.; Morgan Stanley Children's Hospital in New York, N.Y.; and Rady's Children's Hospital in San Diego, Calif.



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