Children’s Cardiomyopathy Foundation to Call Attention to a Heart Disease that is a “Silent Killer”

Children’s Cardiomyopathy Awareness Month Urges Families to #KnowYourHeart to Learn Risk Factors

TENAFLY, N.J.—September 1, 2018— All too often, we read about a star athlete who suddenly collapses on the night of the big game, or a baby who dies in her sleep. Chances are, a little known heart disease named cardiomyopathy is the cause. This September, the Children’s Cardiomyopathy Foundation (CCF) is celebrating Children’s Cardiomyopathy Awareness Month to shine a spotlight on pediatric cardiomyopathy, a chronic and potentially life-threatening heart disease.

Cardiomyopathy is an incurable and often progressive heart disease that affects how the heart pumps blood through the body. It is a disease that is largely unrecognized even though it is the leading cause of sudden cardiac arrest and heart transplants in children under the age of 18. Many times, it is “silent” in its symptoms and not diagnosed until after a tragedy occurs.

According to the American Heart Association, approximately 7,000 children under the age of 18 will have a sudden cardiac arrest with only 10.7 percent surviving. Children’s Cardiomyopathy Awareness Month calls attention to the signs, symptoms, and risk factors for cardiomyopathy, which can help identify undiagnosed, at-risk children get the appropriate medical attention they need to prevent sudden death.

Protecting children from premature death is a top priority for CCF — a national organization founded by Lisa Yue, a mother who lost two children to cardiomyopathy. Determined to help other families avoid the same tragedy, she formed CCF in 2002 to focus on research, education, and awareness of cardiomyopathies affecting children. “I believe knowledge of the disease and evaluating a family’s cardiac health can help save lives,” said Lisa Yue, CCF founding executive director. “This September we urge physicians, nurses, coaches, teachers and community leaders to unite and join us in educating the public about cardiomyopathy.”

Cardiomyopathy can strike at any age and sideline seemingly healthy children and teens. Sammi Chan of California was a competitive swimmer when she was diagnosed with dilated cardiomyopathy at 13 years old. “For most of my life, I have lived with the risk of sudden cardiac arrest,” said Sammi. “Today, I am on six different medications to regulate my heart, and my implantable cardioverter defibrillator (ICD) has saved my life many times.” Sammi, now 23 years old, participates every year in awareness month activities and shares her story with others.

CCF will celebrate awareness month with 17 partners, including the American College of Cardiology, American Heart Association, American Academy of Pediatrics, National Association of School Nurses, and National Alliance for Youth Sports. In addition to 30 days of fun, educational activities to encourage the public to #KnowYourHeart, CCF will host the 4th Annual Walk for a Cure in New Jersey. Visit CCF’s website for more information and a listing of awareness month partners: www.childrenscardiomyopathy.org.

About The Children’s Cardiomyopathy Foundation

The Children’s Cardiomyopathy Foundation (CCF) is a national organization focused on finding causes and cures for all forms of pediatric cardiomyopathy, the leading cause of heart transplants and sudden cardiac arrest in children. CCF started in 2002 with one family’s determination to call attention to this poorly understood heart disease and to take action on the lack of medical progress and public awareness. Since then, CCF has grown into a global community of families, physicians, and scientists and has raised more than $12 million for research and education initiatives, family support, and awareness and advocacy measures.

###

P.O. Box 547 • Tenafly, New Jersey • 07670 • Tel 866.808.CURE • Fax 201.227.7016 • childrenscardiomyopathy.org