CHILDREN'S CARDIOMYOPATHY FOUNDATION

Heart to Heart

July 2026 | Issue 2

NEWS & HIGHLIGHTS

ADVOCACY

CCF Joins National Effort to Advance Heart Research

Kathy Swenson, CCF's executive director, joined 28 heart organizations at the **Annual National Congenital Heart Disease (CHD) Advocacy Summit** on Capitol Hill to to prioritize federal funding for pediatric heart disease and represent the needs of children with cardiomyopathy. The action day was sponsored by Every 100th Heart, a national coalition dedicated to bringing advocates together to advance a coordinated federal policy agenda.

At the two-day summit, CCF urged Congress to fund the National Heart, Lung, and Blood Institute (NHLBI) at $4.3 billion in FY27, and

RESEARCH

CCF Family Survey Helps Shape Understanding of Gene Therapy

At the annual meeting of the **American Society of Gene and Cell Therapy (ASGCT)**, survey findings from a study conducted by CCF in collaboration with Tenaya Therapeutics were presented by Leah Mumm, CCF's director of family and physician relations, and Kim Cohee of Tenaya Therapeutics.

The poster, "Perceptions and Attitudes Towards Gene Replacement Therapy in Parents of Children With Cardiomyopathy," surveyed caregivers from CCF's online community to determine awareness of emerging gene therapies. The findings

provide appropriations for the Cardiomyopathy HEARTS Act signed into law in December 2024.

Download Summary Sheet →

underscore the importance of genetic testing, counseling, and access to reliable information.

Download Summary Sheet →

AWARENESS

CCF Family Highlights the Power of Patient Voices at NYBio Summit

CCF family member Mariclare Rivera was a guest speaker at the **2026 New YorkBio Patient Engagement Summit**, which connected leaders in the patient community with leaders in the biotech and life science fields. Rivera's story about her daughter's diagnosis and treatment serves as a powerful reminder to companies and researchers that the patient perspective is critical to developing treatments and cures.

Learn More →

CCF Ambassador Program: Share Your Story and Support Families

CCF is seeking parents and caregivers to join our **Ambassador Program, a volunteer leadership initiative connecting families** for informational and emotional support. CCF will provide training and guidance to help you build relationships with newly diagnosed families, physicians and hospitals in your community. Interested in sharing your experience and supporting others? Complete the Ambassador Interest Form.

Apply Here →

Get Ready for September Awareness Month and Walk for a Cure

Pennsylvania, New Jersey, Massachusetts, California, Texas, and Florida already have community walks planned for September! Add your state to the map and help raise awareness and critical funds for pediatric cardiomyopathy research, education, and family support programs. It takes a team to defeat cardiomyopathy! Join a local walk, start a team, or support an event. Every step helps fund research and provide resources for affected families.

Start Walking →

HEART KID

Maison

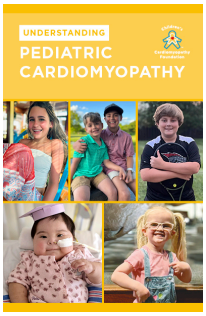
Dilated Cardiomyopathy (DCM)

Meet CCF Heart Kid Maison from Kentucky! Maison, 17 years old, was diagnosed with dilated cardiomyopathy (DCM) in 2022 after experiencing extreme fatigue while playing sports and taking long walks. Although she had to step away from competitive swimming, Maison found a new passion in archery and now holds the highest individual score at her high school. With treatment, her heart function has improved, and she currently manages her condition with medication and an implantable cardioverter-defibrillator (ICD). Maison is excited about starting college, where she plans to study environmental science.

FAST FACT

Dilated Cardiomyopathy (DCM) can reduce the heart's ability to pump blood effectively, leading to fatigue and shortness of breath.

RESOURCES

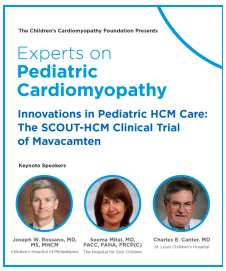


Updated Materials for Families

Our newly updated **Understanding Pediatric Cardiomyopathy** materials feature updated medical information reviewed by CCF advisors, refreshed designs, and inspiring stories from our Heart Kids.

The **booklet and five inserts** are a free resource and provide essential guidance for families and healthcare professionals navigating the complexities of pediatric cardiomyopathy.

Download PDFs →



Latest Webinars on CCF's Website

Our latest Experts on Pediatric Cardiomyopathy webinar highlights preliminary results from the SCOUT-HCM clinical trial, which is a multi-center study to evaluate mavacamten in adolescents with symptomatic obstructive hypertrophic cardiomyopathy (oHCM). THe oral medication was FDA approved for use in adults with oHCM in 2022.

This presentation was not affiliated with or endorsed by Bristol Myers Squibb.

CCF webinars are available free-of-charge on our **website**.

View Webinars →

CENTERS OF CARE

As the only organization dedicated exclusively to pediatric cardiomyopathy, CCF understands that children are not simply small adults.

CCF's Cardiomyopathy Centers of Care Program works with the top children's hospitals around the U.S. and recognizes specialty medical centers that follow a comprehensive care approach to managing children with cardiomyopathy. View our list of recognized centers and learn what distinguishes these expert pediatric heart programs.

View Centers of Care

Jay Wilkinson, M.D., M.P.H. VANDERBILT UNIVERSITY MEDICAL CENTER

PHYSICIAN SPOTLIGHT

CCF mourns the loss of **Jay Wilkinson, M.D., M.P.H.**, former director of the Center for Clinical and Translational Research at Vanderbilt University Medical Center and long-time contributor to the NHLBI-funded North American Pediatric Cardiomyopathy Registry (PCMR), a multicenter observational study that CCF has partnered with for more than two decades.

Dr. Wilkinson served as the director of the PCMR Administrative Coordinating Center, where he helped manage NHLBI grant submissions, manuscript development and publication, and scientific conferences. He also contributed to several PCMR publications, serving as first author of "Lessons Learned from the Pediatric Cardiomyopathy Registry (PCMR) Study Group" published in Cardiology in the Young. "**We greatly appreciate Dr. Wilkinson's longstanding commitment to advancing**

pediatric cardiomyopathy research," said Lisa Yue, CCF founder and president.

Dr. Wilkinson's dedication to collaborative research and clinical investigation helped strengthen the PCMR over many years. His contributions have had a lasting impact on the field and on the children and families it serves.

In Memoriam →

UPCOMING EVENTS

CCF EVENTS

July 20	**23rd Annual Golf for a Cure** Ridgewood Country Club Paramus, NJ	**Register**
August 17	**North Star Charity Golf Tournament** Bloomington, MN	**Learn more**
August 22	**16th Annual Casen's Crew Golf Tournament** Abilene, TX	**Learn more**

GOLF FOR A CURE
CHILDREN'S CARDIOMYOPATHY FOUNDATION

Join us for our most popular event — the **23rd Annual Golf for a Cure** taking place **July 20** at the historic and prestigious Ridgewood Country Club in northern New Jersey. Playing spots are limited at this championship course.

Reserve Your Spot Today

Give back and make a difference.

When you give to CCF, you're making sure the next family that gets a diagnosis isn't alone. You're funding the research that could change a child's future. Every gift

matters more than you know.

Make a Gift Today

OUR CORPORATE PARTNERS

Children's Cardiomyopathy Foundation

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