



## NEWS & HIGHLIGHTS

### ADVOCACY



### CCF Connects with Global Leaders at ISHLT 2026

CCF Executive Director Kathy Swenson and Senior Director of Family & Physician Relations Leah Mumm attended the **47th Annual Meeting of the International Society for Heart and Lung Transplantation (ISHLT)** in Toronto, April 22–25.

Research from five CCF Medical Advisors was featured, including studies on a promising blood test to reduce invasive heart biopsies in children, transplant rejection risks during transition to adult care, and a successful recovery case involving a toddler with severe heart failure.

### EDUCATION



### New Video Series Helps Families Understand PCM

Our new, six-part video series, **Understanding Pediatric Cardiomyopathy (PCM)**, features CCF medical advisors answering common questions families face after diagnosis.

Topics include what causes pediatric cardiomyopathy, treatment options, whether there is a cure, and what schools need to know to help keep children safe and supported throughout daily activities and social settings. Designed for newly diagnosed families and caregivers alike, the series offers trusted education families can revisit and share.

## AWARENESS



### CCF Takes Part in Pediatric Transplant Conference

CCF participated in the 2026 **Pediatric Transplant Conference** where CCF Medical Advisor **Ashwin K. Lal, MD**, presented on navigating cardiomyopathy to transplant. The session offered guidance on disease progression, care, and transplant evaluation.

[View Presentation →](#)



### “Exploding Hearts” Quilt Supports Children with Cardiomyopathy

Congratulations to **Jennifer Blake**, winner of our “Exploding Hearts” quilt raffle. As part of CCF’s **Create for a Cure** initiative, the raffle united our community to support critical research and awareness of the disease.

[Give to Create for a Cure →](#)



### Get Ready for September Awareness and Walk for a Cure

CCF is preparing for this year’s **Walk for a Cure** during September Awareness Month and invites families and friends to form walk teams to help raise awareness of pediatric cardiomyopathy and support for critical programs.

[Register Your Team →](#)

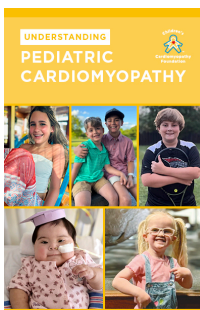
## RESOURCES



### CCF's 2025 Annual Report

The Children’s Cardiomyopathy Foundation Annual Report highlights the progress we’ve made together in advancing research, supporting families, and raising awareness of pediatric cardiomyopathy.

[View Report →](#)

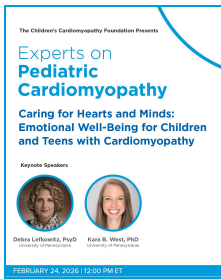


### Updated Materials for Families

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 Now Available

Two, new webinars are now available free for all CCF families, covering emotional well-being for children and teens with cardiomyopathy and guidance on genetic testing and family planning. Led by top experts, these sessions offer trusted information and compassionate support for families navigating diagnosis and care.

[View Webinars →](#)

CCF SUPPORTS FAMILIES WORLDWIDE

**3,930**

families served in 100 countries

**47**

Cardiomyopathy Centers of Care

**\$20M**

invested in research and educational initiatives

[Join Our Community](#)

### IMPACT



**50-60%**

of pediatric cardiomyopathy cases are diagnosed as dilated cardiomyopathy

### RESEARCH

A CCF-funded study published in **Circulation: Heart Failure** found that children who develop dilated cardiomyopathy (DCM) after myocarditis have a significantly higher rate of rare, potentially harmful heart-gene variants. **Alicia Kamsheh, MD**, served as lead author with CCF Medical Advisory Board Chair **Steven Lipshultz, MD**, as senior author.

**DCM** is the most common form of cardiomyopathy in children with the highest incidence occurring in infants under one year old.

[View Article →](#)



### PHYSICIAN SPOTLIGHT

CCF Medical Advisor **Teresa M. Lee, MD, MS**, was recently featured on the **Columbia Global Paris Center podcast Atelier**. In the episode, "Repairing the Living, Honoring the Empty Spaces" she reflects on the ethical and emotional dimensions of caring for children with heart failure and guiding families through transplant. Dr. Lee also discusses her research on the genetic causes of cardiomyopathy in children.

Dr. Lee was a Reid Hall Faculty Visitor at the Columbia Global Paris Center, which is part of a network of 11 global centers of

UPCOMING EVENTS

CCF EVENTS

**June 9**

**Experts on Cardiomyopathy Webinar**  
"Innovations in Pediatric HCM Care: The SCOUT-HCM Clinical Trial of Mavacamten"

[Register](#)

**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](#)



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](#)



**Help another family find their way.**

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  
24 West Railroad Avenue, Suite 408  
Tenafly, NJ 07670 US

You are receiving this email because of a prior contact, involvement, or donation to the Children's Cardiomyopathy Foundation.

© 2026 Children's Cardiomyopathy Foundation. All rights reserved.

[Unsubscribe](#) | [Update Profile](#) | [Constant Contact Data Notice](#)