CHILDREN'S CARDIOMYOPATHY FOUNDATION

Heart to Heart

September 2026 | Issue 3

NEWS & HIGHLIGHTS

September is Pediatric Cardiomyopathy Awareness Month

Every September, the Children's Cardiomyopathy Foundation (CCF) leads **Pediatric Cardiomyopathy Awareness Month** to raise awareness of a rare and often underdiagnosed heart disease affecting children. The annual observance encourages families and healthcare professionals to educate others about pediatric cardiomyopathy because recognizing its signs and symptoms and knowing a family's cardiac history can lead to earlier diagnosis, timely referral, and specialized care.

Throughout September, the CCF community turns awareness into action. Families share their stories, educate others, advocate for legislative support, and participate in **Walk for a Cure**, CCF's signature Awareness Month event. This year, 13 family-led walks are planned across the country, raising awareness and funds for CCF's family support programs and services.

Whether you attend a walk, share resources, or start a conversation about pediatric cardiomyopathy, every action helps families find answers sooner and reminds them they are not

alone in their journey.

Learn more about Awareness Month →

Join Families Across the Country for Walk for a Cure this September

Now in its 12th year, Walk for a Cure brings families and communities together to raise awareness and support children affected by pediatric cardiomyopathy. Whether you walk on your own, with family and friends, or join one of 13 community walks across the country, every step helps raise awareness and funds for CCF's family support programs and services. We'll provide the tools and support—you just choose how and where to walk.

Register for Walk for a Cure →

Help More Families Recognize Cardiomyopathy Sooner

Most people have never heard of pediatric cardiomyopathy until it affects someone they love. This September, you can help change that. Share your story, download our **Awareness Month Resources**, and use our ready-to-share facts, social media graphics and educational resources to help others learn about a rare and potentially life-threatening heart disease. Every conversation helps our community recognize pediatric cardiomyopathy.

Support Awareness Month →

EVENT HIGHLIGHT

GOLF FOR A CURE
CHILDREN'S CARDIOMYOPATHY FOUNDATION

2026 Tournament Champions: Andrew Block, Jeff Longmuir, Max Schulman and Shaun Kenney

Golf for a Cure Celebrates Its 23rd Year

The Children's Cardiomyopathy Foundation's Golf for a Cure welcomed **150 golfers to Ridgewood Country Club** in New Jersey on July 20. Thanks to the generosity of event participants, donors, and 50 sponsors, the event raised more than $400,000 to advance pediatric cardiomyopathy research, education, and family support.

Congratulations to tournament champions **Andrew Block**, **Jeff Longmuir**, **Max Schulman**, and **Shaun Kenney**, who captured first place with a winning score of 55. The evening reception featured an exciting live auction with winning bids for a Tuscan Villa for 12 with a private chef and a Food Network Star Chef dining experience.

A heartfelt thank you to our golf committee, sponsors, volunteers, donors, and everyone who helped make this year's event such a tremendous success.

View Program and Photos →

Brian Hewitt & Family · Brian McGowan & John O'Meara · Carney Hawks & Family · Dan & Stacie Allen
Emil Costa & Family · The Faughnan Family · Scott Gooch & Family · The Petrick Family · The Yu Family
Chaney & Marisa Sheffield · Doug & Elizabeth Pardon · Daniel Shatz · Eric Guevara & Family · Frank Fiorito · Gene Pagnozzi · Gilbert Nathan
Jason & Jessica Glennon · Rick Lam · Rocco & Maureen D'Alleva · Si Lund · Steven Bleier · Sunil Aggarwal · William McCarthy

HEART KID

Justin

Age 12, Illinois

With a glove in hand and his cleats laced up, there's no place Justin would rather be than on the baseball field. His dream is to become the first Major League Baseball player with hypertrophic cardiomyopathy (HCM).

For Justin, baseball is his greatest joy. His path took an unexpected turn when he was diagnosed with HCM after an emergency room visit for COVID-19. Fortunately, Justin is asymptomatic and continues to play under the guidance of his medical team.

His diagnosis hasn't changed his dream. If anything, it has given him even more reason to chase it. This year he hit a home run during the Cooperstown youth tournament, and his team advanced to the semifinals of the Little League World Series.

FAST FACT

Did You Know?

Hypertrophic cardiomyopathy is often inherited, making family cardiac history an important part of diagnosis and care.

Learn More About Hypertrophic Cardiomyopathy →

OUR MISSION IN ACTION

A Birthday Party Raises Awareness

When Pedro, a CCF Heart Kid diagnosed with dilated cardiomyopathy (DCM), celebrated his birthday, his family used the occasion to educate friends and family about his heart condition and journey to a heart transplant. With assistance from New York-Presbyterian Morgan Stanley Children's Hospital, they shared CCF's educational materials and highlighted the family support CCF provides. Families interested in raising awareness can learn more about CCF's Fundraise Your Way initiative.

Read More →

RARE Bears Bring Comfort to Kids

Through our collaboration with Tenaya Therapeutics, CCF is helping bring handmade Rare Bears to hospitalized children with cardiomyopathy and children who have received a transplant at a CCF-recognized Cardiomyopathy Center of Care. The Rare Bear Project, created by RARE Science, connects children with rare diseases to one-of-a-kind bears made by volunteer Bear Makers like Tenaya. CCF helped to distribute the bears to bring comfort to children during their hospital stay.

Read More →

Communities Tee Off for Kids with Cardiomyopathy

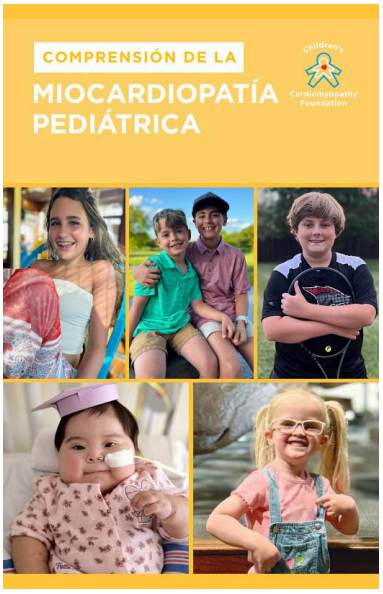
Two golf tournaments in August united CCF families, friends, and supporters to raise funds for pediatric cardiomyopathy research and education.

The **North Star Charitable Golf Tournament** in Bloomington, Minnesota, led by Wes Sharp, honors his two sons, Bennett and Mason, who have a genetic mutation associated with noncompaction cardiomyopathy (NCCM). Now in its third year, the August 17 event raised $130,000 to support CCF's mission.

Casey and Heather Riley held their annual **Casen's Crew Golf Tournament** in Abilene, Texas, in honor of their son, Casen, who died from hypertrophic cardiomyopathy (HCM) at six months old. Now in its 16th year, the event garnered more than 15 sponsors to honor Casen's life and raise funds to support children and families affected by cardiomyopathy.

Read More →

RESOURCES

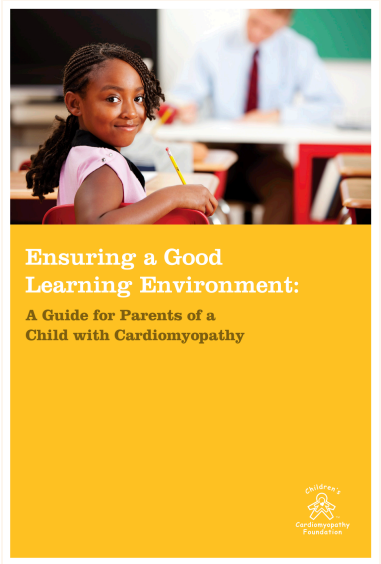


Educational Materials Now Available in Spanish

CCF's educational materials are now available in Spanish, giving more families access to trusted, expert-reviewed information to better understand pediatric cardiomyopathy and their child's care.

Los materiales educativos de CCF ya están disponibles en español, brindando a más familias acceso a información confiable y revisada por expertos para comprender mejor la miocardiopatía pediátrica y el cuidado de sus hijos.

Download Spanish Materials →



Back-to-School Resources for Families

Help your child start the school year with confidence. CCF's Ensuring a Good Learning Environment – A Cardiomyopathy School Resource Kit gives parents the tools to educate school staff, communicate their child's needs, and advocate for appropriate accommodations. The free toolkit includes guides, sample letters, and planning templates to help ensure a safe and supportive school experience.

For families affected by Danon disease, we offer an additional resource that can be shared with teachers and others to help explain the disease and encourage discussion.

View Back-to-School Resources →

EDUCATIONAL WEBINAR SERIES

From Diagnosis to Action: Register for Our Next Expert Webinar

Benjamin A. Olsen, M.D., of Children's Hospital Colorado will be our featured speaker on our next *Experts on Pediatric Cardiomyopathy* webinar, "Fundamentals of Pediatric Cardiomyopathy: From Diagnosis to Action" on Wednesday, September 16, at 12:00 p.m. ET.

Designed for families, Dr. Olsen will discuss what to expect after a pediatric cardiomyopathy diagnosis, including navigating care, building a support network, and accessing trusted resources.

Register for Webinar

Benjamin A. Olsen, MD
Children's Hospital Colorado

RESEARCH SPOTLIGHT

Multicenter Study Advances Understanding of Carvedilol in Children With Dilated Cardiomyopathy

A newly published multicenter study offers new insight into the use of carvedilol in children with dilated cardiomyopathy (DCM). Researchers found that **carvedilol was generally safe and well tolerated in children with DCM** with few serious adverse events. Children treated with carvedilol also showed improvement in heart function over time, although additional research is needed to better understand its effects in children with DCM.

CCF supported this study, conducted through the NHLBI-funded Pediatric Cardiomyopathy Registry (PCMR). The study's first author, Neha Bansal, M.D., is also a CCF Senior Scholar.

Studies like this deepen our understanding of pediatric cardiomyopathy and improve care and outcomes for diagnosed children.

View Publication →

WALK FOR A CURE

CHILDREN'S CARDIOMYOPATHY FOUNDATION

Walk your way and help raise awareness of pediatric cardiomyopathy to support children and families affected by the disease. Every step makes a difference.

🎵 **Every walk needs a great soundtrack!** What's your favorite song to walk to? **Email us** your top pick and help us build this year's **Walk for a Cure Spotify playlist**.

Register Your Walk

Upcoming Walks for a Cure

September 10

Noah's Walk for a Cure
Phoenxville, Pennsylvania
Learn more

September 19

Marylu's Walk for a Cure
Bloomfield, New Jersey
Learn more

CCF's First Annual 5K & Family Fun Walk
Okeechobee, Florida
Learn more

September 26

Strong Like Sis
Lake Orion, Michigan
Learn more

Texas Children's Hospital
Houston, Texas
Learn more

September TBA

Aidan's Army
Learn more

Deniz' Walk for a Cure
Messkirch, Germany
Learn more

Faith Walkers	Learn more
Grant's Walk for a Cure	Learn more
Jenny's Walk for a Cure	Learn more
Ashley's Walk for a Cure	Learn more
Always Ahsha	Learn more

UPCOMING EVENTS

September 26	**Golf for Owen** Shrub Oak, New York	Learn more
October 4	**Live Music Big Hearts Fundraiser** Thornton, Illinois	Learn more
October 21	**Team Cytokinetics Bake for a Cure** San Francisco, California	Learn more

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

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