MILESTONES + MOMENTUM

2024

ANNUAL REPORT

Children's
Cardiomyopathy
Foundation

CONTENTS

A Cause for Today. A Cure for Tomorrow.

LETTER FROM FOUNDER + EXECUTIVE DIRECTOR

Dear Friends and Supporters,

As we reflect on the past year, we are proud to share our progress in improving outcomes for children with cardiomyopathy. Through the dedication of our community, researchers, and advocates, we have advanced scientific understanding, furthered research, and championed life-saving legislation.

A major milestone was the **6th International Scientific Conference on Pediatric Cardiomyopathy**, where researchers and clinicians shared discoveries, discussed best practices, and explored new treatments. Through our partnership with the Pediatric Cardiomyopathy Registry and Cincinnati Children's Heart Institute, the conference encouraged collaboration and innovation with the aim of improving diagnosis, treatment, and long-term care for children with cardiomyopathy.

Our **research milestones include a study showing elevated NT-proBNP levels signal increased risk of heart transplant and mortality in children with heart failure**. Another study found MicroRNAs may help predict whether children with dilated cardiomyopathy recover or worsen.

In advocacy, we made strides with **President Biden signing the HEARTS Act into law**. Since 2010, CCF has worked tirelessly with Representative Frank Pallone (NJ-06) to support this legislation that was inspired by two students with undiagnosed cardiomyopathy who collapsed and died at school. It is the first legislation focused on cardiomyopathy, which educates schools and families on the signs, symptoms, and risk factors for cardiomyopathy.

These accomplishments would not be possible without our donors, volunteers, and partners. Your commitment fuels research, advocacy, and hope for families affected by pediatric cardiomyopathy.

The road ahead is full of promise, and we look forward to another year of remarkable progress.

With heartfelt appreciation,

Kathy Swenson
Kathy Swenson
Executive Director

Lisa Yue
Lisa Yue
Founder & Board President

FOUNDATION OVERVIEW

The mission of the **Children's Cardiomyopathy Foundation** (CCF) is to accelerate the search for causes and cures for pediatric cardiomyopathy through increased **research**, **education**, **awareness and advocacy**, as well as to provide **support** to affected families.

DISEASE FOCUS

- Arrhythmogenic Cardiomyopathy (AC)
- Dilated Cardiomyopathy (DCM)
- Hypertrophic Cardiomyopathy (HCM)
- Left Ventricular Noncompaction Cardiomyopathy (LVNC)
- Restrictive Cardiomyopathy (RCM)

BOARD OF DIRECTORS

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Communication & Development

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Project & Event Manager

Leah Mumm
Patient & Physician
Support Coordinator

CHARITY NAVIGATOR
Four Star Charity

GREATNONPROFITS
2024 TOP-RATED
NONPROFIT

Platinum
Transparency
2024
Candid.

RESEARCH

IMPACT BRIEF: CCF-funded research continues to drive improvements in the diagnosis and treatment of children with cardiomyopathy.

Genetic Insights Save Lives
Reinterpreting genetic test results over time can impact treatment decisions.

Advancing Diagnostics
Cardiac MRI is a powerful tool helping pediatric cardiologists determine the need for implantable defibrillators.

Biomarkers Predict Outcomes
Elevated NT-proBNP levels signal increased risk of heart transplant and mortality in children with heart failure.

6TH INTERNATIONAL SCIENTIFIC CONFERENCE

The 6th International Conference on Cardiomyopathy in Children was held virtually on May 10–11. With more than 300 registrants from 32 countries, the CME-accredited medical event was hosted in partnership with Cincinnati Children's Heart Institute and the NIH-funded Pediatric Cardiomyopathy Registry. The scientific conference is the only medical gathering dedicated exclusively to research and education on pediatric cardiomyopathy.

CONFERENCE CO-CHAIRS

Steven Lipshultz, MD
Professor of Pediatrics
University at Buffalo

Teresa Lee, MD, MS
Columbia University
Medical Center

Thomas Ryan, MD, PhD
Cincinnati Children's
Hospital Medical Center

6th International Conference
on Cardiomyopathy in Children
MAY 10 – 11, 2024 • VIRTUAL • PCMCONF.ORG

300 REGISTRANTS **32** COUNTRIES

NEW CCF MEDICAL ADVISORS

CCF expanded its medical advisory board members to include three clinician-scientists involved with the NIH-funded Pediatric Cardiomyopathy Registry.

Charles E. Canter, MD
Washington University
School of Medicine

Teresa M. Lee, MD, MS
Columbia University
Medical Center

Paul F. Kantor, MBBCh, MSc, FRCPC
Children's Hospital
Los Angeles

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CLINICIAN-SCIENTISTS

CCF funded research resulted in 5 peer-reviewed publications and 2 medical presentations in 2024.

5

MEDICAL PUBLICATIONS

“Genetic Testing Resources and Practice Patterns Among Pediatric Cardiomyopathy Programs”
Godown J, Kim EH, Everitt MD, Chung WK, et al.
Pediatric Cardiology, May 7, 2024

“NT-proBNP for Predicting All-Cause Death and Heart Transplant in Children and Adults with Heart Failure”
Schmitt W, Diedrich C, Hamza TH, Meyer M, et al.
Pediatric Cardiology, May 9, 2024

“Assessing Cardiovascular Health in Pediatric Hypertrophic Cardiomyopathy Using the CANHEART Health Index”
Srbely V, Jeewa A, Pidborochynski T, Lemaire-Paquette S, et al.
CJC Pediatric and Congenital Heart Disease, July 8, 2024

“Pediatric Cardiomyopathy Illustrates the Importance of Reinterpreting the Significance of Genetic Variants”
Lee T, Miller E, Sridhar A, Fan X, et al.
Progress in Pediatric Cardiology, Sept. 1, 2024

“Myocardial Scarring and Sudden Cardiac Death in Young Patients With Hypertrophic Cardiomyopathy: A Multicenter Cohort Study”
Chan RH, van der Wal L, Liberato G, Rowin E, et al.
JAMA Cardiology, Sept. 25, 2024

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MEDICAL PRESENTATIONS

“Cardiomyopathy-Associated Pathogenic Variants in Pediatric Myocarditis”
Kamsheh A, Ware S, Bhatnagar S, Martin L, Lee T, et al.
Presented at American Heart Association Scientific Sessions; Circulation, Nov. 17, 2024

“Circulating miRNAs Are Differentially Expressed in Pediatric Dilated Cardiomyopathy Patients With Favorable vs. Poor Outcomes”
Stuart S, Miyamoto S, Lipshultz S, Hernandez AL, et al.
Presented at American Heart Association Scientific Sessions, Nov. 16, 2024

Alicia M. Kamsheh, MD, MSCE received an Outstanding Research Award in Pediatric Cardiology at the AHA Scientific Sessions for her publication, “Cardiomyopathy-Associated Pathogenic Variants in Pediatric Myocarditis.”

MEETING SPONSORSHIPS

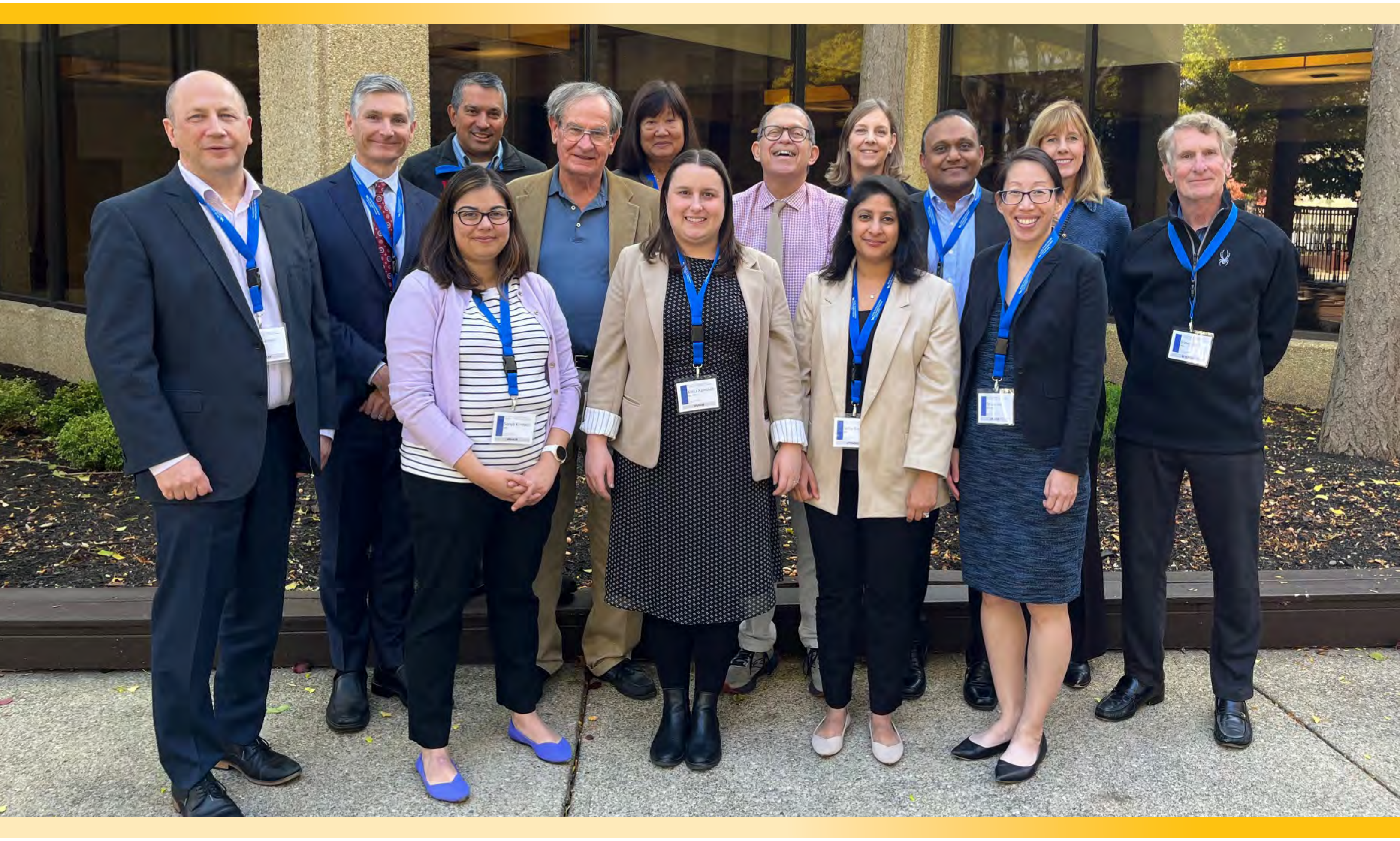
DDC Clinic Cardiogenetics Scientific Summit
CCF sponsored a 3-day cardiogenetics and family health summit to raise awareness of genetic cardiac disorders among the Amish community. The educational event began with a scientific summit attended by 120 physicians including Steven E. Lipshultz, MD, CCF Medical Advisor Chair, who presented "Management and Treatment Strategies for Cardiomyopathies in Children."

3 DAYS

120 PHYSICIANS

MEETING SPONSORSHIPS

North America Pediatric Cardiomyopathy Registry Retreat
Sponsored by CCF, the Pediatric Cardiomyopathy Registry (PCMR) working group met in Buffalo, NY to further multi-center research on cardiomyopathies in children. Led by Steven E. Lipshultz, MD, CCF medical advisor chair, 30 PCMR investigators from the top academic medical centers across the U.S. convened to discuss research priorities, research studies in progress, and publications in development.



PCMR INVESTIGATORS 30

EDUCATION


Unite
Annual Summit
CONNECTIONS
Global Heart Hub
Amyloidosis UK
amyloidosisuk.org
#ListenToYourHeart

IMPACT BRIEF: Disease education was a priority in 2024, and CCF expanded its virtual programming, “Experts on Pediatric Cardiomyopathy” to five webinars. With new topics geared towards physicians and practical topics suggested by our caregiver community, viewership increased to 2,400 views.

EDUCATIONAL WEBINARS

Management and Treatment Strategies for Cardiomyopathies in Children
Steven E. Lipshultz, MD,
University at Buffalo Jacobs School
of Medicine and Biomedical Sciences

Listening Session:
Cardiomyopathy Care Considerations
Steven E. Lipshultz, MD,
University at Buffalo Jacobs School
of Medicine and Biomedical Sciences
Nadine Kasparian, PhD, MAPS,
Cincinnati Children’s Hospital Medical Center

Kyle Landra, M.Ed.,
Children’s Wisconsin

Parent Panelists: Ranae Stewart,
Regina Vaughn, Karen Wellman

Highlights from the 6th International Conference on Cardiomyopathy in Children
Steven E. Lipshultz, MD
University at Buffalo Jacobs School
of Medicine and Biomedical Sciences

Teresa M. Lee, MD, MS,
Columbia University Medical Center

Thomas D. Ryan, MD, PhD,
Cincinnati Children’s Hospital Medical Center

Evaluating Children with Cardiomyopathy: Importance of Cardiac MRI
Steven E. Lipshultz, MD,
University at Buffalo Jacobs School
of Medicine and Biomedical Sciences

Charles E. Canter, MD,
Washington University St. Louis

Sonya Kirmani, MD,
University of Wisconsin Madison

When Should Genetic Testing Be Repeated?
Teresa M. Lee, MD, MS,
Columbia University Medical Center

5 WEBINARS

GLOBAL HEART HUB ANNUAL UNITE SUMMIT

CCF joined fellow patient advocates and organizations at the Global Heart Hub's Unite Summit in Dublin, Ireland. The event united 165 delegates from 34 countries and featured 20 speakers. It served as a dynamic forum for patient groups, clinicians, and global stakeholders to share insights on the challenges of living with cardiovascular disease and to collaborate on future coalition efforts and awareness campaigns.

165 DELEGATES

20 SPEAKERS

4TH ANNUAL GENE THERAPY PATIENT ENGAGEMENT

CCF President & Founder, Lisa Yue joined patient advocacy leaders and pharmaceutical executives to discuss patient and caregiver education and clinical trial needs at the 4th Gene Therapy Patient Engagement Summit in Boston, Mass.

ADVOCACY

IMPACT BRIEF: The passage of the Cardiomyopathy HEARTS Act was a significant milestone for CCF after years of collaboration with legislators in the House and Senate. New Jersey Representative Frank Pallone and Senator Andy Kim were major supporters of the bill.

CARDIOMYOPATHY HEARTS ACT

President Biden signed the Cardiomyopathy Health Education, Awareness, and Research and AED Training in Schools (HEARTS) Act into law. This bipartisan legislation is the first to focus on cardiomyopathy and requests the development of educational materials on the heart condition and dissemination of these resources in schools. It also requests additional provisions to protect children from sudden cardiac death.

CARDIOMYOPATHY HEALTH EDUCATION, AWARENESS, AND RESEARCH AND AED TRAINING IN SCHOOLS ACT

The legislation requires the Secretary of Health and Human Services (HHS) to coordinate with the Centers for Disease Control and Prevention (CDC), as well as patient advocacy and health professional organizations, to develop educational materials and resources on cardiomyopathy for public awareness with additional requests to:

- Distribute educational materials on cardiomyopathy through schools to increase awareness of signs and symptoms among school professionals and families.
- Provide risk assessment resources to help identify children at risk for sudden cardiac arrest.
- Call for surveillance research from the CDC and NIH to better understand cardiomyopathy in children.
- Support AEDs and CPR school programs and training to encourage emergency preparedness.

BREAKING NEWS

President Biden signed the Cardiomyopathy Health Education, Awareness, and Research and AED Training in Schools (HEARTS) Act into law.

POLARIS MEETING: HYPERTROPHIC CARDIOMYOPATHY IN FOCUS

CCF participated in a patient advocacy meeting in San Francisco, Calif., hosted by Cytokinetics, to share patient insights and exchange educational strategies on hypertrophic cardiomyopathy (HCM). Patients living with HCM, along with four patient organizations including CCF, attended to provide testimony and perspectives on the real-life impact of the condition.

ADDITIONAL ADVOCACY WORK

- Strengthen school safety measures in New York by incorporating Cardiac Emergency Response Plans (CERPs) into the public school safety framework.
- Advocate for the passage of H.R. 1691, ensuring Medicare patients have timely and streamlined access to innovative medical technology.
- Joined 123 nonprofit organizations to request continued support of the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense with a five percent increase in appropriation for defense health research programs by five percent plus inflation in the FY 2025 Defense Appropriations Act.
- Joined 22 pediatric transplant organizations in submitting public comment opposing proposed changes to the U.S. Organ Procurement and Transplantation Network (OPTN) Modernization Initiative, which would restructure the OPTN Board of Directors and reduce independent representation.

AWARENESS


IT TAKES A TEAM
CCF
TO DEFEAT
BLACK BEAR
LACROSSE
WALK FOR A CURE
Phillies

IMPACT BRIEF: From coast to coast, supporters united with community events and creative fundraisers. September's Awareness Month featured a standout Dunkin' Supports Cardiomyopathy event while families led their own Walk for a Cure efforts nationwide. Globally, CCF joined forces with 21 organizations in 13 countries to launch the "Think Cardiomyopathy!" campaign, amplifying awareness on an international scale.

AMERICAN HEART MONTH

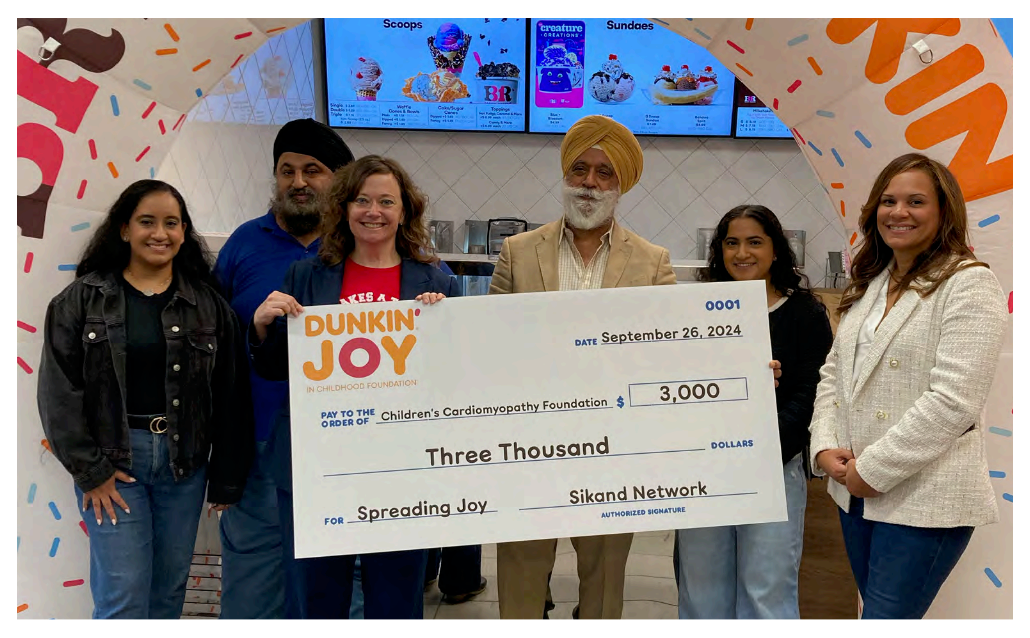
Supporters nationwide wore red, spread awareness, and organized events like a volleyball fundraiser in New Jersey. From senior living homes to student-led bake sales, communities came together to raise funds and awareness.

WEAR RED DAY

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

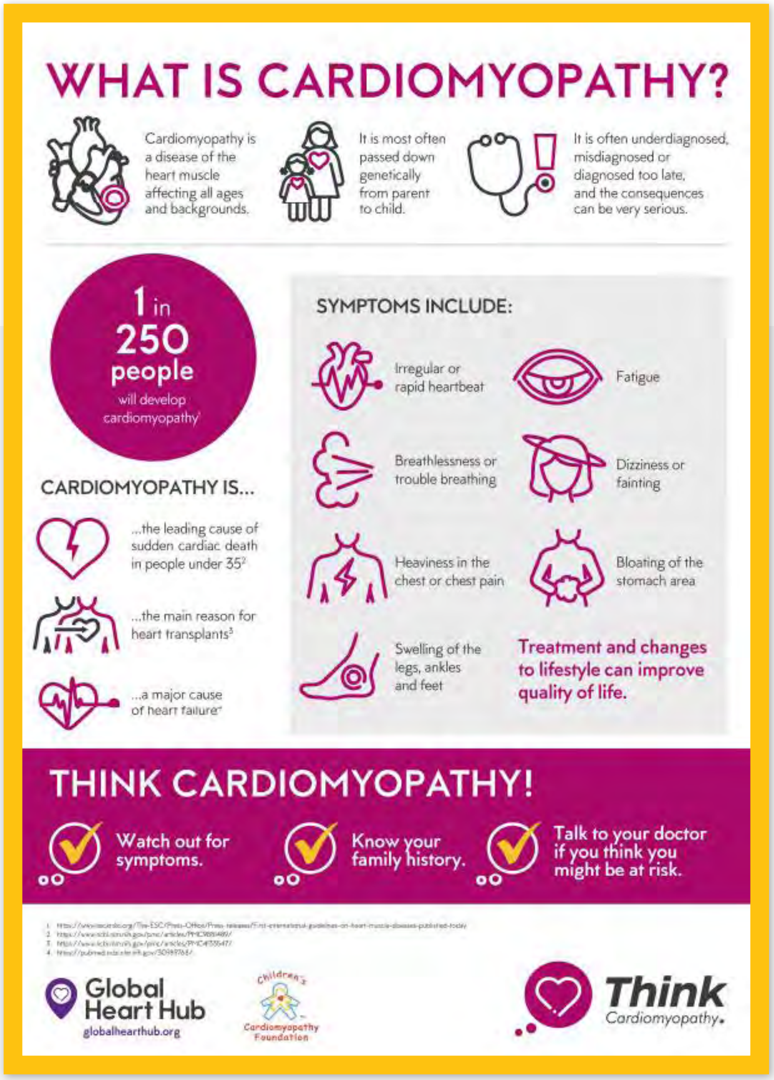
Amrik Sikand and the Sikand Network, in partnership with the Dunkin' Joy in Childhood Foundation, showed their support of pediatric cardiomyopathy with a Dunkin' Supports Cardiomyopathy community event in September.

Families across the country also contributed by organizing their own Walk for a Cure event to raise awareness. The Skinner family held their Annual Walk for a Cure in Pennsylvania in honor of their late son, Noah.



THINK CARDIOMYOPATHY GLOBAL AWARENESS CAMPAIGN

As part of the Cardiomyopathy Patient Council, CCF worked with Global Heart Hub and its alliance of 21 associations from 13 countries to launch "Think Cardiomyopathy!" a global cardiomyopathy awareness campaign.



WHAT IS CARDIOMYOPATHY?

Cardiomyopathy is a disease of the heart muscle affecting all ages and backgrounds.

It is most often passed down genetically from parent to child.

It is often underdiagnosed, misdiagnosed or diagnosed too late, and the consequences can be very serious.

1 in 250 people will develop cardiomyopathy[1]

CARDIOMYOPATHY IS...

...the leading cause of sudden cardiac death in people under 35[2]

...the main reason for heart transplants[3]

...a major cause of heart failure[4]

SYMPTOMS INCLUDE:

- Irregular or rapid heartbeat
- Fatigue
- Breathlessness or trouble breathing
- Dizziness or fainting
- Heaviness in the chest or chest pain
- Bloating of the stomach area
- Swelling of the legs, ankles and feet

Treatment and changes to lifestyle can improve quality of life.

THINK CARDIOMYOPATHY!

✓ Watch out for symptoms.

✓ Know your family history.

✓ Talk to your doctor if you think you might be at risk.

Global Heart Hub
globalhearthub.org

Children's Cardiomyopathy Foundation

Think Cardiomyopathy.

21 ASSOCIATIONS

13 COUNTRIES

FAMILY SUPPORT

PATIENT & FAMILY SUPPORT

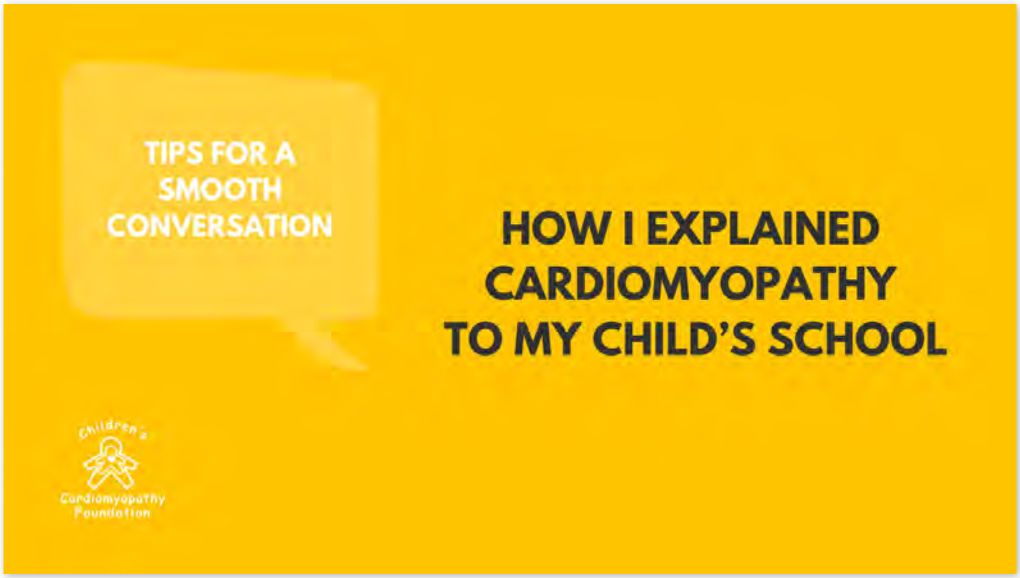
CCF welcomed 99 new registrants in 2024, bringing total members served to 3,820 across 98 countries. To support families, CCF hosted a Heart-to-Heart Coffee Chat on school accommodations and featured six resilient children through its CCF Heart Kids social media campaign. These efforts reflect our growing reach and ongoing commitment to education, connection, and community.

BY THE NUMBERS

99	TOTAL NEW REGISTRANTS (2024)
98	TOTAL COUNTRIES SERVED
82	NEW FAMILIES
17	NEW PROFESSIONALS
2285	CCF CONNECT FAMILIES
3820	TOTAL MEMBERS SERVED

HEART-TO-HEART COFFEE CHAT

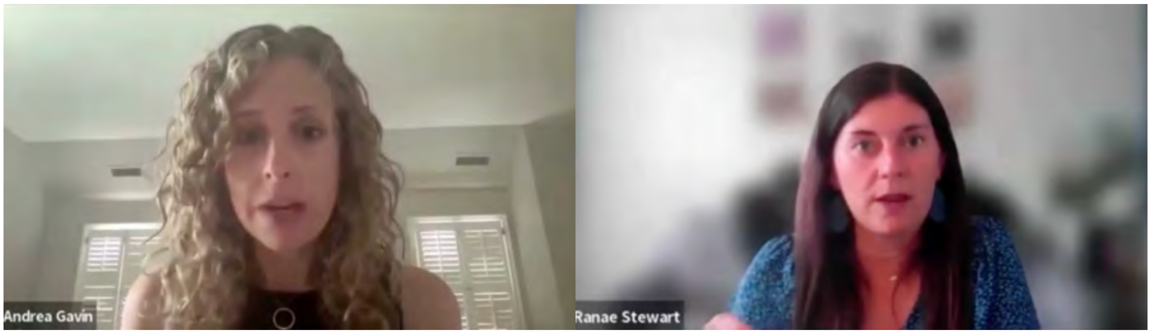
To help families prepare for the school year, CCF hosted a Heart-to-Heart Talk where CCF parents Ranae Stewart and Andrea Gavin shared practical tips for discussing classroom accommodations and modifications with schools—ensuring students with cardiomyopathy have the support they need to thrive.



TIPS FOR A SMOOTH CONVERSATION

HOW I EXPLAINED CARDIOMYOPATHY TO MY CHILD'S SCHOOL

Children's Cardiomyopathy Foundation



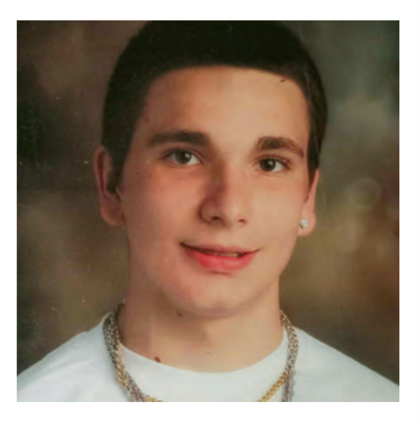
PATIENT + FAMILY SUPPORT

CCF HEART KIDS

As part of an ongoing social media campaign to engage more families, CCF profiled 6 children living with cardiomyopathy.

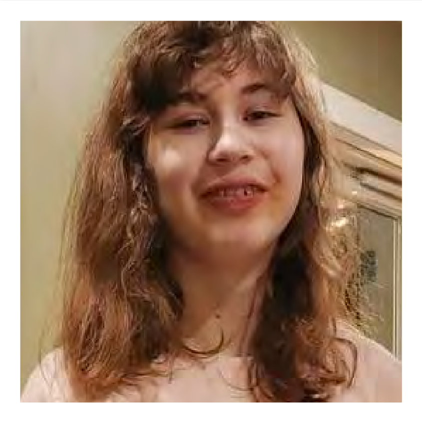

ADRIANNA


RAE


MARKUS


GRAYCEE


MAËLYS


LINDSAY

FUNDRAISING

IMPACT BRIEF: The Children's Cardiomyopathy Foundation's fundraising events brought families and supporters together to raise funds for CCF's research, education, and family support programs.

GOLF FOR A CURE

The 20th Annual Golf for a Cure event was held July 22, 2024 at the championship Ridgewood Country Club course in Northern New Jersey. Fifty-four sponsors raised $403,408 for research and education programs on pediatric cardiomyopathy.

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HG Vora Capital Management · Matthew Maggio · Si Lund · Steve Bleier · Sunil Aggarwal · The Guevara Family · The Yu Family · Whitebox Advisors

CCF FAMILIES RAISED $95,929

From Minnesota to Texas, Pennsylvania to Oregon, families across the country united to support CCF. Fundraisers took place in communities big and small, bringing people together for CCF. Supporters raised $95,929 through various local events such as golf tournaments, art auctions and marathons—proving that anything is possible when passion meets purpose.

$3,545

Peter Noyes selected CCF as the beneficiary of his 100-mile ultra marathon, held at 10,000 feet elevation, in honor of his 9-year-old son Everett, who was born with multiple congenital heart defects and recently diagnosed with LVNC. He raised $3,545, exceeding his original $2,500 goal.

$7,750

The 14th Annual Casen's Crew Golf Tournament was held on August 24, 2024, with 31 teams participating. The event raised $7,750 in support of CCF. Longtime supporters, new attendees, volunteers, and sponsors contributed to the event's success in honor and memory of Casen Riley.

$70,000

Wes Sharp and North Star Resource Group supported CCF through the annual North Star Charitable Golf Event, held in honor of Wes and Alexa Sharp's sons, Bennett and Mason, who have tested positive for the genetic mutation that causes left ventricular non-compaction cardiomyopathy (LVNC). The event drew 136 golfers and raised nearly $70,000 for CCF. Bennett and his sister Ella assisted at the event.

$240

Artist Nikki Contini held a fundraiser selling her fused glass artwork in honor of her niece, Savannah, who was diagnosed with restrictive cardiomyopathy (RCM) and received a new heart in 2021 raising more than $240.

$2,600

The Rivera family conducted its 4th Annual Butterfly Bee Baking Competition and raised more than $2,600 for CCF in honor of Saoirse, who was diagnosed with hypertrophic cardiomyopathy.

$5,000

Thanks to an unforgettable August evening filled with entertainment and generosity, the Ellis Ann Cosby Family Foundation raised $5,000 in honor and memory of their daughter, Ellis Ann's legacy and support the fight against cardiomyopathy.

FINANCIALS

2024 FINANCIAL SUMMARY

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	$270,862
Investments	$2,587,745
TOTAL ASSETS	$2,858,577

LIABILITIES + NET ASSETS

Accounts Payable & Accrued Expenses	$30
Unrestricted Net Assets	$2,858,577
Restricted Net Assets	$0
TOTAL LIABILITIES + NET ASSETS	$2,858,607

STATEMENT OF ACTIVITIES

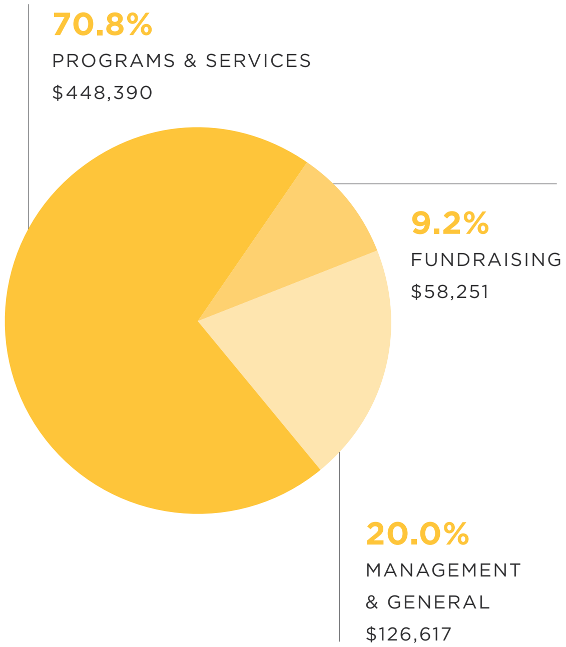
REVENUE

Contributions	$181,477
Fundraising + Special Events	$444,846
Net Investment Return	$260,552
TOTAL REVENUE	$886,875

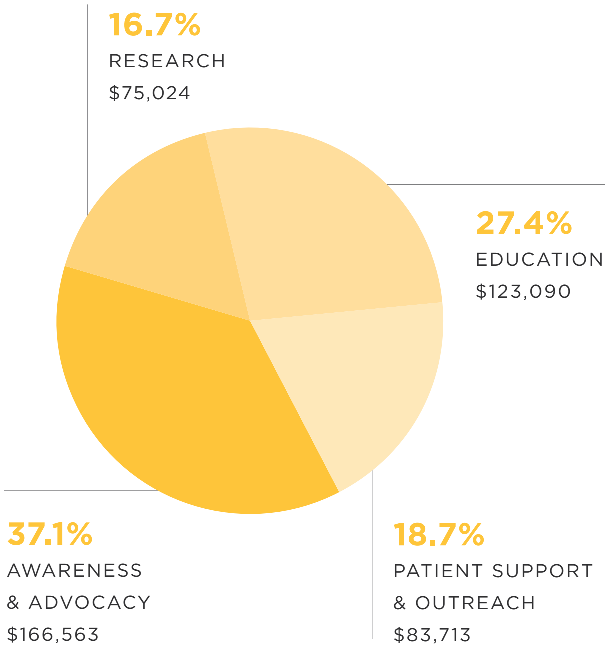
EXPENSES

Programs & Services	$448,390
Management & General	$126,617
Fundraising	$58,251
TOTAL EXPENSES	$633,258
NET INCOME	$253,617

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



Fiscal year ending December 31, 2024

We extend our **heartfelt thanks** to the following corporations, foundations, and individuals who made contributions of $500 or more in 2024.

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Bristol Myers Squibb™ Cytokinetics MERCK TENAYA™ THERAPEUTICS

DONORS $10,000 & OVER

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Dunkin’ Joy in Childhood Foundation
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Learn more about how you can get involved or make a donation by visiting childrenscardiomyopathy.org

Children's Cardiomyopathy Foundation

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