

ENGAGEMENT IN ACTION



2025 ANNUAL REPORT



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A Cause for Today. A Cure for Tomorrow.

A YEAR IN REVIEW: ENGAGEMENT IN ACTION

Dear Friends and Supporters,

At the Children’s Cardiomyopathy Foundation, 2025 was defined by one powerful idea: **Engagement in Action.**

Engagement is more than connection—it is participation, partnership, and progress. This year, we saw what is possible when families, clinicians, researchers, industry leaders, and advocates move from awareness to action together.

In 2025:

- More families received timely diagnosis and treatment support.
- More clinicians partnered with CCF to share expertise and advance understanding.
- Our digital presence and social media reach grew, connecting families to trusted information and to one another.
- Our collaborations with pharmaceutical and biotechnology partners expanded to support the development of new therapies.
- More families shared their stories strengthening our collective voice.

Each connection moved us from awareness to action—improving access, advancing research, and elevating the standard of care for children affected by this rare disease.

Research remains central to our work. Through our ongoing partnership with the North American Pediatric Cardiomyopathy Registry, a study published in *Pediatric Research* examined genetic variants shaping diagnosis, prognosis, and family risk. In addition, “Cardiomyopathy-Associated Pathogenic Variants in Pediatric Myocarditis” was published in *Circulation: Heart Failure*, contributing valuable insight to the field. We also formed a new advisory board of medical experts and caregivers to guide development of a CCF-sponsored Pediatric Cardiomyopathy Patient Registry.

While we are proud of this progress, much work remains. Too many children still face delayed diagnosis and limited access to specialized care. We’ll keep building partnerships, advancing research, and empowering families so every child with cardiomyopathy can thrive.

To our donors, partners, medical advisors, and families—thank you. Your engagement makes this progress possible and moves us closer to our shared goal.

With gratitude and determination,



Lisa Yue
Founder & Board President



Kathy Swenson
Executive Director

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 (ACM)
- Dilated Cardiomyopathy (DCM)
- Hypertrophic Cardiomyopathy (HCM)
- Noncompaction Cardiomyopathy (NCCM)
- Restrictive Cardiomyopathy (RCM)

BOARD OF DIRECTORS

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Columbia University Medical Center

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School of Medicine and Biomedical
Sciences

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Children’s Hospital Colorado

Joseph W. Rossano, MD, MS, MHCM
Children’s Hospital of Philadelphia

Jeffrey A. Towbin, MD, MS
Le Bonheur Children’s Hospital

CCF STAFF

Kathy Swenson
Executive Director

Maggie Conway
Director of Constituent &
Donor Relations

Sheila Gibbons
Senior Director of
Communication & Development

Leah Mumm
Director of Family &
Physician Relations

MEDICAL ADVISORS

Charles E. Canter, MD
Washington University
School of Medicine

Wendy K. Chung, MD, PhD
Boston Children’s Hospital





RESEARCH

RESEARCH

This year, we expanded our outreach to clinicians, researchers, and Cardiomyopathy Centers of Care to elevate the visibility of pediatric cardiomyopathy within the cardiology field and strengthen our collaboration with the medical community. By bringing more experts into the conversation, we are accelerating knowledge sharing and improving the path to earlier diagnosis and better care.



RESEARCH

Through our partnership with the North American Pediatric Cardiomyopathy Registry, CCF funded new multi-center studies, publications, and presentations that advanced understanding of this rare disease. We also supported the professional society leadership of our medical advisors — ensuring pediatric cardiomyopathy is represented in national forums where research priorities and standards of care are shaped.

MEDICAL PUBLICATIONS

“Genomics of Pediatric Cardiomyopathy”

Lee TM, Ware SM, Kamsheh AM, Bhatnagar S, et al.
Pediatric Research, Feb. 8, 2025

“Energy Drink Exposures and Trends in Children and Young Adults Reported to the National Poison Data System”

Lipshultz SE, Fisher SD, Franco VI, Warrick BJ
Progress in Pediatric Cardiology, Sept. 1, 2025

“Mutational Analysis of the Mitochondrial tRNA Genes and Flanking Regions in Lymphocytes from Long-Term Pediatric Cancer Survivors Given Doxorubicin Chemotherapy for Acute Lymphoblastic Leukemia”

Walker VE, Bansal N, Torres SM, Stevenson K, et al.
Cardio-Oncology, Nov. 3, 2025

“Cardiomyopathy-Associated Pathogenic Variants in Pediatric Myocarditis: A Study From the Pediatric Cardiomyopathy Registry”

Kamsheh AM, Ware SM, Bhatnagar S, Martin LJ, et al.
Circulation: Heart Failure, Dec. 5, 2025


MEDICAL PRESENTATIONS

“Biomarkers in Patients with Newly Diagnosed Dilated Cardiomyopathy: A Study from the Pediatric Cardiomyopathy Registry”

Rossano JW, Hamza TH, Colan SD, Wilkinson JD, et al.
Presented at American Heart Association’s Scientific Sessions; *Circulation*, Nov. 9, 2025

“The Impact of Genotype on Phenotypic Severity and Survival in Pediatric Dilated Cardiomyopathy: A Report from the Pediatric Cardiomyopathy Registry”

Kantor PF, Ware SM, Hamza TH, Shi L, et al.
Presented at American Heart Association’s Scientific Sessions; *Circulation*, Nov. 10, 2025



4

Number of medical
publications
published in 2025

RESEARCH

PEDIATRIC CARDIOMYOPATHY PATIENT REGISTRY DEVELOPMENT

CCF began developing a Pediatric Cardiomyopathy Patient Registry by partnering with the National Organization for Rare Disorders (NORD®) and forming an advisory board consisting of CCF medical advisors and family representatives. This registry will allow patients and caregivers to directly contribute their health information through a secure online portal for future research studies. Daphne T. Hsu, MD will serve as principal investigator and Joseph W. Rossano, MD, MS, MHCM will be the chief scientific officer.



CCF Chair of the Medical Advisors, Steven E. Lipshultz, MD, was honored by the American Heart Association as a 2025 Distinguished Scientist for his leadership in pediatric cardiac research.

Other CCF medical advisors, Charles E. Canter, MD; Shelley D. Miyamoto, MD; and Joseph W. Rossano, MD, MS, MHCM, also attended the Scientific Sessions in New Orleans.

RESEARCH

11TH CONGRESS OF THE EUROPEAN ACADEMY OF PAEDIATRIC SOCIETIES



Steven E. Lipshultz, MD, presented “Genetic Susceptibility to Pediatric Cardiomyopathies” in Lisbon, Portugal in October 2025.

WORLD CONGRESS OF PEDIATRIC CARDIOLOGY & CARDIAC SURGERY



CCF Medical Advisors, Daphne T. Hsu, MD; Paul F. Kantor, MBBCh, MSc, FRCPC; Steven E. Lipshultz, MD; and Joseph W. Rossano, MD, MS, MHCM, presented in Hong Kong in December 2025.



EDUCATION

EDUCATION

Education at CCF is both empowering and connective—bringing timely, expert knowledge to families while elevating awareness of pediatric cardiomyopathy across the broader community.

This year, we delivered expert-led webinars on emerging treatments, clinical trials, genetics, and long-term care—providing families and clinicians with practical, actionable information.

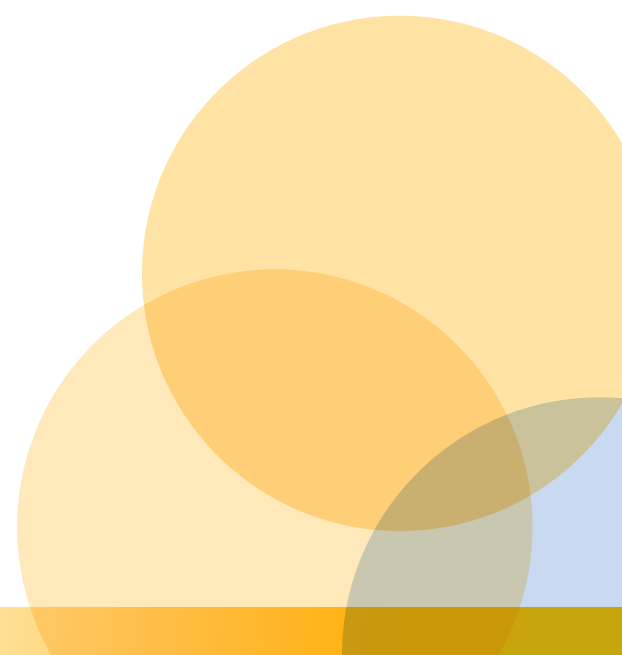
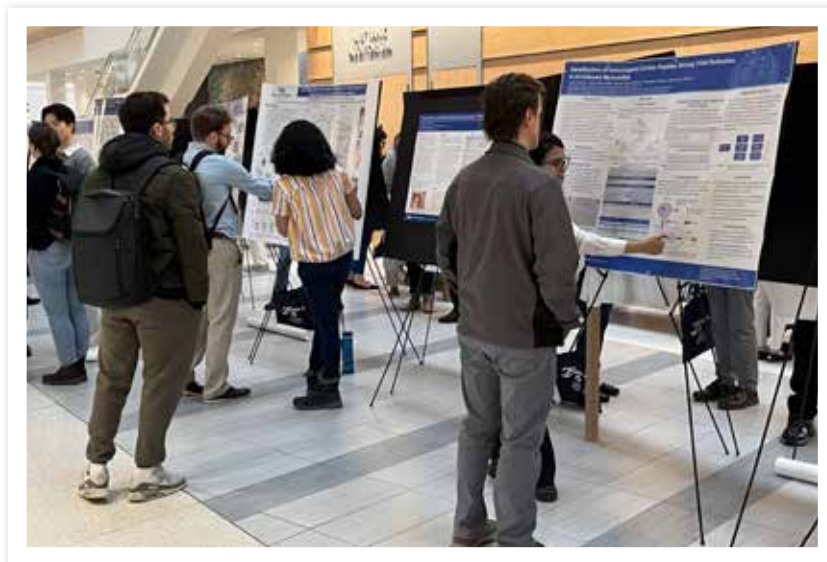
Beyond our own programs, we actively participated in national forums and local community events to ensure pediatric cardiomyopathy has a visible voice. By engaging in disease-specific meetings, we advance public understanding of the disease while advocating for the unique needs of affected children.



EDUCATION

NATIONAL RARE DISEASE DAY

On February 28, the CCF team highlighted the global awareness day at the Jacobs School of Medicine and Biomedical Sciences at the University at Buffalo by reminding others that pediatric cardiomyopathy is one of more than 7,000 types of rare diseases in the world.



EDUCATION

EDUCATIONAL WEBINARS

We expanded the number of disease specialists participating in our programs, strengthening the connection between medical expertise and family experience. Six educational webinars were held, drawing 1,008 total registrations, including 756 physicians and 252 families. The webinars also extended their reach beyond the live events, generating 5,007 views on YouTube.

Advancing Treatment of Pediatric HCM:

The CEDAR-HCM Clinical Trial of Aficamten

Carolyn Y. Ho, MD, Brigham and Women's Hospital
Juan Pablo Kaski, MD, Great Ormond Street Hospital

Current Research Findings on Exercise & Sports Participation

Rachel Lampert, MD, Yale Medical School

Understanding Clinical Trials:

What Parents Need to Know

Joseph W. Rossano, MD, MS, MHCM,
Children's Hospital of Philadelphia

Hypertrophic Cardiomyopathy 2025 Update

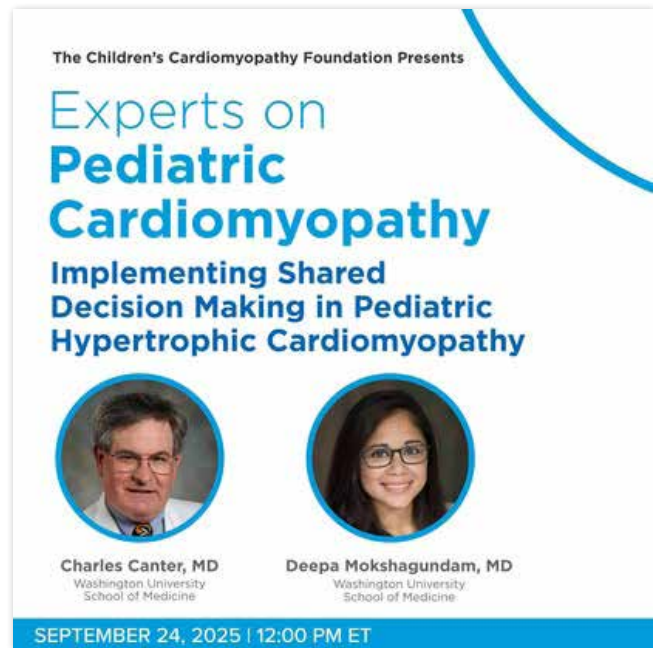
Paul F. Kantor, MBBCh, MSc, FRCPC,
Children's Hospital Los Angeles
Jon Detterich, MD, Children's Hospital Los Angeles

Implementing Shared Decision Making in Pediatric Hypertrophic Cardiomyopathy

Charles E. Canter, MD, St. Louis Children's Hospital
Deepa Mokshagundam, MD, St. Louis Children's Hospital

Caring for Children with Cardiomyopathy: Genetics, Treatment Effects, and Life Beyond Therapy

Steven E. Lipshultz, MD, University at Buffalo Jacobs School of Medicine and Biomedical Sciences



6

Number of educational webinars hosted in 2025

EDUCATION

AMERICAN HEART ASSOCIATION

Leah Mumm, CCF director of family and physician relations, joined CCF medical advisors and Pediatric Cardiomyopathy Registry (PCMR) investigators at the American Heart Association Scientific Sessions in November. More than 10,000 cardiovascular professionals from over 100 countries attended the meeting.

CCF-funded PCMR research, “Biomarkers in Patients with Newly Diagnosed Dilated Cardiomyopathy,” was presented by Steven E. Lipshultz, MD. The conference also provided opportunities to strengthen relationships with physicians, industry partners and patient advocacy groups, and to participate in sessions addressing advances in hypertrophic cardiomyopathy care and the challenges of conducting pediatric cardiovascular clinical trials.



Photo credit: American Heart Association



Number of countries represented at AHA conference

100

EDUCATION

NORD® RARE DISEASES AND ORPHAN PRODUCTS BREAKTHROUGH SUMMIT



Photo credit: National Organization for Rare Disorders (NORD®)



CCF joined 800 attendees from 165 patient advocacy groups and rare disease advocates at the National Organization for Rare Disorders (NORD) Rare Diseases and Orphan Products Breakthrough Summit to update CCF's family community on the future of rare disease treatments, research, and policy.

BIONJ'S 10TH ANNUAL PATIENT ADVOCACY SUMMIT



CCF represented pediatric cardiomyopathy at BioNJ's 10th Annual Patient Advocacy Summit held in Princeton, NJ, attended by more than 50 people representing Patients, Patient Advocacy Groups, Care Partners, Clinicians, Policymakers and R&D Professionals for a day to share best practices in healthcare.

EDUCATION

TRANSPLANT FAMILIES PEDIATRIC TRANSPLANT CONFERENCE



Engaged families during Transplant Families' 2025 Pediatric Transplant Conference in April—held in conjunction with National Pediatric Transplant Week and National Donate Life Month—to educate CCF's community on how to help ensure the best possible transplant and post-transplant experience for children and their families.

COMMUNITY HEALTH EDUCATION



CCF joined Make a Difference Day at Grover Cleveland Middle School in West Caldwell, N.J. More than 550 students took part in CCF's fun and educational AED scavenger hunt, discovering where lifesaving devices are located throughout their school.



ADVOCACY

ADVOCACY

This year, we turned connection into collective action—engaging legislators, federal agencies, national coalitions, and families to protect children and advance research. CCF advanced policies to protect children and accelerate research. The foundation supported Cardiac Emergency Response Plans in New York schools, urged strong funding for the National Institutes of Health alongside the American Society of Gene & Cell Therapy, backed legislation to improve access to AI-driven medical technologies, and joined the National Organization for Rare Disorders in advocating for expanded newborn screening.

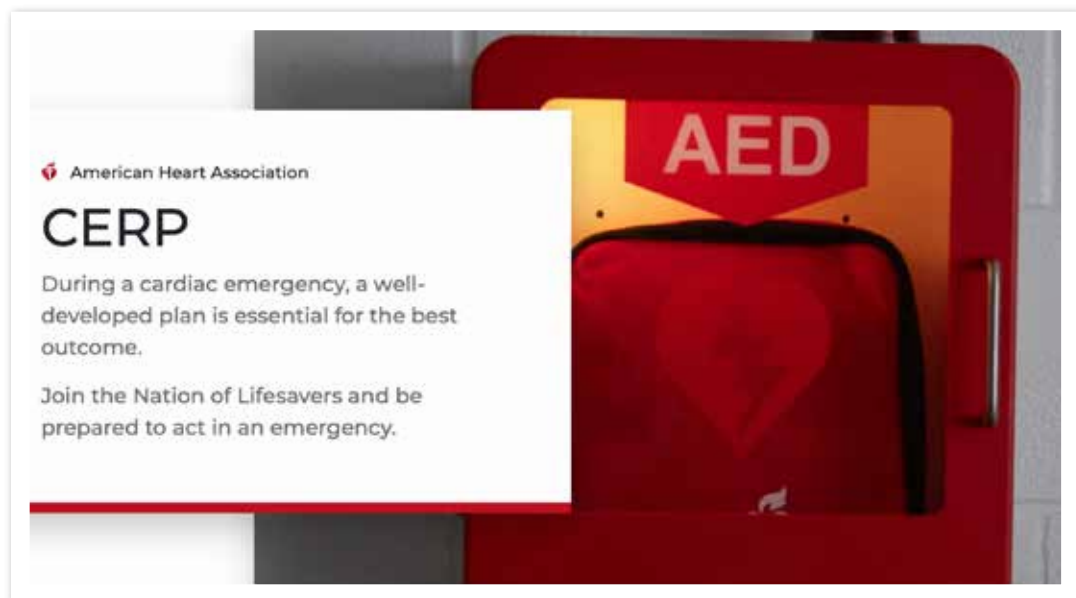


Photo credit: American Heart Association

ADVOCACY



Photo credit: National Organization for Rare Disorders (NORD)

- Partnered with a state coalition to advance Cardiac Emergency Response Plan (CERP) requirements in New York public schools and secure funding for AED maintenance and staff training.
- Joined the American Society of Gene & Cell Therapy™ in advocating for robust National Institutes of Health funding and preservation of essential Facilities & Administrative research infrastructure support.
- Supported the Health Tech Investment Act (S.1399) to establish stable reimbursement pathways for FDA-regulated AI- and machine learning-enabled medical technologies that improve diagnostic precision and patient care.
- Collaborated with the National Organization for Rare Disorder (NORD) to advocate for newborn screening and the reinstatement of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC).

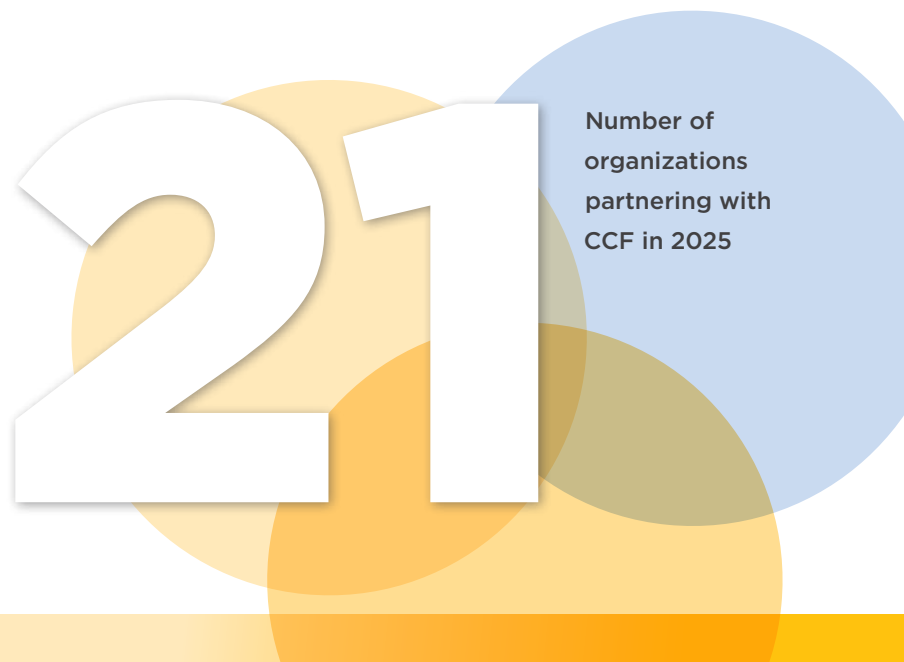


AWARENESS

AWARENESS

In 2025, awareness became action. Families led Walk for a Cure events across the U.S. during September’s Children’s Cardiomyopathy Awareness Month and rallied support during February’s American Heart Month, including local partners in New Jersey.

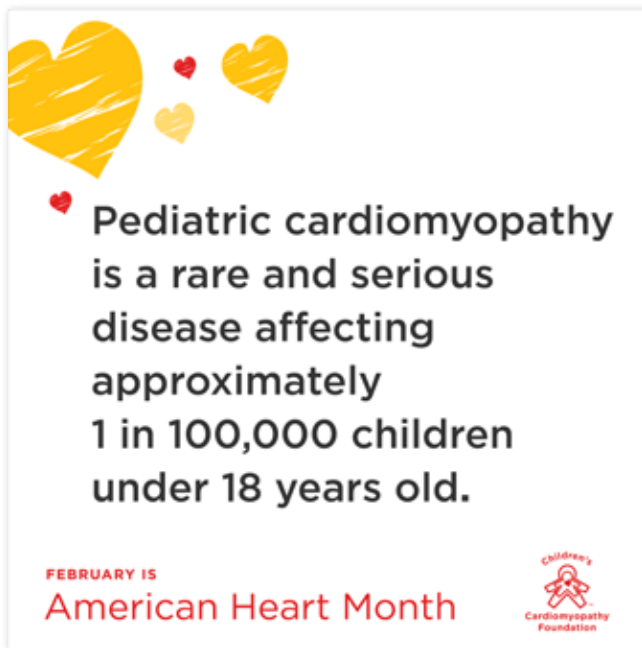
Globally, CCF partnered with 21 organizations in 13 countries to launch the “Think Cardiomyopathy!” video campaign, expanding visibility and reach. By empowering families to lead, share their stories, and engage communities, we were able to turn action into increased awareness of pediatric cardiomyopathy.



AWARENESS


AMERICAN HEART MONTH

American Heart Month was a great success, highlighted by the “Take the Pledge” campaign, in which 45 participants signed the pledge. Of those, 24 were new individuals and families now registered and onboarded. Supporters across the country wore red, shared disease facts on social media, and organized community activities to raise both funds and awareness for pediatric cardiomyopathy.



♥ Pediatric cardiomyopathy is a rare and serious disease affecting approximately 1 in 100,000 children under 18 years old.

**FEBRUARY IS
American Heart Month**



♥ Cardiomyopathy can be life-threatening if not treated and a risk factor for sudden cardiac arrest in certain children.

**FEBRUARY IS
American Heart Month**

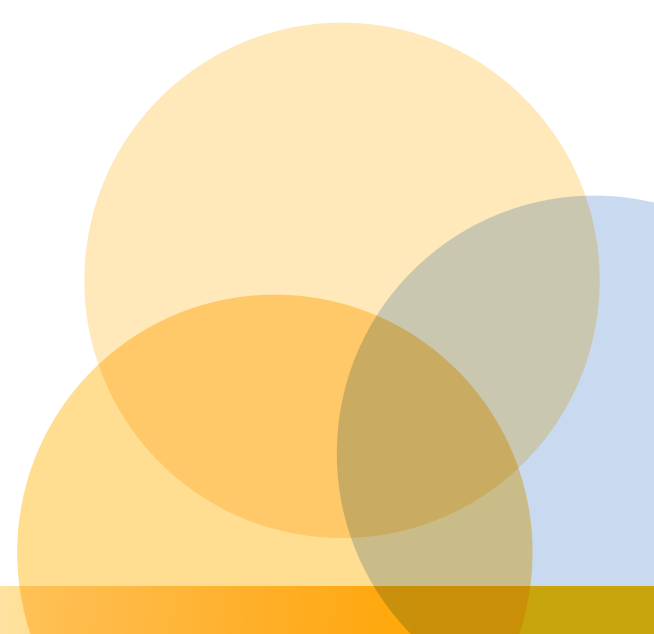


AWARENESS

AMERICAN HEART MONTH • WEAR RED DAY



CLOCKWISE FROM TOP LEFT: Bennett and Mason Sharp, Carter and Carson Reilly, Spoto Family.



AWARENESS

AMERICAN HEART MONTH



\$7,000

The Rivera family hosts their annual Butterfly Bee Baking Competition raising more than \$7,000 in honor of their daughter, Saoirse, who was diagnosed with hypertrophic cardiomyopathy.



\$9,000

Livoti's Old World Market raised \$9,000 through a register round-up campaign. The effort was led by founder John Sr., who lives with hypertrophic cardiomyopathy and is driven by a personal mission to support kids facing the same condition.

AWARENESS

AMERICAN HEART MONTH



\$866

Harrington Park Home and School Association in New Jersey hosted a Have a Heart volleyball tournament for students and staff during American Heart Month raising \$866.



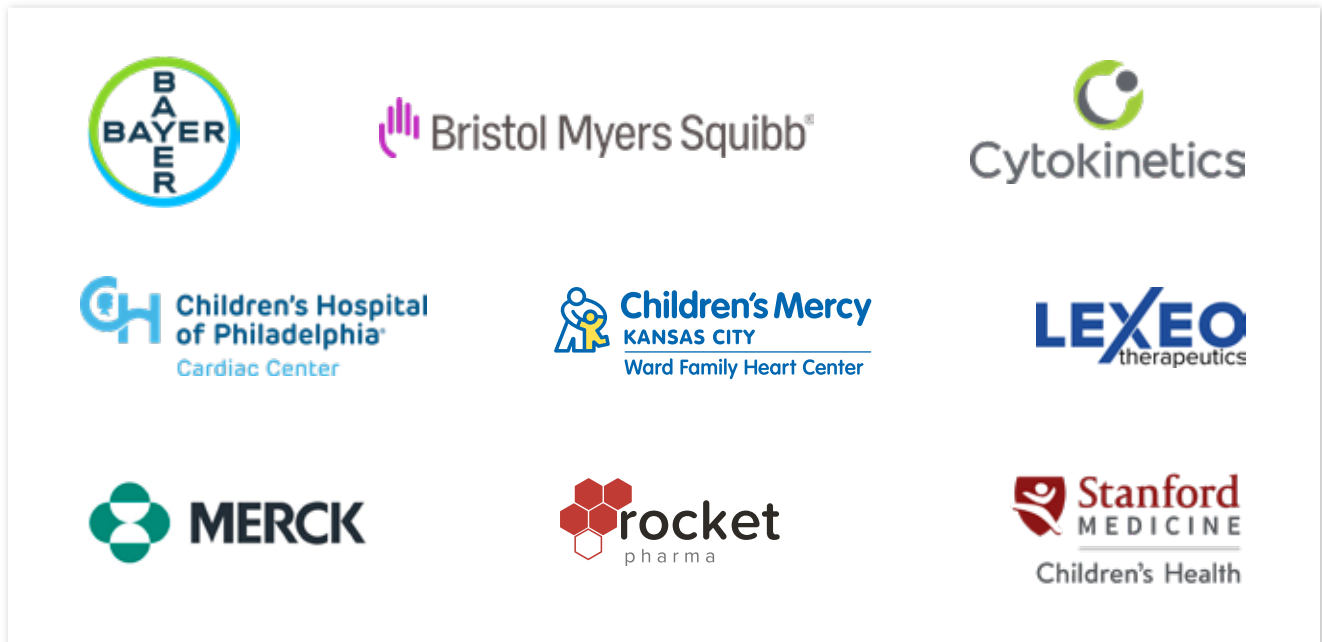
Inspired by their family's experience with inherited cardiomyopathy, Vanessa Lehner created an enamel heart pin to raise awareness of cardiomyopathy.

AWARENESS

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

A record 200 participants raised nearly \$68,000 through Walk for a Cure events across the United States during Children's Cardiomyopathy Awareness Month, with support from nine sponsors. Walks in Pennsylvania, New Jersey, Massachusetts, and California united communities to support children with cardiomyopathy and their families.

The month also featured a webinar on shared decision-making in pediatric hypertrophic cardiomyopathy, the launch of the Let's Talk About Cardiomyopathy video series, and a CCF-sponsored research retreat bringing together 17 investigators from leading U.S. medical centers.



\$68,000

Amount raised
by 200 participants
in annual CCF Walk
for a Cure events

AWARENESS

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH



\$17,016

The Skinner family hosted Noah's Walk for a Cure on September 6 at Phoenixville Park in Pennsylvania in memory of their son, Noah. Seventy-five participants gathered in his honor, raising \$17,016.



\$3,261

The Fratus and Paquin families hosted Henry's Walk for a Cure on September 20 at Charlestown Park in Boston, Massachusetts in honor of Henry, who was diagnosed at age 8 with hypertrophic obstructive cardiomyopathy, raising \$3,261.

AWARENESS

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH



\$962

The Perez family hosted Marylu's Walk for a Cure on September 27 at Branch Brook Park in Newark, New Jersey, in honor of their daughter, Marylu who was diagnosed with histiocytoid cardiomyopathy and then received a heart transplant. 65 participants gathered to raise \$962.



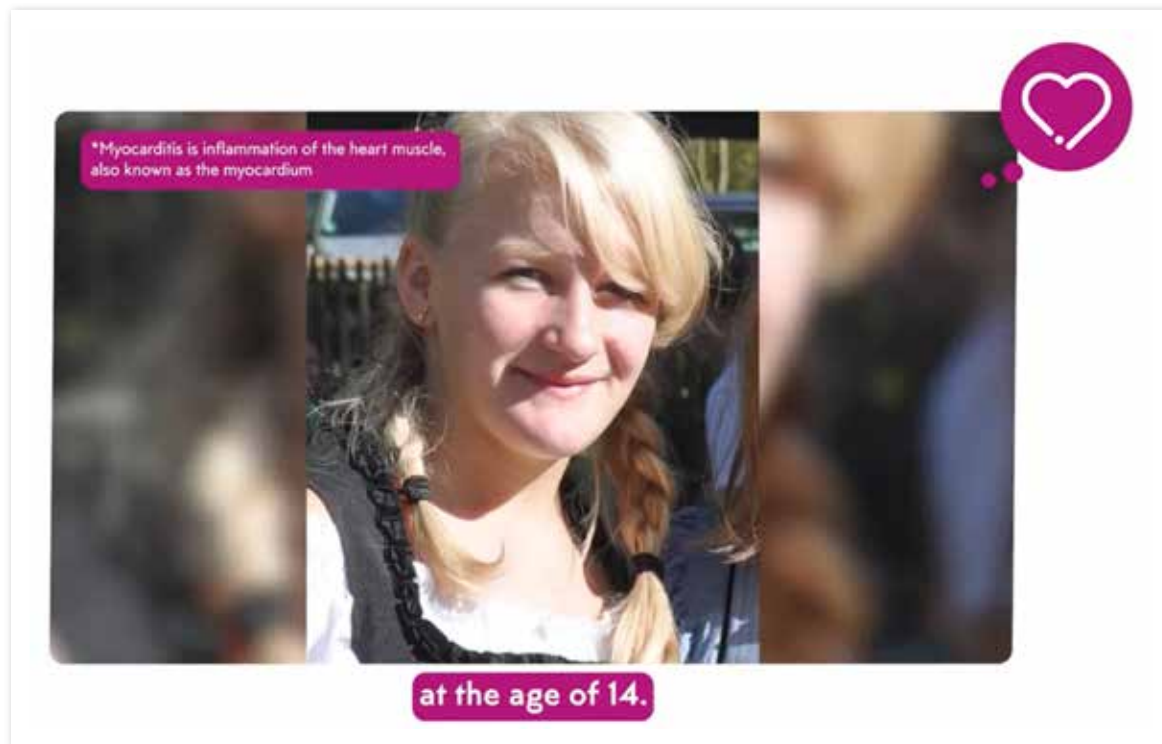
\$2,263

CCF corporate sponsor, Cytokinetics, hosted a Walk for a Cure event on September 11 in San Francisco, bringing together 52 participants and raising \$2,263 to support CCF's programs.

AWARENESS

THINK CARDIOMYOPATHY GLOBAL AWARENESS CAMPAIGN

Partnered with Global Heart Hub, an international affiliate network of 130 patient organizations across 42 countries, on the “Think Cardiomyopathy!” campaign to highlight the impact of cardiomyopathy and the importance of recognizing the signs and symptoms and knowing your family history. The multi-country video campaign raised global awareness of the disease.



130

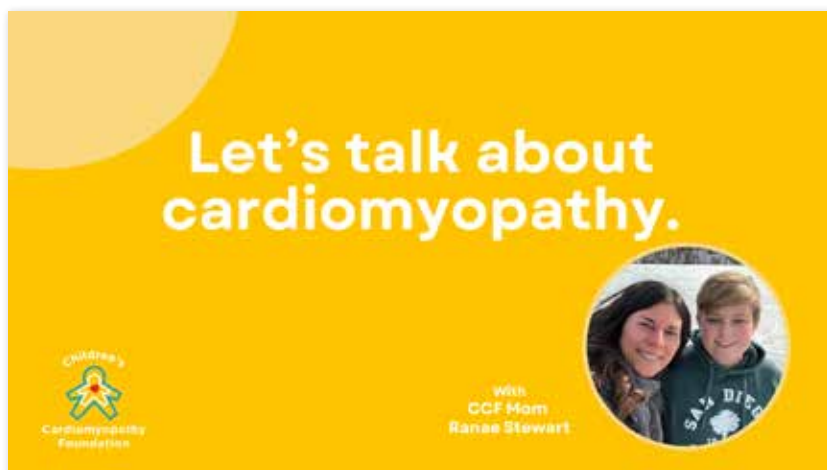
Number of patient organizations in the Global Heart Hub network from 42 countries



PATIENT & FAMILY SUPPORT

PATIENT & FAMILY SUPPORT

Throughout the year, CCF expanded opportunities for families to learn, connect, and share. We welcomed 128 new registrants, bringing our global community to 3,948 members across 100 countries. Families actively participated in programs like the six-part video series *Let's Talk About Cardiomyopathy*, where parents shared personal stories and offered personal advice and inspiration to others.



128

Number of new
CCF registrants

PATIENT & FAMILY SUPPORT

BY THE NUMBERS

128

TOTAL NEW
REGISTRANTS (2025)

105

NEW FAMILIES
3.7% GROWTH

23

NEW PROFESSIONALS
29.8% GROWTH

3,948

TOTAL MEMBERS SERVED

2,334

CCF CONNECT FAMILIES
(94 NEW IN 2025)

PATIENT & FAMILY SUPPORT

BY THE NUMBERS

100

MORE CCF CONNECT
COMMUNITY



260

MORE INSTAGRAM
SUBSCRIBERS



213

MORE YOUTUBE
SUBSCRIBERS



300

MORE FACEBOOK
SUBSCRIBERS



116

MORE LINKEDIN
SUBSCRIBERS



152

MORE
X SUBSCRIBERS



PATIENT & FAMILY SUPPORT

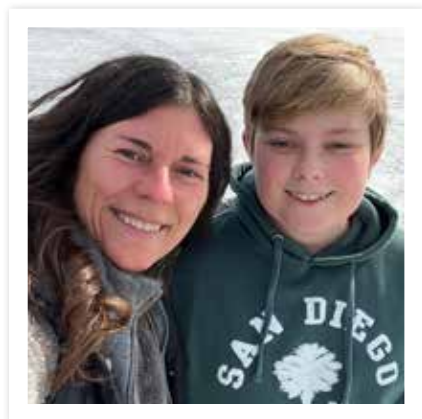
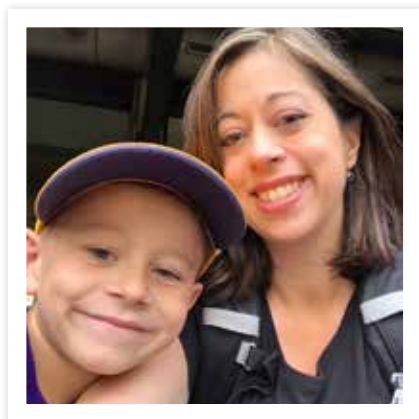
AMBASSADOR PROGRAM

CCF relaunched its ambassador program, training selected parents to provide resources, guidance, and support to families of children diagnosed with cardiomyopathy. By creating opportunities for caregivers to lead, share, and engage, we can build a stronger, more knowledgeable community of cardiomyopathy families.



LET'S TALK ABOUT CARDIOMYOPATHY

The 6-part video series featured parents—Melissa McQueen, Ranae Stewart, and Pragna Bhakta (left to right)—sharing honest, personal stories about their families' journeys with the disease.



PATIENT & FAMILY SUPPORT

CCF HEART KIDS

As part of an ongoing social media campaign to engage more families, CCF profiled 8 children living with cardiomyopathy.



BRINLEY



GRAHAM



BENNETT



LOUIS



LUKE



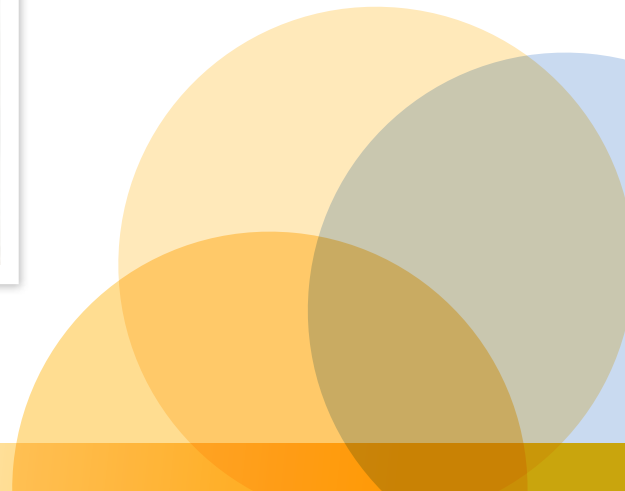
MYLES



GABE



OLIVIA



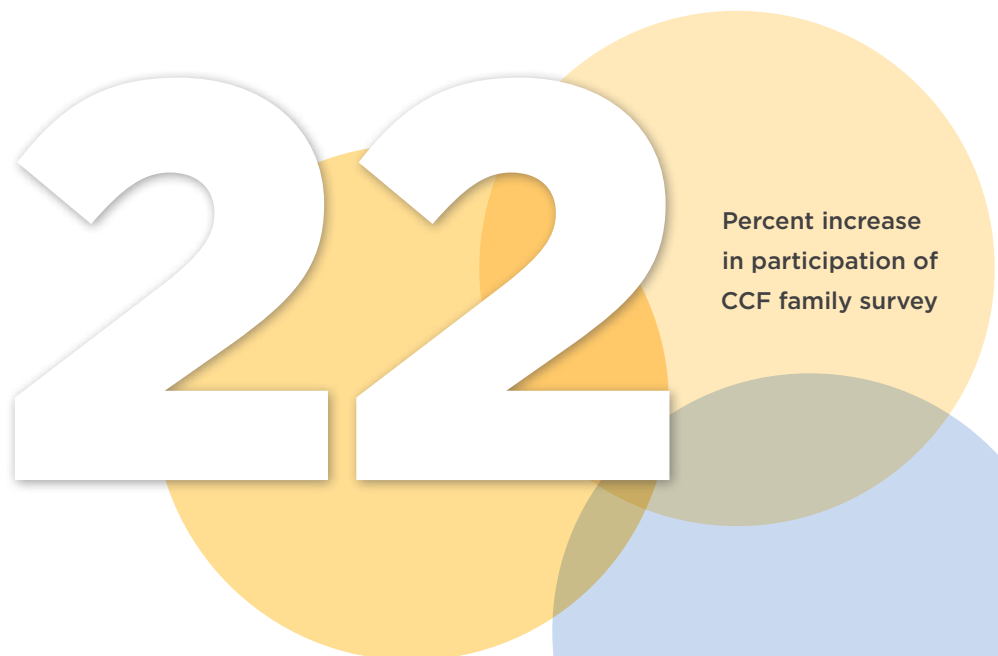
PATIENT & FAMILY SUPPORT

2025 CCF FAMILY SURVEY

We engaged our CCF Connect Community through a family survey to better understand their patient support needs. **Participation increased 22%** over the previous year with 98 family members completing the survey..

KEY INSIGHTS

- **Education is essential:** Families want up-to-date, mobile-friendly resources.
- **Teen-focused content needed:** Programs and tools for adolescents are in high demand.
- **Transparency matters:** Families want to know how their donor support drives real impact.
- **Research remains a priority:** Half of respondents emphasize continued investment in pediatric cardiomyopathy research.
- **Webinars deliver value:** Families highly value practical, application-focused live sessions.





FUNDRAISING

FUNDRAISING

Fundraising events across the country united families, supporters, and corporate partners to advance research and support programs for children with cardiomyopathy. Community-led events, ranging from local tournaments to endurance challenges, contributed an additional \$216,144.



\$216,144

Amount raised
by CCF community
fundraising events

FUNDRAISING

GOLF FOR A CURE

The 21st Annual Golf for a Cure event was held July 21 at the championship Ridgewood Country Club course in Northern New Jersey. 150 golfers and 50 sponsors helped to raise more than \$400,000 to further CCF's research and education programs.

2025 EVENT SPONSORS



Brian McGowan/John O'Meara · Carney Hawks & Family · Chaney & Marisa Sheffield · CIBC Asset Management · Dan & Stacie Allen
 Daniel Shatz · Doug & Elizabeth Pardon · Eddie Yu & Family · Emil Costa & Family · Eric Guevara & Family
 Imperial Ironworks · MarketAxess · Michael & Leslie Petrick · Scott Gooch & Family · Si Lund · Steven Bleier · Sunil Aggarwal



FUNDRAISING

GOLF FOR A CURE



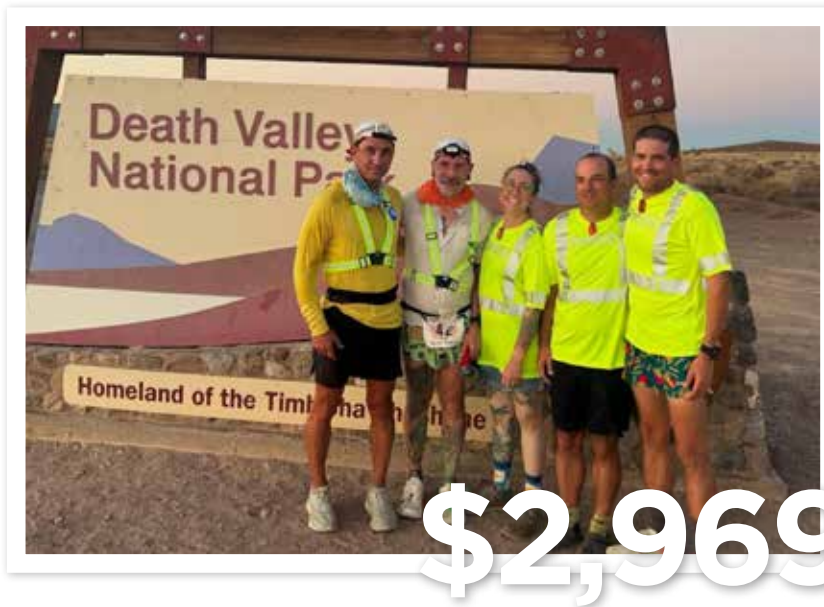
FUNDRAISING

COMMUNITY EVENTS

From Minnesota to Texas and from Pennsylvania to Oregon, families across the country united to raise funds for CCF's programs. People from various communities, big and small, came together to raise \$216,144 through local events such as golf tournaments and athletic challenges.



Wes Sharp and North Star Resource Group supported CCF through the 2nd annual North Star Charitable Golf Event, held in honor of Wes' sons Bennett and Mason, who carry the gene for left ventricular noncompaction cardiomyopathy (LVNC). The event drew 136 golfers and raised nearly \$120,755 for CCF.



Ultramarathon runner Peter Noyes took on the Arizona Monster, a 309-mile journey through the Sonoran Desert to raise funds for CCF. Running for his 10-year-old son, Everett, who was diagnosed with noncompaction cardiomyopathy of the left ventricle (NCCM). He raised \$2,969, exceeding his original \$2,500 goal.

FUNDRAISING

COMMUNITY EVENTS



\$7,750

The 15th Annual Casen's Crew event was held on August 23 with 35 teams participating. The event raised \$7,750 in memory of Casen Riley who was diagnosed with hypertrophic cardiomyopathy (HCM).





FINANCIALS

FINANCIALS

Fiscal year ending December 31, 2025

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents.....	\$472,701
Investments.....	\$2,830,582
TOTAL ASSETS.....	\$3,323,283

LIABILITIES + NET ASSETS

Accounts Payable & Accrued Expenses	\$34,634
Unrestricted Net Assets.....	\$3,288,649
Restricted Net Assets	\$0
TOTAL LIABILITIES + NET ASSETS.....	\$3,323,283

STATEMENT OF ACTIVITIES

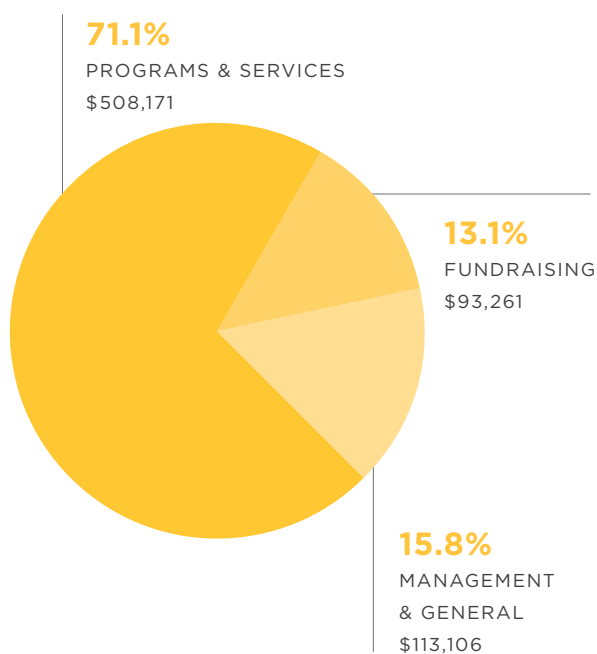
REVENUE

Contributions.....	\$373,689
Fundraising + Special Events.....	\$528,045
Net Investment Return	\$242,877
TOTAL REVENUE	\$1,144,611

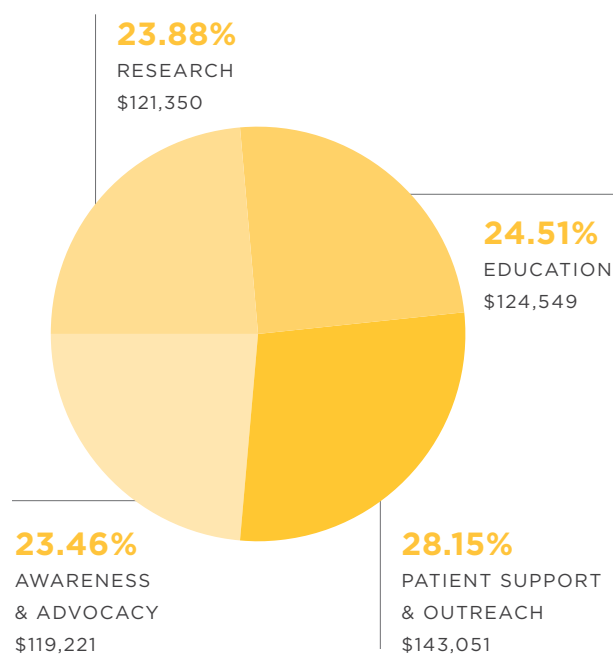
EXPENSES

Programs & Services.....	\$508,171
Management & General	\$113,106
Fundraising	\$93,261
TOTAL EXPENSES.....	\$714,539
NET INCOME.....	\$430,072

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



DONORS

We extend our heartfelt thanks to the following corporations, foundations, and individuals who made contributions of \$500 or more in 2025.

INDUSTRY PARTNERS



DONORS \$10,000 & OVER

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Casen's Crew
Imperial Clinical Research Services
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MacKay Shields
Mary Collazo
Merck
Merewether Investment Management
Nick Benedetti
North Star Foundation
Rocket Pharmaceuticals
Secretome Therapeutics
Stanford Children's Health at Lucile Packard
Children's Hospital
Tenaya Therapeutics

DONORS \$9,999-\$5,000

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Robert and Heather Gallivan
Robert Grogan
Scott Gooch

DONORS

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TD Securities
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TP ICAP
TPG Global

DONORS \$4,999-\$1000

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Andy Block
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