

Celebrating

20

Research
Education
Advocacy
Awareness
Family Support

2022 ANNUAL REPORT

Years



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Dear Friends,

Twenty years of funding research.

Twenty years of supporting families.

Twenty years of building awareness.

Since 2002 the Children's Cardiomyopathy Foundation (CCF) has focused on cardiomyopathies affecting children and the special considerations affecting their care. In 2002, CCF was formed in response to the lack of medical research and support services for families affected by cardiomyopathy. Twenty years later, CCF is the only patient advocacy organization working with the medical, legislative, and patient communities to improve diagnosis and treatment. Our reach continues to expand globally with members from 92 countries, along with our work with the Global Heart Hub and attendees from 25 countries participating in our scientific conference.

As I reflect on two decades of work, I am proud of our work in elevating pediatric cardiomyopathy within the research and medical field. Our collaboration with the Pediatric Cardiomyopathy Registry has produced more than 450 research publications and medical presentations on pediatric cardiomyopathy elevating a little-known disease with no treatment options to a disease for which biotech and pharmaceutical companies are interested in developing therapies.

In this report, we share some of our milestones — from hosting our first Scientific Conference and educational webinars to developing a range of patient materials and initiating the introduction of the first cardiomyopathy bill to identify and protect at-risk children from sudden cardiac arrest.

Over the years, we have developed a trusting and caring relationship with many, and that has been reflected in the work that we do, the research partnerships that have led to improved outcomes, and the recognition that we have received from charity monitoring groups and federal agencies.

While we have met certain milestones in the twenty years of our existence, there is more to do in the next two decades. As our outreach to families and physicians expands, we continue to refine and prioritize our programs and services to meet critical unmet needs.

We remain committed to our vision — a day when all children with cardiomyopathy can live full and active lives. I hope you will join me as we embark on the next chapter.

Sincerely,

Lisa Yue

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, and to support families affected by the disease.

DISEASE FOCUS

- + Dilated Cardiomyopathy (DCM)
- + Hypertrophic Cardiomyopathy (HCM)
- + Restrictive Cardiomyopathy (RCM)
- + Arrhythmogenic Right Ventricular Cardiomyopathy (ARVC)
- + Left Ventricular Noncompaction Cardiomyopathy (LVNC)



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Research



Research

CCF furthers important research on pediatric cardiomyopathy in a variety of ways, including

Partnering

with the Pediatric Cardiomyopathy Registry to fund multi-center studies and publications

Sponsoring

international scientific conferences and regional working group meetings

Assisting

industry partners in patient recruitment for caregiver advisory boards and clinical trials

Advocating

for increased Federal research funding

Through our work with the National Institutes of Health-funded Pediatric Cardiomyopathy Registry and our industry partners, we are advancing our understanding of pediatric cardiomyopathy and driving the development and availability of new therapies.

PEDIATRIC CARDIOMYOPATHY REGISTRY

Research Specialist

Supported a senior research specialist at the University of Buffalo to oversee the management of the Pediatric Cardiomyopathy Registry (PCMR) Administrative Coordinating Center and coordination of research projects, manuscripts, and meetings.

Investigator Retreat

Sponsored a two-day PCMR Virtual Investigator Retreat with the University at Buffalo Jacobs School of Medicine and Biomedical Sciences on April 19-20 to convene 45 clinician-scientists and study coordinators from top academic medical centers in North America. The working group session discussed research priorities and reviewed study and publication plans.

20TH ANNIVERSARY CCF HEART KID SPOTLIGHT

Charlie

AGE 15, MAINE

Hypertrophic Cardiomyopathy

Diagnosed at age 12 and unable to engage in competitive sports, Charlie now plays recreational golf and volunteers with the Special Olympics as a basketball coach.



CCF FUNDED PEDIATRIC CARDIOMYOPATHY RESEARCH

The following medical presentations, publications, and National Institutes of Health funded studies resulted from CCF supported research studies.

Medical Presentations

- “Immune Profiling Utilizing Mass Cytometry in Pediatric Heart Failure”

Meghna D. Patel, MD

*American Academy of Pediatrics National Conference and Exhibition in Anaheim, CA
October 9, 2022*

- “Circulating MicroRNAs Predict Recovery in Pediatric Dilated Cardiomyopathy Patients”

Miyamoto S, Lipshultz SE, Neltner B, Hamza T, Wilkinson J, Karimpour-Fard A, Colan S, Sucharov CC, Pediatric Cardiomyopathy Registry Investigators

*American Heart Association Scientific Sessions,
Abstract Poster Session in Chicago, IL, Nov 5, 2022*

Medical Publications

- “The Genetic Architecture of Pediatric Cardiomyopathy”

Ware SM, Bhatnagar S, Dexheimer PJ, Wilkinson JD, Sridhar A, Fan X, Shen Y, Tariq M, Schubert JA, Colan SD, Shi L, Canter CE, Hsu DT, Bansal N, Webber SA, Everitt MD, Kantor PF, Rossano JW, Pahl E, Rusconi P, Lee TM, Towbin JA, Lal AK, Chung WK, Miller EM, Aronow B, Martin LJ, Lipshultz SE.

*American Journal of Human Genetics, Feb 3, 2022;
vol 109 (2), 282-298*

- “Heart Failure with Preserved Ejection Fraction in Children”

Das B, Deshpande S, Akam-Venkata J, Shakti D, Moskowitz W, Lipschultz S

Pediatric Cardiology, Aug 17, 2022

- 9 additional manuscripts are drafted and being prepared for submission to major peer-reviewed medical journals.

National Institutes of Health Funding

Andrew Landstrom, MD, a 2019 Children’s Cardiomyopathy Foundation and American Academy of Pediatrics Early Career Award recipient, received funding from the National Heart, Lung, and Blood Institute for his CCF-funded study on exploring the role of PRDM 16 in pediatric heart failure and cardiomyopathy.



INDUSTRY COLLABORATIONS

The Children's Cardiomyopathy Foundation (CCF) created a new Corporate Roundtable program to foster collaboration with pharmaceutical, biotechnology, biopharmaceutical, medical device, and genetic testing companies with an interest in heart failure, cardiomyopathy, and heart transplantation.

CCF strengthened its working relationship with industry by assisting in caregiver advisory boards and clinical trial recruitments to support the development of new therapies for cardiomyopathy.

20TH ANNIVERSARY CCF HEART KID SPOTLIGHT

Leo

6 MONTHS OLD, COLORADO
Dilated Cardiomyopathy

Leo was diagnosed at 3 months old after spending several weeks in the NICU. Leo's smile lights up the room, especially when he plays with his stuffed lion Leroy and gets to snuggle with his mom and dad.



20 YEAR ANNIVERSARY SPOTLIGHT

Improving Medical Management and Patient Outcomes

A Pediatric Cardiomyopathy Registry (PCMR) study that CCF funded identified risk factors to aid cardiologists in determining which children with hypertrophic cardiomyopathy are at greatest risk of death and in need for an earlier heart transplant. Before this study, there were no clinical guidelines for predicting a child's outcome.

The paper, "Risk Stratification at diagnosis for children with hypertrophic cardiomyopathy: an analysis of data from the Pediatric Cardiomyopathy Registry," was published in *The Lancet* in 2013.

"Before this study, nobody knew which factors were more or less important in predicting outcomes. Yet for a select group of high-risk children with HCM, transplant is key for survival."

STEVE E. LIPSHULTZ, M.D., PCMR
PRINCIPAL INVESTIGATOR



Education



Education

CCF works to improve awareness and understanding of the disease by

Promoting

the importance of genetic testing and family screening among at-risk and affected family members

Developing

and distributing patient education materials to hospitals and schools nationwide

Encouraging

medical centers to establish comprehensive care programs to improve medical management

Establishing

standards of care guidelines with experts in the field to ensure consistency in diagnosis and treatment

Throughout the year, the Children's Cardiomyopathy Foundation continued its focus on disease education to address topics of interest from the patient and caregiver community.

EDUCATIONAL WEBINARS

CCF rebranded its webinar series to "Experts on Pediatric Cardiomyopathy" and offered five educational webinars featuring medical leaders in the field of cardiomyopathy.



- Pediatric Cardiomyopathy: Transitioning to Adult Care
Anjali Owens, MD and Kimberly Lin, MD
Penn Medicine and Children's Hospital of Philadelphia
February 2, 2022
- Evaluating for ICD Placement & Psychosocial Considerations Related to ICD Placement
Johannes von Alvensleben, MD
Children's Hospital Colorado
April 12, 2022
- Understanding Natural History Studies
Elfriede Pahl, MD, FACC, FAHA, FAAP
Ann and Robert H. Lurie Children's Hospital
July 21, 2022
- Therapeutic Approach to Pediatric Cardiomyopathy Using Gene Therapy
Barry Bryne, MD
University of Florida
September 14, 2022
- Cardiomyopathy: Is It In Our Genes?
Wendy Chung, MD, PhD
Columbia University
November 16, 2022

NY BIO PATIENT ENGAGEMENT SUMMIT

CCF partnered with NY Bio, a leading advocate for the life science industry in New York. CCF Ambassador and Patient Advocate Joanna Pascal shared her experience with cardiomyopathy at their Annual Patient Engagement Summit on April 6.

NEW YORK
BIO



COMMUNITY HEALTH EVENTS

On April 30, CCF volunteers from the Bay area set up an educational table at Stanford Medicine's annual "My Heart Counts" 5k run event.



20 YEAR ANNIVERSARY SPOTLIGHT

Ensuring Consistent and Comprehensive Care

Launched in 2017, the Cardiomyopathy Centers of Care Program acknowledges medical centers providing high-quality cardiac care and specialized disease management to children with cardiomyopathy.

CCF engages with 45 recognized centers on various projects, and center profiles are provided to newly diagnosed families to help them select a care provider. In addition, CCF has distributed more than 16,000 pieces of educational materials to hospitals and patients free of charge for the past 20 years.



Advocacy



Advocacy

Elevating the voices of affected children and families through

Advocating

for increased federal funding of research, awareness and education programs

Promoting

policies and programs to legislators and federal agencies that will improve outcomes and prevent premature death.

Partnering

with relevant coalitions and organizations on legislative initiatives to protect children at risk of sudden cardiac arrest

At the Federal level, the Children's Cardiomyopathy Foundation continued to identify key decision makers and legislative opportunities to advance cardiomyopathy-related initiatives on Capitol Hill.

HEALTH LEGISLATION

On April 12, U.S. Senator Bob Menendez (D-NJ) and Congressman Bill Pascrell, Jr. (NJ-09) reintroduced the Supporting Athletes, Families, and Educators to Protect the Lives of Athletic Youth (SAFEPLAY) Act, bicameral legislation that aims to improve sports safety and protect student athletes from life-threatening incidents such as cardiac arrest and concussion.

The SAFEPLAY act is the most comprehensive federal legislation on youth sports safety.

Since 2012 CCF has actively worked with legislators to ensure that schools have the resources and information to properly identify warning signs and respond quickly in the event of a cardiac medical emergency.

“The number of fatalities from cardiac arrest can be reduced if a potentially life-threatening heart condition, like cardiomyopathy, is detected early and treated appropriately. The SAFEPLAY Act addresses this very issue and includes preventive measures to safeguard at-risk children.”

LISA YUE, FOUNDER OF CHILDREN'S
CARDIOMYOPATHY FOUNDATION



RESEARCH FUNDING

The Department of Defense Peer-Reviewed Medical Research Program (PRMRP) added cardiomyopathy to the approved topic list for the 2022 call for research proposals. This was the fourth year that CCF secured federal funding for cardiomyopathy research through lobbying efforts.

Peer Reviewed Medical Research Program



\$43.9M

Awarded to 24 cardiomyopathy studies from FY2018 to FY 2021

20 YEAR ANNIVERSARY SPOTLIGHT

Spearheading Lifesaving Legislation

In 2011 the Children's Cardiomyopathy Foundation worked with Senators Robert Menendez (NJ) and Frank Lautenberg (NJ) and Representative Frank Pallone (NJ-6) to introduce the first cardiomyopathy related federal legislation.

Supported by 23 Senate and House cosponsors the Cardiomyopathy Health, Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act proposed that the Centers for Disease Control (CDC) develop educational materials on cardiomyopathy and disseminate them through the public school system and the CDC website to raise awareness of the signs and symptoms and identify at risk family members.





Awareness

Awareness

Shining a spotlight on pediatric cardiomyopathy by:

Expanding

public awareness of pediatric cardiomyopathy through media relations and publicity initiatives

Training

volunteers and CCF members to educate their local communities about pediatric cardiomyopathy

During National Heart Month in February and Children's Cardiomyopathy Awareness Month in September, the Children's Cardiomyopathy Foundation focused on raising awareness of the signs and symptoms of cardiomyopathy.

NATIONAL HEART MONTH

#NationalHeartMonth

- Families and friends wore red, handed out CCF valentines, and distributed materials about cardiomyopathy.
- CCF participated in the Heart Failure Society of America's Twitter chat on the topic of heart transplants.
- Anjali Owens, MD and Kimberly Lin, MD hosted a CCF webinar on Transitioning to Adult Care.
- More than 125 guests celebrated National Heart Month at CCF's Night for a Cure virtual charity poker tournament.



CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

#KnowYourHeart

- 17 national partners utilized CCF's awareness kit to urge families to learn about the signs, symptoms, and risk factors of cardiomyopathy via social media channels.
- National Alliance for Youth Sports ran a two-part series on pediatric cardiomyopathy on their Sporting Kid Live news site targeted to coaches, parents and school administrators.
- For the 8th year, supporters across the country organized Walk for a Cure events to raise awareness of pediatric cardiomyopathy in their community.

American Academy of Pediatrics

AMERICAN COLLEGE of CARDIOLOGY

American Heart Association

American School Health Association

Conquering CHD

Harboring Hearts

HFSA Heart Failure Society of America

little mended hearts

NAYS National Alliance for Youth Sports

Pediatric Nurse Practitioners

NASN National Association of School Nurses

NIA National Intestinal Anomalies Association

Parent Heart Watch

SPCN The Society of Pediatric Cardiovascular Nurses

The Society of Thoracic Surgeons

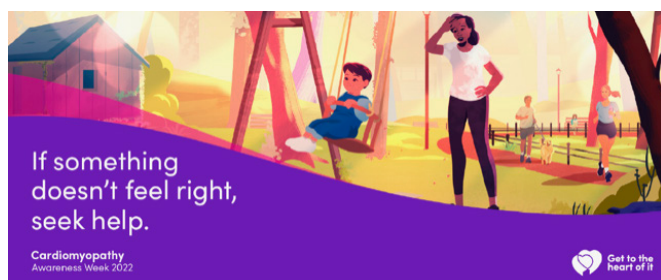
American Medical Association

Sudden Cardiac Arrest Association

GLOBAL HEART HUB

As a member of the Heart Failure Patient Council and Cardiomyopathy Patient Council, the Children's Cardiomyopathy Foundation participated in two multi-country campaigns to promote Heart Failure Awareness Week (May 9-15) and Cardiomyopathy Awareness Week (June 20-26).

CCF collaborated with patient organizations across 9 countries on a "Get to the Heart of It" social media campaign to generate awareness of the diagnosis and management of cardiomyopathy.



20TH ANNIVERSARY CCF HEART KID SPOTLIGHT

Zafeiris

6 MONTHS OLD, COLORADO
Left Ventricular Non-Compaction
Cardiomyopathy

Born premature at 28 weeks, Zafeiris spent 16 months in the pediatric intensive care unit in heart failure. Today, he is vibrant and playful. He loves cars, riding his bike, and playing with his cat.



20 YEAR ANNIVERSARY SPOTLIGHT

Building Disease Awareness

In 2014, 13 national partners participated in CCF's inaugural Children's Cardiomyopathy Awareness Month. Highlights included an AED Hunt on the Hill event on Capitol Hill inviting legislators to participate and an Action Day on the Hill giving families an opportunity to share their stories with congressional members. The Centers for Disease Control and Prevention (CDC) added a new webpage on pediatric cardiomyopathy, and several media outlets covered the awareness month.

Cardiomyopathy Awareness month has been recognized each year since its inception and continues to grow with public engagement industry partners.



Patient & Family Support



Patient & Family Support

Supporting families is at the cornerstone of CCF's mission. CCF guides newly diagnosed families by

Offering

support services such as family matching, teen programs, Q&A sessions, webinars, and an online community

Serving

as an access point for information on the disease

Assisting

families in locating a specialty center and care provider

CCF HEART KIDS

As part of an ongoing social media campaign, the Children's Cardiomyopathy Foundation profiled six children living with cardiomyopathy.



Lena



Leo



Saoirse



Virginia



Zara



Mackenzie

CCF supports affected families in

92 countries

CCF responded to

700+

phone and email requests
for information

CCF grew its online support
community to

2,200+

members, and have generated
more than 500 posts and
6,000 comments annually

CCF has served approximately

7,000

families through its education
and support resources

20TH ANNIVERSARY CCF HEART KID SPOTLIGHT

Isabel, Jason & Jaxon

AGES 5 & 4, ARIZONA

Restrictive Cardiomyopathy

All three siblings received heart transplants before their 3rd birthdays. Isabel received hers 4 months after her diagnosis in 2018, Jason and Jaxon received theirs in 2020 after experiencing heart failure and suffering a sudden cardiac arrest. Today, the siblings are healthy, happy, and active.



20 YEAR ANNIVERSARY SPOTLIGHT

Uniting Families Across the U.S.

In addition to sponsoring several regional family conferences with the Sarcomeric Human Cardiomyopathy Registry (SHaRe), the Children's Cardiomyopathy Foundation (CCF) planned its first family and patient conference in 2019.

The two-day conference, held in Philadelphia and hosted in partnership with the Children's Hospital of Philadelphia and Penn Medicine, brought together patients, caregivers, and medical professionals to encourage discussions.



Fundraising



Fundraising

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

NIGHT FOR A CURE

More than 125 players went all-in on February 9 to support the Children's Cardiomyopathy Foundation's 14th annual Night for a Cure. The virtual charity poker tournament raised over \$83,000. Alec Rome of Faded Spade was host with influential poker vlogger Jaman Burton as his special guest commentator.



GOLF FOR A CURE

The Children's Cardiomyopathy Foundation (CCF) 19th Annual Golf for a Cure event was held July 25 at the championship Ridgewood Country Club course in New Jersey. With the support of 170 attendees and 48 sponsors, the event raised more than \$344,000 for research and education initiatives.



WALK FOR A CURE

Team captains from around the country organized 65 virtual walkers to celebrate Children's Cardiomyopathy Awareness Month in September raising nearly \$10,000.



20 YEAR ANNIVERSARY SPOTLIGHT

Increasing Family Involvement

Over the years the Children's Cardiomyopathy Foundation has built a strong patient community committed to raising awareness of cardiomyopathy in their community. Families have organized fundraisers of all sizes to support CCF's programs.

Two notable annual fundraisers are Heather Riley of Casen's Crew, which has raised \$116,000 in honor of Casen Riley and Megan Cosby of the EAC Family Foundation, which has raised \$94,670 in honor of Ellis Ann Cosby.



BAKE FOR A CURE

Bake for a Cure events took place during National Heart Month to raise community awareness and research funding for pediatric cardiomyopathy. 11 families participated in Bake for a Cure events across the U.S.



FAMILY FUNDRAISERS

Families supported CCF in many creative ways, including setting up Facebook fundraisers for birthdays and anniversaries and sharing the page with family and friends. Family fundraisers raised more than \$28,000 in 2022 with \$9,810 coming from Facebook fundraisers.

20 YEAR ANNIVERSARY SPOTLIGHT

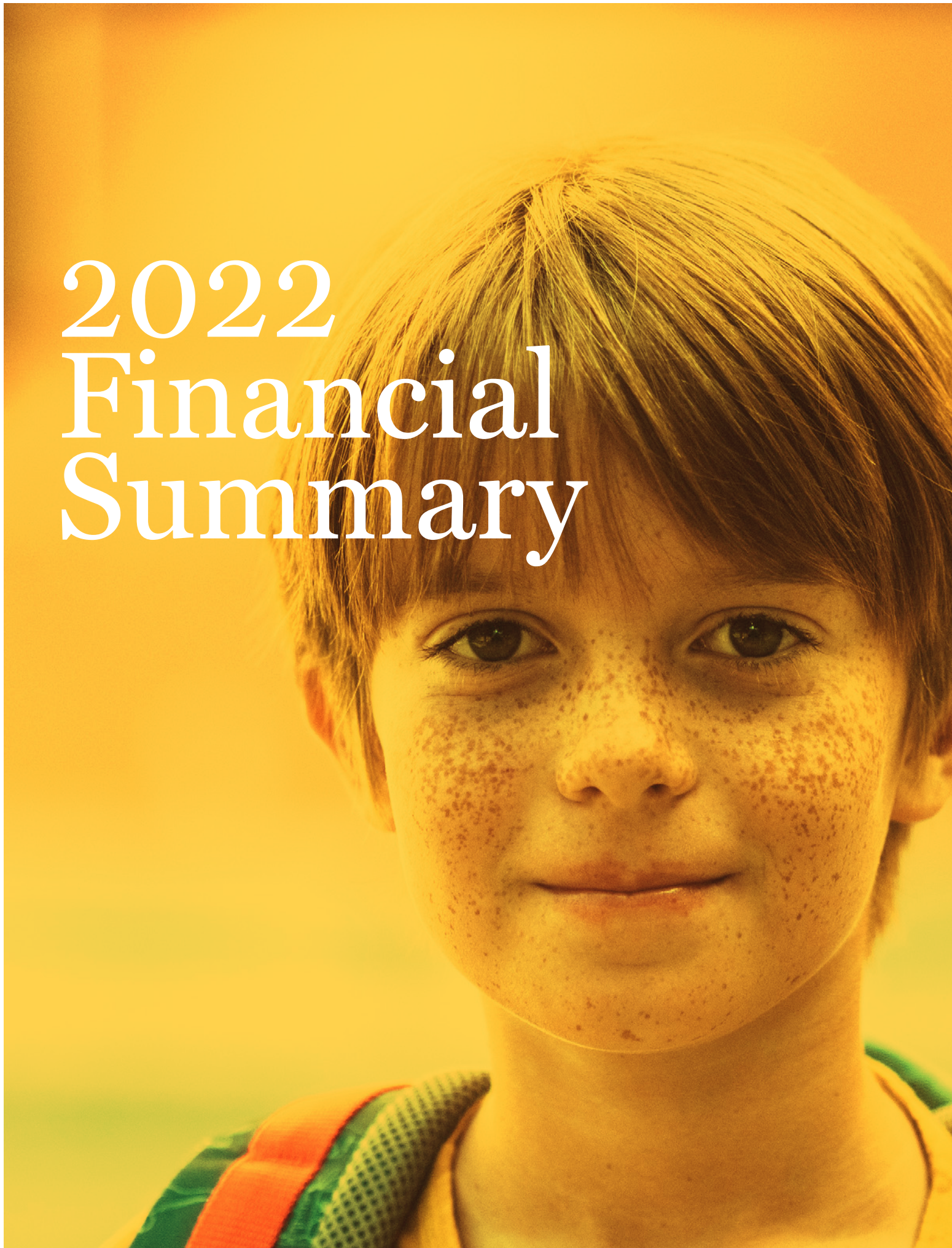
Walking to Raise Disease Awareness

The Children's Cardiomyopathy Foundation's First Annual Walk for a Cure took place in Essex County, New Jersey in 2015 to commemorate Children's Cardiomyopathy Awareness Month.

The community event raised \$40,734 and has since grown to include hundreds of walkers in multiple states.



2022 Financial Summary



2022 Financial Summary

Statement of Financial Position

Fiscal year ending December 31, 2022

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	\$ 628,344
Investments	\$ 1,874,016
Intangible Net Assets	\$ 6,136
TOTAL ASSETS	\$ 2,508,496

LIABILITIES + NET ASSETS

Accounts Payable & Accrued Expenses	\$ 57,287
SBA EIDL Loans	\$ 112,000
Unrestricted Net Assets	\$ 2,339,209
Restricted Net Assets	\$ 0
TOTAL LIABILITIES + NET ASSETS	\$ 2,508,496

STATEMENT OF ACTIVITIES

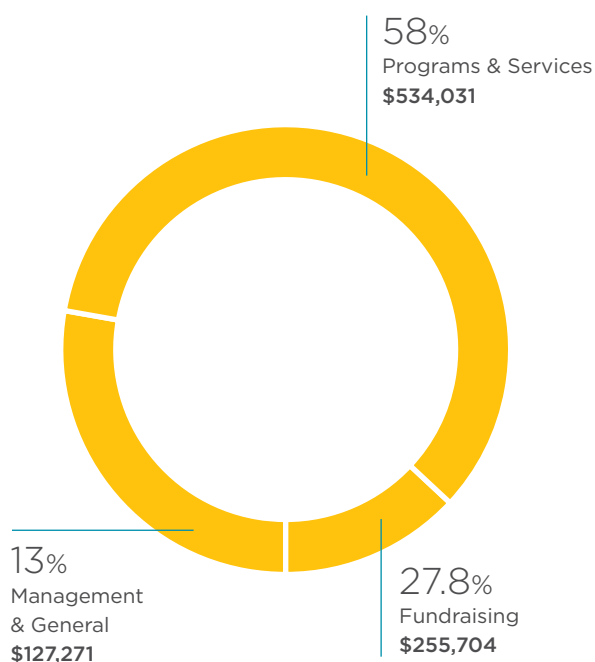
REVENUE

Contributions	\$ 220,044
Fundraising + Special Events	\$ 441,429
Net Investment Return	(\$ 212,109)
TOTAL REVENUE	\$ 449,364

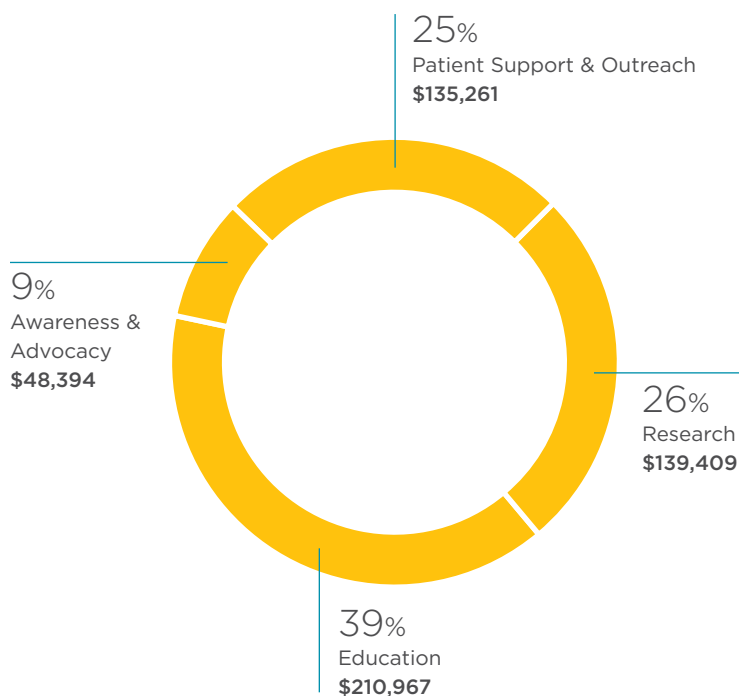
EXPENSES

Programs & Services	\$ 534,031
Management & General	\$ 127,271
Fundraising	\$ 255,704
TOTAL EXPENSES	\$ 917,006
NET INCOME	(\$ 467,642)

TOTAL EXPENSES



EXPENSES BY PROGRAM AND SERVICES



2022 Top Donors

We extend our heartfelt thanks to all who have contributed to the Children's Cardiomyopathy Foundation. The following corporations, foundations, and individuals made contributions of \$500 or more to the Foundation in 2022.

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Donors \$10,000 & Over

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(continued)**

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