

# MOVING FORWARD



2021 ANNUAL REPORT

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A Cause for Today.  
A Cure for Tomorrow.

# FOUNDER'S LETTER



Dear Friends,

It's hard to believe that the Children's Cardiomyopathy Foundation (CCF) will celebrate its 20th anniversary in 2022! Over the years, we have stayed steadfast in our mission to support children with cardiomyopathy and their families. It is rewarding to see the impact of CCF's investment into research, education, awareness, and advocacy. With nearly 450 research presentations and publications resulting from our funded initiatives, we have had a direct impact on the medical care and quality of life for children with cardiomyopathy.

The past two years have been challenging, but fortunately our work has not stalled. New relationships have been formed, and opportunities have emerged from working with industry partners, medical centers, professional societies, and advocacy groups. I am happy to share this year's achievements in this annual report and highlight the following:

- **Research:** CCF held its 5th International Conference on Cardiomyopathy in Children virtually, enabling medical professionals and academic researchers from around the globe to participate and learn from experts in the field.
- **Family Support:** A new Regional Ambassador Program was launched to increase family engagement and strengthen CCF's relationships with patients across the U.S.
- **Education:** Over 20 articles on pediatric cardiomyopathy were published in peer-reviewed journals, and educational materials were translated into Spanish to meet the needs of the Hispanic community.

During these uncertain times, we are especially grateful for our loyal donors, volunteers, and families. The CCF team remains focused and determined as we move forward with new initiatives. There is no limit to what we can achieve in the next 20 years!

Sincerely,

A handwritten signature in black ink that reads "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, advocacy**, and **family support**.

## DISEASE FOCUS

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



## BOARD OF DIRECTORS

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Alexa DeVantier  
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**MOVING  
FORWARD**



**IN RESEARCH**

# MOVING FORWARD IN RESEARCH

Through CCF's ongoing partnership with the **National Institutes of Health-funded Pediatric Cardiomyopathy Registry**, research projects moved forward and completed manuscripts were submitted to various peer-reviewed journals.

Findings from **CCF-funded studies** were presented at several medical meetings and published in a number of peer-reviewed **scientific** and **medical journals**.

Funding for new studies were put on hold due to financial constraints imposed by the coronavirus pandemic.

## PRESENTATIONS

"Registry-Based Research for Pediatric Rare Diseases:  
NIH Pediatric Cardiomyopathy Registry"

*University at Buffalo Pediatric Grand Rounds*  
February 2021

"Beginning with the End in Mind: Cardiotoxicity After  
Childhood Cancer"

*Multinational Association of Supportive Care in  
Cancer International Society for Oral Oncology  
2021 Annual Meeting*  
June 2021

*University at Buffalo Cancer Research Consortium  
Seminar Series*  
September 2021

*MD Anderson Cardiology Grand Rounds*  
October 2021

*University at Buffalo Department of Medicine Grand Rounds*  
November 2021



**National Institutes  
of Health**

# MOVING FORWARD IN RESEARCH

## PUBLICATIONS

“Genetic Causes of Cardiomyopathy in Children: First Results from the Pediatric Cardiomyopathy Genes Study”

Ware SM, Wilkinson JD, Tariq M, Schubert JA, Sridhar A, Colan SD, Shi L, Canter CE, Hsu DT, Webber SA, Dodd DA, Everitt MD, Kantor PF, Addonizio LJ, Jefferies JL, Rossano JW, Pahl E, Rusconi P, Chung WK, Lee T, Towbin JA, Lal AK, Bhatnagar S, Aronow B, Dexheimer PJ, Martin LJ, Miller EM, Sleeper LA, Razoky H, Czachor J, Lipshultz SE

*Journal of the American Heart Association*  
May 2021

“Pediatric and adult dilated cardiomyopathy are distinguished by distinct biomarker profiles”

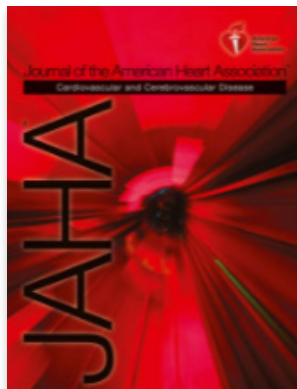
Gropler MRF, Lipshultz SE, Wilkinson JD, Towbin JA, Colan SD, Canter CE, Lavine KJ, Simpson KE

*Pediatric Research*  
August 2021

“Impact of Genetic Testing for Cardiomyopathy on Emotional Well-Being and Family Dynamics: A Study of Parents and Adolescents”

Ahimaz P, Sabatello M, Qian M, Wang A, Miller EM, Parrott A, Lal AK, Chatfield KC, Rossano JW, Ware SM, Parent JJ, Kantor P, Yue L, Wynn J, Lee TM, Addonizio LJ, Appelbaum PS, Chung WK

*Circulation: Genomic and Precision Medicine*  
August 2021



# MOVING FORWARD IN RESEARCH

## SCIENTIFIC CONFERENCE PUBLICATIONS

17 articles from CCF's 5th International Conference on Cardiomyopathy in Children were published in two special issues of *Progress in Pediatric Cardiology*.

### September 2021 Issue

"Introduction to 5th International Conference on Cardiomyopathy in Children Special Issue I"

Lee TM, Lipshultz SE

"Risk stratification and management of decompensated heart failure in pediatric dilated cardiomyopathy: Questions and opportunities"

Weisert M, Su J

"When and how does dilated cardiomyopathy recover in children?"

Everitt MD

"Spectrum of phenotype of ventricular noncompaction in adults"

Di Toro A, Urtis M, Arbustini E

"Imaging in ventricular noncompaction"

Taylor C, Nutting A

"Arrhythmogenic left ventricular cardiomyopathy in an adolescent patient with DSP mutation"

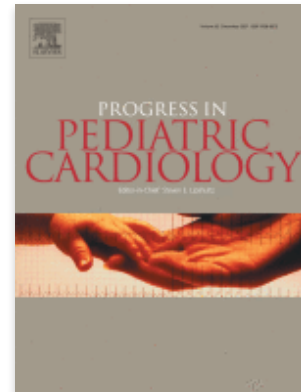
Choi NH, Liberman L, Lee TM

"Phenocopies of sarcomere gene mediated hypertrophic cardiomyopathy in children"

Brown E, Murphy AM

"Prevention of sudden cardiac death in childhood-onset hypertrophic cardiomyopathy"

Kaski JP, Norrish G





# MOVING FORWARD IN RESEARCH

“Overview of pediatric restrictive cardiomyopathy—2021”

Denfield SW

“The clinical utility of pediatric cardiomyopathy genetic testing:  
From diagnosis to a precision medicine-based approach to care”

Parker LE, Landstrom AP

## **December 2021 Issue**

“Introduction to the 5th International Conference on Cardiomyopathy  
in Children Special Issue II”

Lee TM, Lipshultz SE

“Clinical and genetic features of arrhythmogenic cardiomyopathy:  
Diagnosis, management and the heart failure perspective”

Castrichini M, Eldemire R, Groves DW, Taylor MRG, Miyamoto S, Mestroni L

“Clinical and genetic features of arrhythmogenic cardiomyopathy:  
the electrophysiology perspective”

Przybylski R, Abrams DJ

“Optimal imaging strategy for surveillance in children with hypertrophic  
cardiomyopathy”

Lee S, Pahl E

“Genetic correction strategies for Duchenne muscular dystrophy  
and their impact on the heart”

Johnston JR, McNally EM

“Novel therapies in inherited cardiomyopathies”

de Feria A, Owens AT

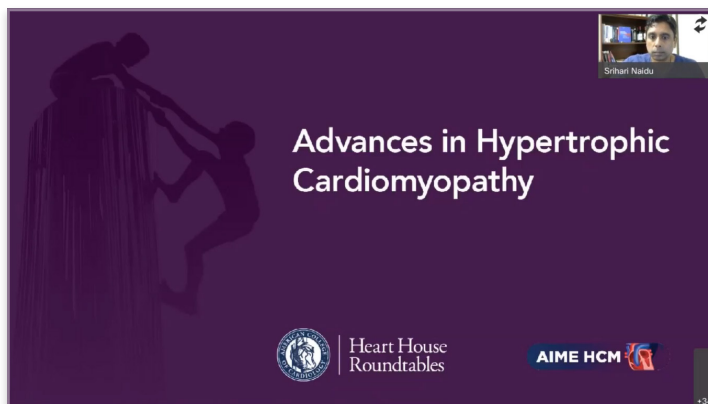
“Pediatric cardiomyopathy and the PCM Genes study: A summary with  
insights on genetic testing, variant interpretation, race and ethnicity”

Ware SM on behalf of the Pediatric Cardiomyopathy Registry

# MOVING FORWARD IN RESEARCH

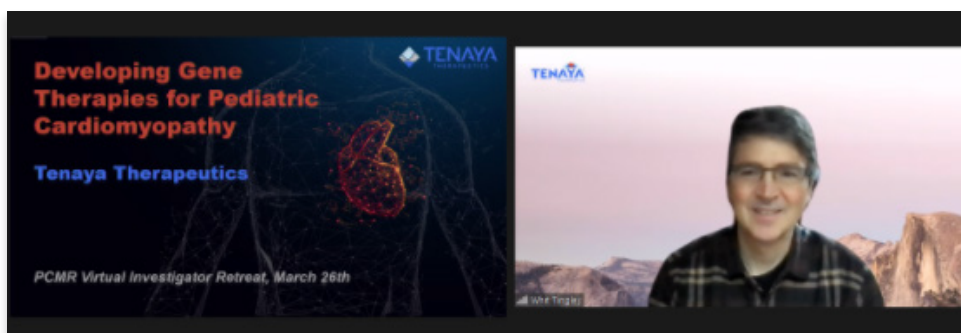
## AMERICAN COLLEGE OF CARDIOLOGY ROUNDTABLE ON ADVANCES IN HYPERTROPHIC CARDIOMYOPATHY

The Children's Cardiomyopathy Foundation took part in the American College of Cardiology roundtable, "Advances in Hypertrophic Cardiomyopathy," held virtually on June 8. Joseph Rossano, MD, MS of the Children's Hospital of Philadelphia represented CCF in discussions on clinical challenges related to managing and treating patients with hypertrophic cardiomyopathy.



## ANNUAL PEDIATRIC CARDIOMYOPATHY REGISTRY INVESTIGATOR RETREAT

The North America Pediatric Cardiomyopathy Registry (PCMR) Annual Investigator Retreat was held virtually on March 26 and sponsored by CCF and Tenaya Therapeutics. Over 40 medical professionals from the top pediatric heart failure and cardiomyopathy programs gathered to discuss research findings, review manuscripts in development, and evaluate new study opportunities.



# MOVING FORWARD IN RESEARCH

## 5TH INTERNATIONAL CONFERENCE ON CARDIOMYOPATHY IN CHILDREN

CCF's 5th International Conference on Cardiomyopathy in Children was held virtually on March 5 – 6.



The conference featured six sessions with presentations and live panel discussions. A final “Future Directions for Pediatric Cardiomyopathy” live session featured an international panel of 14 leading cardiomyopathy experts.

March 5 • 12:00 p.m. to 4:15 p.m. EST	March 6 • 9:00 a.m. to 2:15 p.m. EST
<ul style="list-style-type: none"><li>♦ <b>Dilated Cardiomyopathy</b> Steve Lipshultz, M.D., Daphne Hsu, M.D., Paul Kantor M.B.B.Ch., M.Sc.</li><li>♦ <b>Noncompaction Cardiomyopathy</b> Melanie Everitt, M.D., Brian Feingold, M.D., John Lynn Jefferies, M.D., Ph.D.</li><li>♦ <b>Arrhythmogenic Cardiomyopathy</b> Jeff Towbin, M.D. and Teresa Lee, M.D.</li></ul>	<ul style="list-style-type: none"><li>♦ <b>Hypertrophic Cardiomyopathy</b> Charlie Canter, M.D., Steve Colan, M.D., Robert Weintraub, M.B.B.S.</li><li>♦ <b>Restrictive Cardiomyopathy</b> Joseph Rossano, M.D., Michael Burch, M.B.ChB., M.D.</li><li>♦ <b>Genetics of Cardiomyopathy</b> Wendy Chung, M.D., Ph.D., Shelley Miyamoto, M.D., Stephanie Ware, M.D., Ph.D.</li></ul>

# MOVING FORWARD IN RESEARCH

More than 260 medical and healthcare professionals from 25 countries attended to learn about developments in pediatric heart failure, cardiomyopathy, and heart transplantation.

**Statistical Approaches to Randomized, Observational Trials**

Christopher S. Almond M.D., M.P.H.  
Professor of Pediatrics  
Stanford University

 5th International Conference on Cardiomyopathy in Children

Christopher S. Almond, MD, MPH



Professor of Pediatrics  
Stanford University

**Study Population: Are Kids Just Small Adults?**

- It is tempting to extrapolate results from successful DCM trials in adults
- Pediatric-specific clinical trials help answer important questions:
  - Safety profile
  - Appropriate dosing
  - Does it truly work in kids?
- A good understanding of the proposed therapy is key
  - What were the characteristics of the population in which successful trial(s) have been performed?
  - What is the purported mechanism of the therapy?
  - What pediatric population is most likely to also benefit?

 5th International Conference on Cardiomyopathy in Children

Kimberly Y. Lin, MD



Medical Director  
Pediatric Cardiomyopathy Program  
The Children's Hospital of Philadelphia

The conference was sponsored by 9 sponsors.





# MOVING FORWARD



# IN EDUCATION

# MOVING FORWARD IN EDUCATION

Throughout the year, the Children's Cardiomyopathy Foundation updated the medical community on **research publications, medical meetings, funding opportunities, and new family resources** related to pediatric cardiomyopathy.

- Three new **Cardiomyopathy Centers of Care** were recognized for their high-quality cardiac care and comprehensive approach to treatment. These additions increase the number of pediatric cardiomyopathy specialty centers to 45 hospitals in the U.S. and Canada.
- Key educational materials were **translated into Spanish** to meet the needs of a diverse patient community. Updated patient materials include a general information booklet, inserts on each form of cardiomyopathy, and a CCF overview pamphlet.



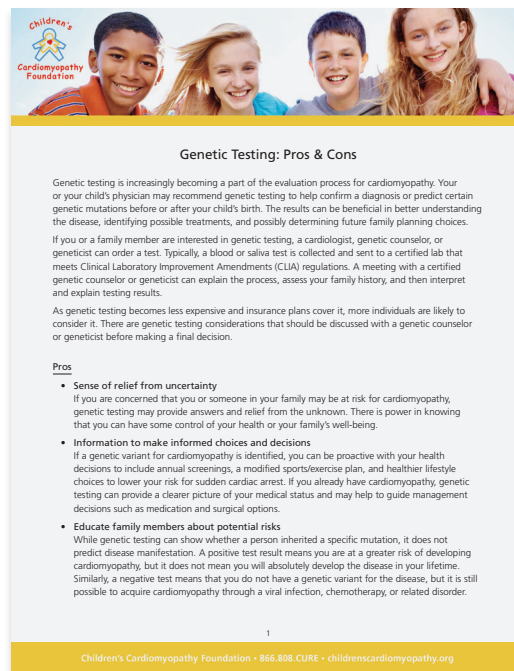
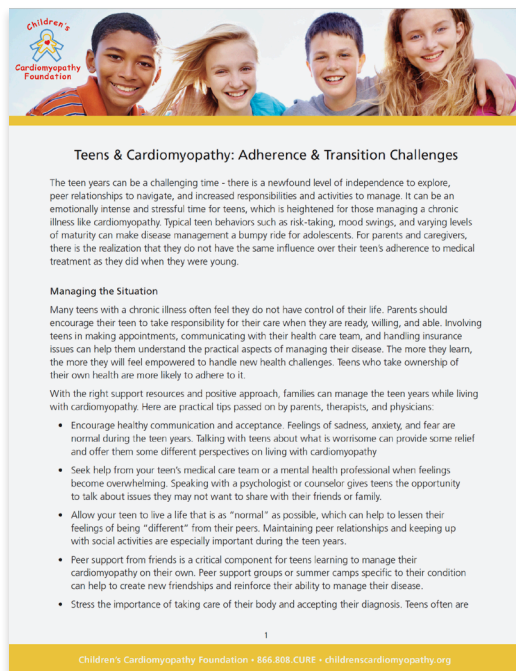
# MOVING FORWARD IN EDUCATION

- Created three new fact sheets:

*Genetic Testing: Pros & Cons*

*Teens & Cardiomyopathy: Adherence and Transition Challenges*

*What is a Ventricular Assist Device?*



- Bristol-Myers Squibb and Pfizer joined as partners in supporting CCF's patient education initiatives.





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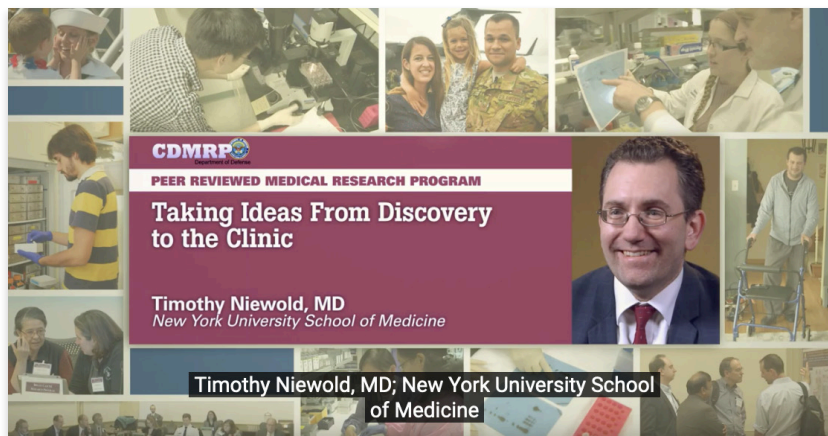
**IN ADVOCACY**



# MOVING FORWARD IN ADVOCACY

At the **Federal level**, the Children's Cardiomyopathy Foundation continued to foster relationships with key Congressional leaders to elevate pediatric cardiomyopathy on their legislative agendas.

- CCF worked with the National Coalition for Heart and Stroke Research, National Health Council, National Organization for Rare Disorders, and EveryLife Foundation for Rare Diseases to support various appropriation and legislative efforts related to cardiovascular health and rare diseases.



- Through CCF's federal lobbying efforts, cardiomyopathy was an approved disease topic for receiving **federal research funding** from the Department of Defense Peer Reviewed Medical Research Program (PRMRP). For FY 21 \$370 million appropriated by Congress will be allocated to research studies covering 42 priority diseases.
- Four parents nominated by CCF served as **consumer advocates** for the Department of Defense PRMRP program to provide a patient perspective in the evaluation of cardiomyopathy research applications.

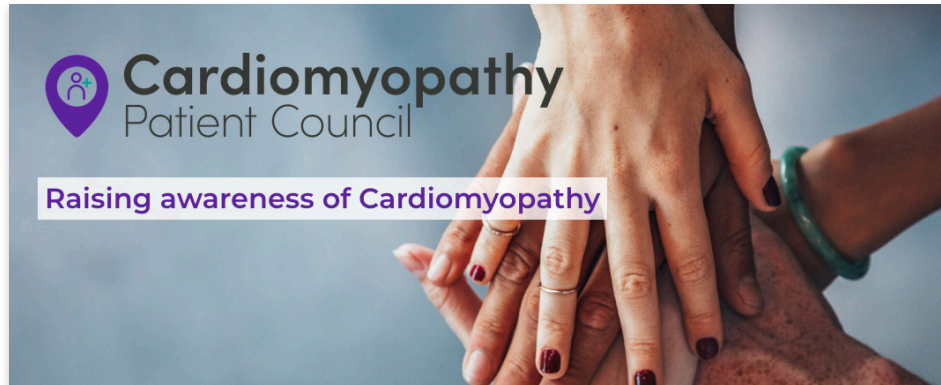
**MOVING  
FORWARD**



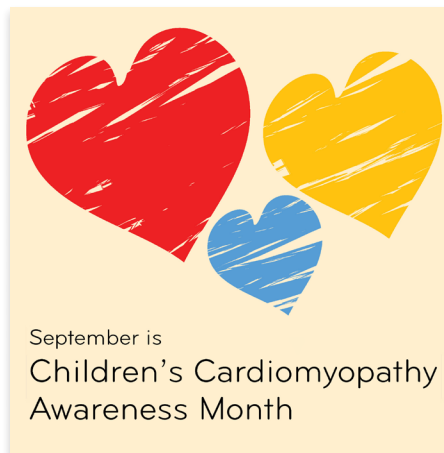
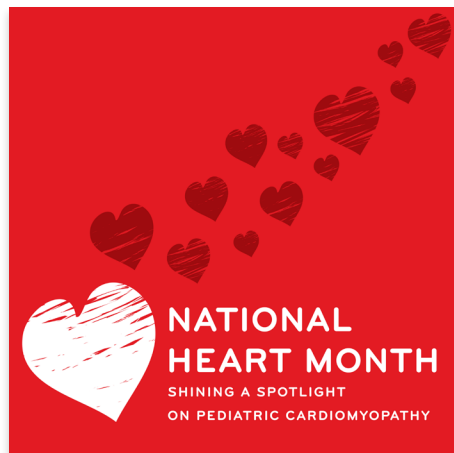
**IN AWARENESS**

# MOVING FORWARD IN AWARENESS

**Internationally**, the Children's Cardiomyopathy Foundation continues to work with Global Heart Hub, an **multi-country alliance** of patient advocacy organizations, on various awareness campaigns.



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



# MOVING FORWARD IN AWARENESS

## NATIONAL HEART MONTH

### #NationalHeartMonth

- Nearly 2,000 people shared facts about cardiomyopathy, and 14,000 people viewed CCF's social media posts.
- Families and friends wore red, handed out CCF valentines, and distributed materials about cardiomyopathy.
- CCF hosted a Facebook Live event with teens Bethany and Hannah of Heartcharged to talk about living with cardiomyopathy.
- CCF participated in the Heart Failure Society of America's Twitter chat on the topic of heart transplants.
- Dr. Rakesh Singh, Medical Director of Heart Failure and Transplantation at Hassenfeld Children's Hospital at NYU Langone was the featured webinar guest on CCF's "Living with Heart Failure" webinar.
- 150 guests celebrated National Heart Month at CCF's Night for a Cure charity poker tournament.





# MOVING FORWARD IN AWARENESS

## CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

### #KnowYourHeart

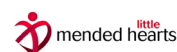
- CCF and 20 national partners urged families to learn the signs, symptoms, and risk factors of cardiomyopathy.
- Newsletter articles educated the public on the importance of knowing one's family heart history.
- Over 7,000 supporters liked and shared our posts with over 53,000 people viewing the posts.
- Jami N. Gross, PhD presented a webinar, "Emotional Side Effects of Cardiomyopathy in Teens."
- For the 7th year, supporters across the country organized Walk for a Cure events to raise awareness of pediatric cardiomyopathy in their community.
- CCF Regional Ambassador, Aly Pearce, was featured in a blog post at the Institute for Patient Access.



## AWARENESS MONTH

### PARTNERS

American Academy  
of Pediatrics



**MOVING  
FORWARD**



**IN PATIENT &  
FAMILY SUPPORT**

# MOVING FORWARD IN PATIENT & FAMILY SUPPORT

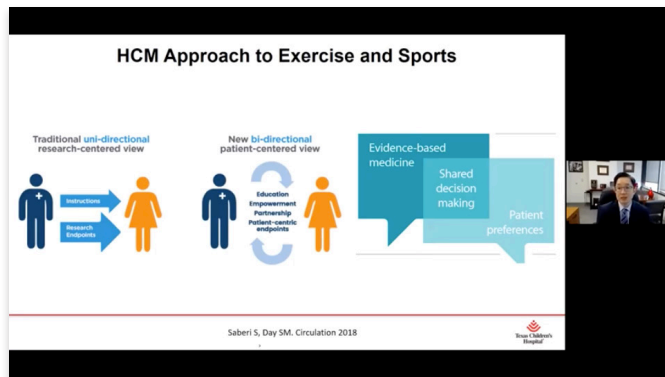
CCF focused on **online connections** and **virtual meetings** to support affected families worldwide during the pandemic.

- Overall, 7,000 families from 92 countries are served by CCF.
- 400 new members joined CCF, increasing the membership base to 4,000.
- The CCF Connect Community on Facebook grew to over 2,100 members.
- A membership survey was conducted to ensure that CCF priorities and actions are in line with family needs.
- A new Regional Ambassador Program was created to increase family engagement and strengthen CCF's community of patients. This leadership program consists of eight parent ambassadors from across the U.S. who assist in the development of family resources, build relationships with local families and physicians, and raise awareness of cardiomyopathy in their community.



# MOVING FORWARD IN PATIENT & FAMILY SUPPORT

- **5 educational webinars** featured leaders in the field of cardiomyopathy.



## UPDATES IN LIVING WITH HEART FAILURE FOR THE PEDIATRIC CARDIOMYOPATHY COMMUNITY

Rakesh Singh, MD, MS  
Hassenfeld Children's Hospital at NYU Langone  
February 18, 2021

## HEART FAILURE AND VENTRICULAR ASSIST DEVICES

Neha Bansal, MD  
Children's Hospital of Montefiore  
May 5, 2021

## THE ROLE OF RESEARCH IN IMPROVING CARE FOR PATIENTS WITH PEDIATRIC CARDIOMYOPATHY

Daphne Hsu, MD  
Children's Hospital at Montefiore  
August 17, 2021

## EMOTIONAL SIDE EFFECTS OF CARDIOMYOPATHY IN TEENS

Jami N. Gross, PHD  
Children's Mercy Kansas City  
September 24, 2021

## HYPERTROPHIC CARDIOMYOPATHY AND YOUTH SPORTS PARTICIPATION

Jeffrey Kim, MD  
Texas Children's Hospital  
December 2, 2021



# MOVING FORWARD IN PATIENT & FAMILY SUPPORT

- CCF collaborated with **Transplant Families** during National Pediatric Transplant week to present at their April Pediatric Transplant Conference.



- CCF was featured in **2 podcasts**:

“Into the Flow” featured CCF medical advisor Dr. Steven Lipshultz on the formation of the Pediatric Cardiomyopathy Registry and the role CCF played in furthering care for children with cardiomyopathy.

“Losing a Child” featured CCF Ambassador Myesha Bruce on how CCF’s resources and online community helped her overcome her loss.





**MOVING  
FORWARD**



**IN FUNDRAISING  
& FINANCIALS**

# MOVING FORWARD ON FUNDRAISING & FINANCIALS

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 150 guests attended CCF's 13th annual Night for a Cure on February 10. The virtual charity poker event raised \$120,000 and was hosted by Tom Wheaton, CEO of Faded Spade Poker and poker professionals Matt Berkey and Jamie Kerstetter. WSOP poker legend Phil Gordon made a surprise guest appearance.



## GOLF FOR A CURE

CCF was back on the course for the 18th annual Golf for a Cure at the historic Ridgewood Country Club in northern New Jersey. The July 26 event raised over \$245,000 and was supported by 38 sponsors and 140 attendees.



# MOVING FORWARD ON FUNDRAISING & FINANCIALS

## WALK FOR A CURE

Walkers from around the country organized 50 virtual walk teams in 10 states to celebrate Children's Cardiomyopathy Awareness Month in September.



## 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.





# MOVING FORWARD ON FUNDRAISING & FINANCIALS

## FAMILY FUNDRAISERS

Families impacted by cardiomyopathy planned creative fundraisers to support CCF's programs, including a 5k run in Alaska, a beach walk in Australia, and a golf outing in Alabama.



# 2021 FINANCIAL SUMMARY

Fiscal year ending December 31, 2021

## STATEMENT OF FINANCIAL POSITION

### ASSETS

Cash & Cash Equivalents	\$947,424
Investments	\$2,028,877
Intangible Net Assets	\$18,342
<b>TOTAL ASSETS</b>	<b>\$2,994,643</b>

### LIABILITIES + NET ASSETS

Accounts Payable & Accrued Expenses	\$37,892
SBA EIDL Loans	\$149,900
Unrestricted Net Assets	\$2,781,851
Restricted Net Assets	\$25,000
<b>TOTAL LIABILITIES + NET ASSETS</b>	<b>\$2,994,643</b>

## STATEMENT OF ACTIVITIES

### REVENUE

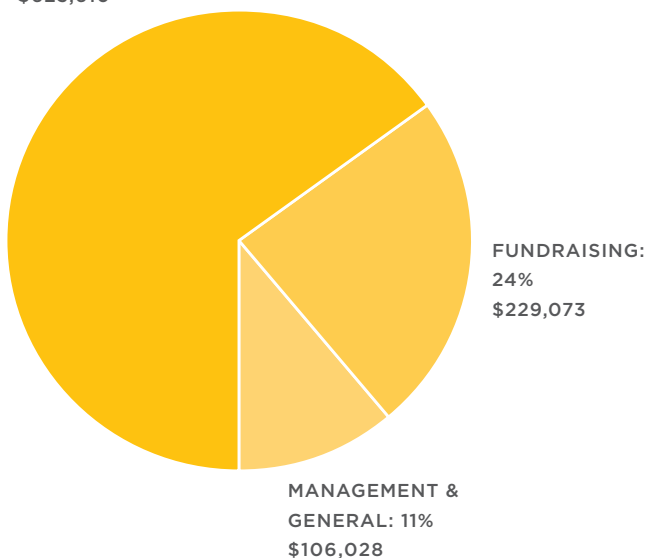
Contributions	\$409,478
Fundraising + Special Events	\$360,406
Net Investment Return	\$395,363
PPP Loan Forgiveness	\$151,716
<b>TOTAL REVENUE</b>	<b>\$1,316,963</b>

### EXPENSES

Programs & Services	\$623,610
Management & General	\$106,028
Fundraising	\$229,073
<b>TOTAL EXPENSES</b>	<b>\$958,711</b>
<b>NET INCOME</b>	<b>\$358,252</b>

## TOTAL EXPENSES

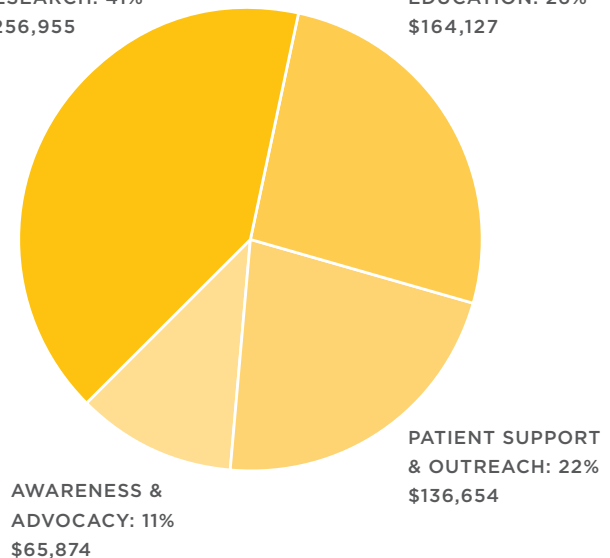
PROGRAMS & SERVICES: 65%  
\$623,610



## EXPENSES BY PROGRAM & SERVICES

RESEARCH: 41%  
\$256,955

EDUCATION: 26%  
\$164,127





# 2021 TOP DONORS

We extend our **heartfelt thanks** to all who have contributed to the Children's Cardiomyopathy Foundation this year. The following corporations, foundations, and individuals made contributions of \$500 or more to the Foundation in 2021.

## DONORS \$10,000 AND OVER

American Legion Child Welfare Foundation  
The Bauer Foundation  
Bristol Myers Squibb Company  
Cytokinetics  
Rob Gallivan  
Goldman Sachs & Co.  
Kathleen Lenihan  
MacKay Shields  
Macquarie Group Foundation  
Michael & Leslie Petrick  
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Senator Investment Group  
Tenaya Therapeutics

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

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UBS  
US Bank  
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## DONORS \$4,999-\$1,000

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# 2021 TOP DONORS

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Pieter van der Heide  
Van der Linden Family Foundation  
Wells Fargo  
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Dick & Maggie Yue  
Frederick Zuck

## DONORS \$999-\$500

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David Breazzano  
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Dale Kleszynski

# 2021 TOP DONORS

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