STRENGTH + RESILIENCE

2020 ANNUAL REPORT
CHILDREN’S CARDIOMYOPATHY FOUNDATION
CONTENTS

Founder’s Letter ................................................................. 3
Foundation Overview .......................................................... 4
Research .................................................................................. 6
Education ................................................................................ 10
Advocacy ................................................................................ 13
Awareness ............................................................................. 16
Patient & Family Support ...................................................... 20
Fundraising & Financials ....................................................... 25

A CAUSE FOR TODAY . . .
A CURE FOR TOMORROW
Dear Friends,

2020 has been a year like no other. It has been eventful and challenging with a global pandemic, racial injustice, and political tensions in the background. Even with these disruptions, the Children’s Cardiomyopathy Foundation (CCF) remained focused on its core mission of supporting children with cardiomyopathy. We adapted to the circumstances with strength and resilience—coming together during a period of uncertainty and isolation. As we reflect on this turbulent year, we are grateful that we have weathered the storm and are able to continue serving the pediatric cardiomyopathy community.

In spite of this year’s obstacles, we were able to make an impact in several areas:

- **COVID-19 Response:** CCF quickly responded to conflicting information on COVID-19 by providing reliable and pertinent health information on our website and taking the initiative to collect data on the impact of COVID-19 on children with cardiomyopathy.

- **Education:** Two new educational materials were developed: an Arrhythmogenic Cardiomyopathy insert and a Pediatric Heart Failure Guidebook in collaboration with specialists from 13 medical centers across the U.S. and Australia. Additionally, both resources were translated into Spanish.

- **Advocacy:** Working with family members and legislators, CCF took the lead in getting two cardiomyopathy-related bills introduced. The SAFE PLAY Act was introduced during National Heart Month in the House and Senate, and the Cardiomyopathy HEARTS Bill was a bipartisan bill introduced in the House of Representatives during Sudden Cardiac Arrest Month.

In 2020, we persevered and were able to adapt thanks to our donors and supporters. We stayed strong and forged ahead with projects to support the patient/family and medical/healthcare community.

Sincerely,

Lisa Yue
Founding Executive 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, and to support families whose children are 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)

BOARD OF DIRECTORS

Lisa Yue  
President

Brian Nold  
Treasurer

Raymond Yue  
Secretary

Won Choi

Carney Hawks

Carolyn Kong

Eddie Yu

MEDICAL ADVISORS

Wendy Chung, M.D., Ph.D.  
Columbia University Medical Center

Steve Colan, M.D.  
Boston Children’s Hospital

Daphne Hsu, M.D.  
Children’s Hospital at Montefiore

Steve Lipshultz, M.D.  
University at Buffalo School of Medicine and Biomedical Sciences

Shelley Miyamoto, M.D.  
Children’s Hospital Colorado

Joseph W. Rossano, M.D., M.S.  
Children’s Hospital of Philadelphia

Jeff Towbin, M.D.  
Le Bonheur Children’s Hospital

CCF STAFF

Lisa Yue  
Founding Executive Director

Lisa Maher  
Director of Development & Communications

Caryn Anatriello  
Director of Patient Outreach & Support

Cindy Andrake  
Manager of Family Support

Janine Burke  
Manager of Medical Outreach

Lauren Zenreich  
Administrative Manager & Bookkeeper
The Children’s Cardiomyopathy Foundation (CCF) responded to the COVID-19 pandemic by providing **reliable sources of information** to families of children with cardiomyopathy and taking the **initiative to collect data** on the impact of this novel virus on children with cardiomyopathy.

**COVID-19 RESOURCES**

**WEB RESOURCES**
- Provided relevant information on CCF Connect and a dedicated webpage of resources.

**WEBINARS**
- Hosted 4 webinars for the CCF community.
  - *COVID-19 Updates for Cardiomyopathy Families*
    Daphne Hsu, M.D. & Neha Bansal, M.D.
  
  - *Research Study Update: Psychological Stress in Pediatric Cardiac Patients and Caregivers During COVID-19*
    Melissa Cousino, Ph.D. & Kurt Schumacher, M.D., M.S.
  
  - *Emotional Considerations for Pediatric Cardiomyopathy Families During COVID-19 and Beyond*
    Debra Lefkowitz, Psy.D.
  
  - *COVID-19 Information and Updates*
    Daphne Hsu, M.D. & Margaret Aldrich, M.D.

**SURVEYS**
- Distributed an online survey to 2,260 patients and 590 physicians. Findings were shared with the medical community to provide **baseline information and guidance** on COVID-19 treatment for children.
- Collaborated with the University of Michigan on an international COVID-19 survey to **determine the impact** on congenital heart disease care and related psychological stress.
STRENGTH 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.

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

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

**MEDICAL PRESENTATIONS**

“Perceived Barriers to Medication Adherence in Pediatric Cardiomyopathy: Child & Parent Perspectives”
Mirbod V., Wijesekera K., Aralis H., Barrera W., Sinclair M., Kiff C., Alejos J., Lester P.

*American Psychological Association Convention*
Philadelphia, PA, August 2020

“Distinct Biomarker Profiles for Pediatric and Adult Dilated Cardiomyopathy”

*American Heart Association Scientific Sessions*
Virtual, November 2020

“Balancing Exercise Risk with Cardiovascular Health in Pediatric Hypertrophic Cardiomyopathy”

*American Heart Association Scientific Sessions*
Virtual, November 2020

**TOP TO BOTTOM:**
Patricia Lester, M.D.
Kathleen Simpson, M.D.
Jennifer Conway, M.D., F.R.C.P.C.
SCIENTIFIC AND MEDICAL PUBLICATIONS

“Cardiovascular Diseases in Survivors of Childhood Cancer”
Bansal N., Blanco J.G., Sharma U.C., Pokharel S., Shisler S., Lipshultz S.E.
*Cancer and Metastasis Reviews*  
February 2020

“Reversible Mitochondrial Fragmentation in iPSC-Derived Cardiomyocytes from Children With DCMA, a Mitochondrial Cardiomyopathy”
*Canadian Journal of Cardiology*  
April 2020

“Elevated Heart Rate and Survival in Children with Dilated Cardiomyopathy: A Multicenter Study from the Pediatric Cardiomyopathy Registry”
Rossano J., Kantor P.F., Shaddy R.E., Shi L., Wilkinson J.D., Jefferies J.L., Czachor J.D., Razoky H., Wirtz H.S., Depre C., Lipshultz S.E.
*Journal of the American Heart Association*  
July 2020

“Distinct Biomarker Profiles for Pediatric and Adult Dilated Cardiomyopathy” Abstract
*Circulation*  
November 2020

“Impact of the COVID-19 Pandemic on Congenital Heart Disease Care and Emotional Wellbeing”
Cousino M., Pasquali, S., Romano, J., Norris, M., Yu, S., Reichle, G., Lowery, R., Viers, S., Schumacher, K.
*Cardiology in the Young*  
December 2020
CCF continues its research partnership with the American Heart Association, American Academy of Pediatrics, North American Pediatric Cardiomyopathy Registry, and the Kyle John Rymiszewski Foundation to accelerate research on pediatric cardiomyopathy.

**AMERICAN HEART ASSOCIATION**

**Melanie R. F. Gropler, M.D.** of Washington University School of Medicine in St. Louis, Mo. was selected by the American Heart Association Young Hearts Council as the 2020 Early Career Investigator for her CCF-funded work on children with dilated cardiomyopathy. This award recognizes young physicians conducting high quality research on pediatric cardiovascular disease.

**KYLE JOHN RYMISZEWSKI FOUNDATION**

**Suzanne M. Mone, M.D., M.S.** was awarded the Children’s Cardiomyopathy Foundation and Kyle John Rymiszewski Foundation 2020 Research Scholarship to work on studies with the Pediatric Cardiomyopathy Registry. The scholarship offers a mentored fellowship that trains clinical researchers interested in studying hypertrophic cardiomyopathy in children.
STRENGTH IN EDUCATION
STRENGTH IN EDUCATION

Throughout the year, CCF updated the medical community on research publications, medical meetings, funding opportunities, and new family resources related to pediatric cardiomyopathy.

- **42 Cardiomyopathy Centers of Care** in the U.S. and Canada were recognized during Children’s Cardiomyopathy Awareness Month. These specialty centers were recognized for their high-quality cardiac care and comprehensive approach to treating children with cardiomyopathy.

- Due to recommendations issued by the Centers for Disease Control on large gatherings, many live conferences were cancelled, postponed, or changed to virtual events. As a result, CCF limited its presence to 3 conferences in 2020.

  *Parent Heart Watch*
  *Pediatric Congenital Cardiovascular Disease Annual Update*
  *Rady Children's Hospital Annual Heart Party*

- **CCF’s 5th International Conference in Children** planned for April 30–May 1 in Washington D.C. was postponed to 2021 due to travel restrictions placed on medical professionals and health concerns associated with COVID.

  “Through CCF, I learned how important it is to find a cardiologist who specializes in pediatric cardiomyopathy. I also found the support system that I needed to help with the struggles of having a child with this disease.”
CCF developed **two new educational resources** to meet the informational needs of more families.

**PEDIATRIC HEART FAILURE GUIDEBOOK**

Pediatric heart failure specialists from 13 medical centers across the U.S. and Australia collaborated with CCF to develop *Pediatric Heart Failure: A Guide for Patients and Families*. The comprehensive guidebook, funded in part by Novartis, serves as a companion piece to CCF’s *Pediatric Heart Transplants: A Guide for Patients and Families*.

**ARRHYTHMOGENIC CARDIOMYOPATHY INSERT**

To complete the “Understanding Pediatric Cardiomyopathy” series of patient materials, an “Understanding Arrhythmogenic Cardiomyopathy” insert was developed with physician input. The new piece is being distributed to CCF’s network of hospitals throughout the U.S.

“Not only did CCF provide us with support, but they offered a wealth of resources that made our journey easier. Along the way, CCF’s information gave us hope.”
STRENGTH IN ADVOCACY
At the Federal level, CCF built relationships with key Congressional leaders to elevate pediatric cardiomyopathy on their legislative agenda. Support for cardiomyopathy legislation was overshadowed by congressional focus on larger issues such as the COVID outbreak, an economic recession, and a contentious impeachment and election process.

- **CCF Works with Legislators to Introduce SAFE PLAY Act during National Heart Month.** During National Heart Month in February, CCF worked with Senator Robert Menendez (D-NJ) and Representative Bill Pascrell (NJ-09) to introduce the Supporting Athletes, Families and Educators to Protect the Lives of Athletic Youth (SAFE PLAY) Act. The bill includes important provisions that protect student athletes from sports-related medical emergencies such as sudden cardiac arrest, which is commonly associated with cardiomyopathy.

- **CCF Takes the Lead in Supporting the Cardiomyopathy HEARTS Bill.** CCF is taking an active role in supporting the bipartisan Cardiomyopathy HEARTS Act (H.R. 6166) introduced on March 10 by Reps. Andy Kim (NJ-03) and Andy Barr (KY-06). The Cardiomyopathy HEARTS Act calls for the establishment of surveillance research on cardiomyopathy across the lifespan and the development of educational materials targeted to school administrators, educators, and families.

“The cardiomyopathy bills can save lives and help families, like mine, who have been impacted by the disease.”
Sarah Foye of New Jersey was nominated by CCF to participate as a consumer advocate in the review of research applications submitted to the Department of Defense Congressionally Directed Peer Reviewed Medical Research Program. Foye, along with Melissa McQueen, Joseph Hillenburg, and Wendy Borsari—all CCF nominated parents—worked with prominent scientists to determine how research funds appropriated by Congress should be spent.

**Department of Defense Peer Reviewed Medical Research Program.** Due to CCF’s advocacy efforts in Washington D.C., cardiomyopathy was included in the Department of Defense Peer Reviewed Medical Research Program for FY21, creating an additional source of federal funding for cardiomyopathy research studies. $370 million will be directed to the Peer Reviewed Medical Research Program.
STRENGTH IN AWARENESS
CCF joined the Global Heart Hub with other patient advocacy organizations from the U.S., Australia, Spain, Germany, Italy, and the Netherlands. The International Cardiomyopathy Council was formed to develop an international campaign in 2021 to raise awareness of the disease and encourage individuals to seek medical help where appropriate.

CCF focused on raising awareness of pediatric cardiomyopathy during National Heart Month in February and Children’s Cardiomyopathy Awareness Month in September.
STRENGTH IN AWARENESS

NATIONAL HEART MONTH
#nationalheartmonth

- Over 500 people shared facts about cardiomyopathy, and nearly 9,000 people viewed CCF posts.

- Families and friends wore red, handed out CCF valentines, and distributed materials on cardiomyopathy.

- Letters were sent to congressional members in Washington D.C. in support of cardiomyopathy-related legislation.

- 8 Bake for a Cure events were hosted by CCF families in their communities.

- 235 guests celebrated National Heart Month at CCF’s Night for a Cure event in New York City.
CHILDREN’S CARDIOMYOPATHY AWARENESS MONTH

#Knowyourheart

- 17 health and school national partners, along with CCF, urged families to learn the **signs, symptoms, and risk factors** of cardiomyopathy.

- **Hundreds of social media postings** and newsletter articles **educated** the public on the importance of knowing one’s family heart history.

- **A webinar featuring Mike Papale** from In a Heartbeat spoke about his personal experience of **surviving** a cardiac arrest and unexpectedly being diagnosed with cardiomyopathy as a teenager.
RESILIENCE IN PATIENT & FAMILY SUPPORT
RESILIENCE IN PATIENT & FAMILY SUPPORT

In a year when self-isolation and social distancing was necessary, CCF emphasized online connections and reached out to more affected families worldwide.

- Welcomed **250 new members**, increasing CCF’s community to over 3,300 members from 78 countries
- **CCF’s Family Facebook Community Group** grew to over 1,900 members, generating 650 posts and 7,000 comments annually
- **CCF Connect**, an online community, has grown to nearly 600 active members
- Responded to over **760 requests for information** through phone and email

“While we were waiting for our son’s new heart, we participated in CCF’s online discussions and drew from CCF’s educational resources so that we could become better informed. Having these resources proved to be invaluable.”
CCF offered opportunities for families to become more informed on living with cardiomyopathy.

- Launched new mobile friendly website with updated copy and new reference sheets on genetic mutations and genetic testing.
- Developed new Hospital Care and Bereavement guidebooks.
RESILIENCE IN PATIENT & FAMILY SUPPORT

- Scheduled **10 educational webinars** featuring **cardiomyopathy leaders** in the field.

**Updates in Medical Management in Pediatric Cardiomyopathy**
Beth Kaufman, M.D.
Lucile Packard Children’s Hospital at Stanford

**Q&A on Cardiac Electrophysiology**
Robert Pass, M.D.
Mount Sinai Kravis Children’s Hospital

**COVID-19 and Pediatric Cardiomyopathy: Information and Updates**
Daphne Hsu, M.D. & Margaret Aldrich, M.D.
Children’s Hospital of Montefiore

**Financial Considerations: Top Things to Help with Transplant Finances**
Rick Lofgren, M.B.A.
Children’s Organ Transplant Association
Allison Pela
Phoenix Children’s Hospital

**Educational Considerations for Your Child: IEP/504 Information For Every Transplant Family**
Stacy Hillenburg, M.Ed.
Right Start Pediatric Therapies

**Emotional Considerations for Pediatric Cardiomyopathy Families During COVID 19 and Beyond**
Debra Lefkowitz, Psy.D.
Children’s Hospital of Philadelphia

**COVID-19 Updates for Cardiomyopathy Families**
Daphne Hsu, M.D. & Neha Bansal, M.D.
Children’s Hospital of Montefiore

**Research Study Update: Psychological Stress in Pediatric Cardiac Patients and Caregivers During COVID-19**
Melissa Cousino, Ph.D. & Kurt Schumacher, M.D., M.S.
C.S. Mott Children’s Hospital

**Supporting Your Diagnosed Child: Suggestions from a Patient**
Mike Papale
In A Heartbeat

**Updates in Genetic Testing Related to Pediatric Cardiomyopathy**
Wendy Chung M.D., Ph.D. & Teresa Lee, M.D.
New York Presbyterian Morgan Stanley Children’s Hospital
RESILIENCE IN PATIENT & FAMILY SUPPORT

- Worked with CCF medical advisors to update the Understanding Pediatric Cardiomyopathy series of materials and increased offering of Spanish language materials.

- CCF collaborated with Transplant Families during National Pediatric Transplant week in April to offer two webinars geared towards pre- and post-transplant families.

- Developed 3 new fact sheets for the CCF Connect online community and updated CCF’s Heart Camps Resource sheet to include 2020 Virtual Heart Camps.

Emergency Identification Resources
Exercise & Sports Information Updates
Travel Considerations with Cardiomyopathy

April 22–26 is National Pediatric Transplant Week

Travel Considerations for Pediatric Cardiomyopathy

When traveling a child with cardiomyopathy should always be prepared for a cardiac emergency. It is recommended to plan your trip and to have an updated understanding of the travel location’s medical resources. It is advised to speak with your child’s cardiologist before major trips, but there are some helpful tips to remember if you travel:

Before Your Trip
- Confirm with a doctor that your child is in adequate condition to travel and participate in activities.
- Obtain a letter from your child’s cardiologist explaining your child’s medical condition, his/her medications, and any surgical procedures performed in case you need to show it to an attending physician.
- Ask your doctor to recommend a medical center or doctor near where you will be visiting. Consider traveling only to areas with good access to medical care.
- Load photos of medication and diagrams on your phone to help communicate your child’s heart condition in the case there are any language barriers on your trip.
- Pack more medication than you need in case some is spilled or lost.
- If vaccinations are required for the trip, talk to your child’s doctor about what guidance to follow and whether or not vaccinations will interfere with his/her medications.
- Check with your airlines to verify carry-on requirements for medications. Always label medications and keep a medication list accessible on your phone. Contact the airport and airline ahead of time to let them know of any accommodations you may need.
- Pack copies of all necessary medical documents such as major tests, explanation of diagnosis, immunization schedule, medication prescriptions, automatic implantable cardioverter defibrillator (AICD) guidebook, and your child’s patient card.
- If going on a cruise or attending summer camp, contact the camp’s principal or camp doctor to make arrangements. If you need to travel with your child on a cruise, contact the cruise line’s medical service line. Load a list of the child’s medications and medical service phone number on your phone.
FOCUS ON FUNDRAISING & FINANCIALS
CCF’s Cure events bring families and supporters together to raise funds for CCF-directed research and education projects. CCF’s fundraising events were severely impacted by prolonged restrictions on in-person gatherings.

Night for a Cure was CCF’s last in-person event before nationwide lockdowns went into effect. From March, CCF pivoted to virtual events for the remainder of 2020.

2020 FUNDRAISERS

**NIGHT FOR A CURE**

More than 235 guests attended CCF’s 12th Annual Night for a Cure on February 5. The event was held at the art deco-inspired Edison Ballroom in New York City. The event raised more than $240,000 for research and education initiatives.

**WALK FOR A CURE**

Walkers from around the country organized virtual walk teams during Children’s Cardiomyopathy Awareness Month in September. More than $16,000 was raised to sustain CCF’s family resources and support services.

**BAKE FOR A CURE**

8 Bake for a Cure events took place during National Heart Month to raise community awareness and research funding for pediatric cardiomyopathy.
FAMILY FUNDRAISERS

Families got creative during the year planning more outdoor and virtual events to keep their community and network engaged.

SUPER HEART HEROES AUCTION

MOMMY & ME DAY

NEIGHBORHOOD YARD SALE
2020 FINANCIAL SUMMARY

FISCAL YEAR ENDING DECEMBER 31, 2020

STATEMENT OF FINANCIAL POSITION

ASSETS
Cash & Cash Equivalents $1,146,868
Investments $1,440,182
Intangible Net Assets $51,163
TOTAL ASSETS $2,638,213

LIABILITIES + NET ASSETS
Accounts Payable & Accrued Expenses $12,500
Refundable Advance $77,114
SBA EIDL Portion $100,000
Unrestricted Net Assets $2,349,918
Restricted Net Assets $98,681
TOTAL LIABILITIES + NET ASSETS $2,683,213

STATEMENT OF ACTIVITIES

REVENUE
Contributions $332,466
Fundraising + Special Events $229,367
Net Investment Return $292,878
TOTAL REVENUE $854,711

EXPENSES
Programs & Services $637,631
Management & General $103,901
Fundraising $187,019
TOTAL EXPENSES $928,551

NET INCOME ($73,840)

TOTAL EXPENSES
PROGRAMS & SERVICES: 69% $637,631
MANAGEMENT & GENERAL: 11% $103,901
FUNDRAISING: 20% $187,019

EXPENSES BY PROGRAM & SERVICES
RESEARCH: 43% $276,188
PATIENT SUPPORT & OUTREACH: 17% $109,035
EDUCATION & AWARENESS: 23% $146,708
ADVOCACY: 17% $105,700
We extend our heartfelt thanks to all who have contributed to the Children’s Cardiomyopathy Foundation this year. The following corporations, foundations, and individuals have made significant contributions to the Foundation in 2020.

**DONORS $10,000 AND OVER**
- Amgen USA
- Megan Cosby & EAC Foundation
- Cytokinetics
- MacKay Shields
- Macquarie Group Foundation
- Heather Riley

**DONORS $9,999–$5,000**
- Dan & Stacie Allen
- Bank of America Merrill Lynch
- Cantor Fitzgerald Securities
- Benji Cheung
- Christopher DeLong
- Lucas Detor
- Goldman, Sachs & Co.
- Carney & Melissa Hawks
- Invitae Corporation
- Kyle John Rymiszewski Foundation
- Kathleen Lenihan
- Geoffrey & Kearby Parker
- Alexander Reiss
- Ian Sandler
- Adam Savarese
- Senator Investment Group
- Stifel Nicolaus & Company
- TP ICAP
- Wells Fargo Securities

**DONORS $4,999–$1,000**
- Akin, Gump, Strauss, Hauer & Feld
- Edward Almenara
- Angel Island Capital Management
- Angelo, Gordon & Co.
- Barclays Capital
- Evan & Beth Bernardi
- Andrew Brenner
- Justin Brody
- Edward Burdick
- William & Holly Caggiano
- Nicholas Casesa
- Christopher Chang
- Won Choi
- Citigroup Global Markets
- Colbeck Capital Management
CCF 2020 TOP DONORS

Eric Cole
Mark Colm
Emil Costa
Martin Cummins IV
David & Carol Davis
DeFeo Materials
Deutsche Bank Securities
Edward Farscht & Lynn Jaeger
David Feldman
Frank Fiorito
Robert Franz
Gibson, Dunn & Crutcher
GLC Advisors & Co.
Eric Guevara
Brian Hewitt
HG Vora Capital Management
HSBC Securities (USA)
Jefferies
Steven Krause
Owen Lipp
Kristin Lobron
Macquarie Capital
Mike & Kristi McCluskey
Glenn McDermott
Brian McGowan
Lee Millstein
Morgan Stanley
MUFG Securities Americas
Brian Mullins
Nomura Securities International
Brett Nunziata
Ronald Ory
Douglas Pardon
Israel Pollack
RBC Capital Markets
Rebeca Romero Rainey
Edward & Krista Renenger
Richards Kibbe & Orbe
Riva Ridge Capital Management

Donald & Mary Lou Rossi
RW Baird
Marc Schwartz
Scotiabank
Jason & Heidi Scribner
Scott & Sarah Snell
Robert Stobo
Michael Tama
Trumid Financial
UBS Investment Bank
Van der Linden Family Foundation
Matthew Williams
Andrew Wise
Eddie Yu & Lisa Yue
Dick & Maggie Yue
Raymond & Evelyn Yue
Richard Zentko