

MAKING AN IMPACT



2019 ANNUAL REPORT
CHILDREN'S CARDIOMYOPATHY FOUNDATION

CONTENTS

Founder’s Letter3

Organizational Overview..... 4

Research5

Education.....12

Advocacy & Awareness.....15

Patient & Family Support..... 20

Financials..... 26

A CAUSE FOR TODAY . . .

A CURE FOR TOMORROW



FOUNDER'S LETTER



Dear Friends,

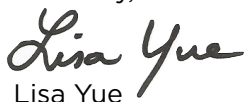
The Children's Cardiomyopathy Foundation has always strived to improve the lives of children with cardiomyopathy and support the families and physicians involved in their care. As we reflect on this year's achievements, we are proud of the impact that our work has had on the cardiomyopathy community.

A FEW HIGHLIGHTS FROM 2019:

- **RESEARCH:** CCF's medical advisors advocated for the American Heart Association to publish an official scientific statement on pediatric cardiomyopathy to declare what is currently known about the disease in children and identify gaps in knowledge.
- **EDUCATION:** In October, we hosted our first regional family conference, *Living with Cardiomyopathy Family Conference*, in partnership with Children's Hospital of Philadelphia and Penn Medicine. With over 135 attendees, this event was well-received by patients, caregivers, and medical professionals.
- **PATIENT SUPPORT:** 5 new centers qualified as Cardiomyopathy Centers of Care, increasing the list of specialty centers to 42 children's hospitals across the U.S. We believe that advocating for consistency in care and promoting medical expertise has a far-reaching impact on the health outcomes of children with cardiomyopathy.
- **FAMILY SUPPORT:** In order to improve each family's hospital experience, we expanded the family care bag program to 10 new hospitals through the generous support of Global Genes. Families can find comfort in knowing that an organization like CCF is beside them in their journey with cardiomyopathy.

Thanks to our many donors and supporters, CCF's impact can be seen in both the patient/family and medical/healthcare communities. From expanding our research efforts and increasing awareness activities to growing our support network and expanding family resources, we will continue to deepen our impact in 2020 with new opportunities.

Sincerely,


Lisa Yue

Founding Executive President

ORGANIZATIONAL OVERVIEW

CCF's mission 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 non-compaction 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

James D. Wilkinson, M.D., M.P.H.
Monroe Carell Jr. Children's Hospital at Vanderbilt

CCF STAFF

Lisa Yue
Founding Executive Director

Lisa Maher
Manager of Development & Communications

Stormy Bell
Manager of Fundraising & Community Engagement

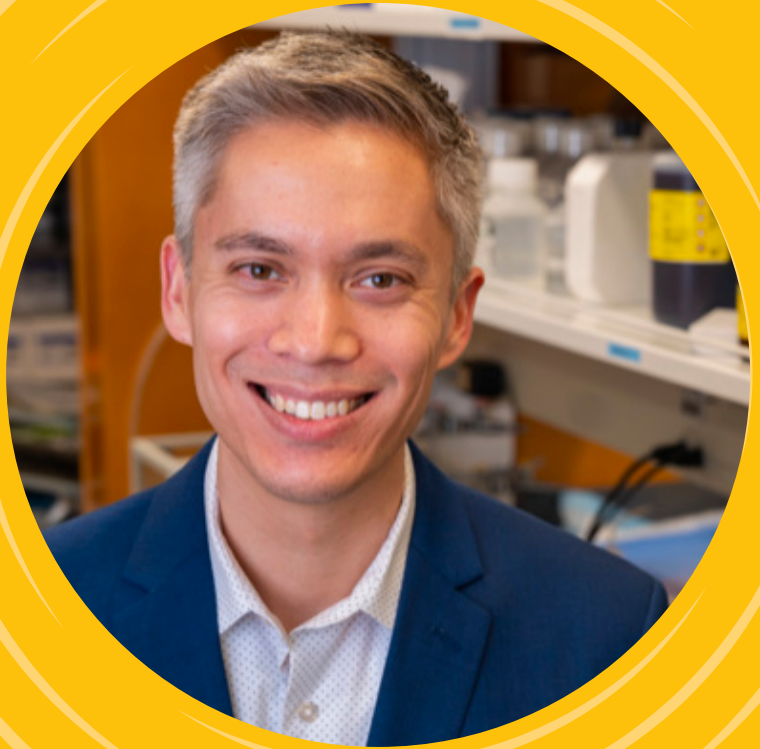
Gina Peattie
Patient Outreach & Support Director

Cindy Andrade
Manager of Family Support

Janine Burke
Manager of Medical Outreach

Lauren Zenreich
Administrative Manager & and Bookkeeper

IMPACT IN RESEARCH



“TWO OUT OF THREE CHILDREN
WITH CARDIOMYOPATHY
DO NOT HAVE A KNOWN CAUSE.”

**CCF IS COMMITTED TO FUNDING
MORE GENETIC RESEARCH STUDIES.**

IMPACT IN RESEARCH

Through CCF's research grant program, three new studies on pediatric cardiomyopathy were funded in 2019. CCF's research grant program provides seed funding to promising researchers for the testing of their hypotheses and for collecting data to secure longer-term funding from the National Institutes of Health.



Daniela Cihakova, M.D., Ph.D.
Therapy for Pediatric Cardiomyopathy by
Targeting IFN- γ /PD-L1 Pathway
JOHNS HOPKINS UNIVERSITY, BALTIMORE, MD



Jennifer L. Conway, M.D., F.R.C.P.C.
Cardiovascular Disease Risk Profile in Children
with Hypertrophic Cardiomyopathy
STOLLERY CHILDREN'S HOSPITAL,
ALBERTA, CANADA



Kathleen E. Simpson, M.D.
Distinction of Serum Biomarkers of Heart Failure
Between Children and Adults with Dilated
Cardiomyopathy
WASHINGTON UNIVERSITY, SAINT LOUIS, MO

IMPACT IN RESEARCH

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

“Novel Diagnostic Approaches to Arrhythmogenic Cardiomyopathies”
ASSOCIATION FOR EUROPEAN PEDIATRIC
CARDIOLOGY
Seville, Spain

“The Role of the Smear Test in Early Diagnosis: A Translational Perspective”
INTERNATIONAL SYMPOSIUM ON
ARRHYTHMOGENIC CARDIOMYOPATHIES
Zurich, Switzerland

“Distinction of Serum Biomarker Profiles Between Adults and Children in Heart Failure with Dilated Cardiomyopathy”
INTERNATIONAL SOCIETY OF HEART AND
LUNG TRANSPLANTATION
Orlando, FL.

“Secrets of Arrhythmogenic Cardiomyopathy”
HELLENIC CARDIOLOGY SOCIETY
SCIENTIFIC SESSIONS
Thessaloniki, Greece

“When do Humans Stop Generating New Heart Muscle Cells?”
THE EPIGENOME ACROSS THE LIFESPAN
CONFERENCE
University of Pittsburgh Clinical and
Translational Science Institute, Pa.

“Myocarditis is Associated with Damaging Variants in Cytoskeletal Cardiomyocyte Genes”
AMERICAN HEART ASSOCIATION
SCIENTIFIC SESSIONS
Philadelphia, Pa.

SCIENTIFIC AND MEDICAL PUBLICATIONS

“Distinction of Serum Biomarker Profiles Between Adults and Children in Heart Failure with Dilated Cardiomyopathy”
JOURNAL OF HEART AND LUNG TRANSPLANTATION

“Control of Cytokinesis by β -adrenergic Receptors Indicates an Approach for Regulating Cardiomyocyte Endowment”
SCIENCE TRANSLATIONAL MEDICINE

“Current Methods for the Maturation of Induced Pluripotent Stem Cell-Derived Cardiomyocytes”
WORLD JOURNAL OF STEM CELLS



IMPACT IN RESEARCH

Research partnerships are critical in CCF's work with the scientific and medical community. CCF's research partners include the American Heart Association, American Academy of Pediatrics, North American Pediatric Cardiomyopathy Registry, and the Kyle John Rymiszewski Foundation.

AMERICAN HEART ASSOCIATION

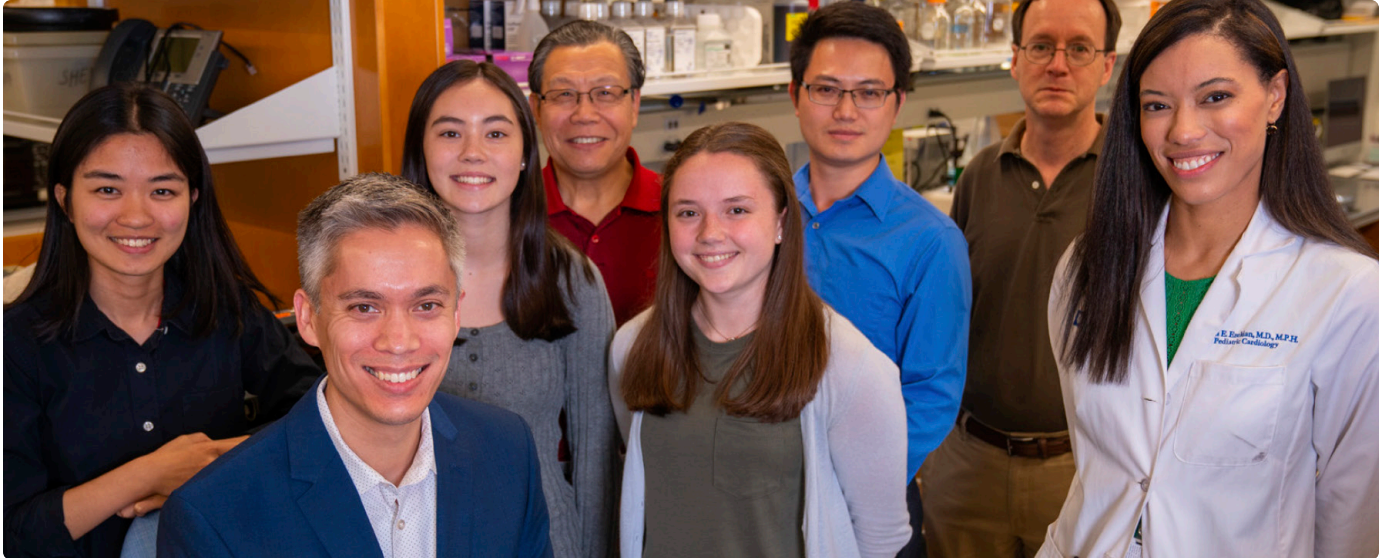
- Developed outreach program to the medical and scientific community to promote the Pediatric Cardiomyopathy Research Award, a CCF-AHA joint research grant program, to increase applications to the Career Development Grant, Innovative Project Award, and Transformational Project Award.
- Advocated for an official scientific statement on pediatric cardiomyopathy with CCF medical advisor, Steve Lipshultz, M.D., leading the writing committee for the American Heart Association publication.
- The consensus statement, "Cardiomyopathy in Children: Classification and Diagnosis," was published in Circulation and provides insights into the diagnosis and treatment of pediatric cardiomyopathy, as well as identifies future research priorities.



“Although we are able to provide effective treatments in many cases, research is urgently needed to understand the causes of the diseases so we can help children with cardiomyopathies live their best lives.”

**—STEVE LIPSHULTZ, M.D.
CHAIRMAN OF PEDIATRICS
UNIVERSITY AT BUFFALO
JACOBS SCHOOL OF MEDICINE &
BIOMEDICAL SCIENCES**

IMPACT IN RESEARCH



AMERICAN ACADEMY OF PEDIATRICS

- Second Pediatric Cardiomyopathy Early Career Research Award announced at the American Academy of Pediatrics National Conference in New Orleans, La.
- Andrew Landstrom, M.D., Ph.D. at Duke University will be funded by CCF for his study, Determining the Role of PRDM16 in Divergent Types of Pediatric Cardiomyopathy.
- Dr. Landstrom's research will center on identifying the unknown causes of cardiomyopathy in children with a goal of identifying other children who might be at risk before they get sick and to discover new therapies to treat pediatric cardiomyopathy.

“Support from AAP/CCF has allowed us to create much needed experimental tools, such as induced pluripotent stem cell-derived cardiac cells, to begin to understand how newly identified genetic variants cause disease.”

**—ANDREW P. LANDSTROM, M.D., PH.D.
ASSISTANT PROFESSOR OF
PEDIATRICS AND CELL BIOLOGY
DUKE UNIVERSITY SCHOOL OF MEDICINE**

IMPACT IN RESEARCH



NORTH AMERICAN PEDIATRIC CARDIOMYOPATHY REGISTRY

- 2 poster presentations at the American Society of Human Genetics Annual Meeting in San Diego, Calif.

“The Genetic Architecture of Pediatric Cardiomyopathy”

“Modeling the ACMG/AMP Guidelines as a Quantitative Approach”

- 2 publications in peer-review medical journals

“Upfront Dexrazoxane for the Reduction of Anthracycline-Induced Cardiotoxicity in Adults with Pre Existing Cardiomyopathy and Cancer”

CARDIO-ONCOLOGY

“Cardiac Biomarkers in Pediatric Cardiomyopathy: Study Design and Recruitment Results from the Pediatric Cardiomyopathy Registry”

PROGRESS IN PEDIATRIC CARDIOLOGY

- Gathered 33 pediatric cardiomyopathy experts from top medical centers for a 2-day meeting in February to review research priorities, discuss study findings, and determine new manuscripts development and research partnerships.



PCMR Administrative Center Team
Savannah, Ga.

IMPACT IN RESEARCH

KYLE JOHN RYMISZEWSKI FOUNDATION

- Collaborated to fund a two-year Pediatric Cardiomyopathy Research Scholar position to train promising young investigators.
- Neha Bansal, M.D. a sponsored Research Scholar, utilized her mentored research position at Children's Hospital of Michigan to study the genetics of cardiomyopathy in children.
- Published "Strategies to Prevent Anthracycline-Induced Cardiotoxicity in Cancer Survivors" in Cardio-Oncology.



"Due to CCF's Research Scholar Program I had the opportunity to pursue my research interest in pediatric cardiomyopathy and focus on my professional development to become a future leader in the field."

—NEHA BANSAL, M.D.

**ASSISTANT PROFESSOR OF PEDIATRICS
ALBERT EINSTEIN COLLEGE OF MEDICINE**



THE COSBY FAMILY

When David and Megan Cosby lost their six-month-old daughter, Ellis Ann, to dilated cardiomyopathy, they turned to the Children's Cardiomyopathy Foundation (CCF) for answers to the many questions they had about Ellis' heart condition.

The Cosby's were connected to CCF Medical Advisor, Dr. Wendy Chung of Columbia University Medical Center who consulted with them on their genetic testing results.

Dr. Chung educated the Cosby's about cardiomyopathy and reassured them that the doctors in their hometown could monitor and provide ongoing care for their two daughters, Harper and Mae Wells.

Today, the Cosby's are devoted to raising awareness of pediatric cardiomyopathy and have pledged their life-long support for CCF.

IMPACT IN EDUCATION



“CARDIOMYOPATHY IS A LEADING
CAUSE OF SUDDEN CARDIAC
ARREST IN THE YOUNG.”

**CCF IS EDUCATING COMMUNITIES
TO IDENTIFY HIGH-RISK CHILDREN.**

IMPACT IN EDUCATION



Throughout the year, CCF has reached out to thousands of medical and health care professionals with information on CCF's research programs, patient and family resources, and support services.

5 NEW CENTERS NAMED CARDIOMYOPATHY CENTERS OF CARE INCREASING TOTAL TO 42 CENTERS

- Children's of Alabama (Birmingham, Ala.)
- Arkansas Children's Hospital (Little Rock, Ark.)
- Children's Healthcare of Atlanta (Atlanta, Ga.)
- John R. Oishei Children's Hospital (Buffalo, N.Y.)
- Children's Mercy Kansas City (Kansas City, Mo.)

2,588 PIECES OF EDUCATIONAL MATERIALS DISTRIBUTED

- 1,353 pieces to hospitals, schools and parents
- 1,235 pieces at medical meetings and conferences



IMPACT IN EDUCATION

11 MEDICAL AND PATIENT CONFERENCES SUPPORTED

- Children's Hospital of Philadelphia Pediatric Cardiology Conference
- American College of Medical Genetics Annual Clinical Genetics Meeting
- International Society for Heart and Lung Transportation Scientific Sessions
- Western Society of Pediatric Cardiology
- ShaRe Cardiomyopathy Registry Affairs of the Heart: Living with Inherited Cardiomyopathy at Duke Heart Center and Yale New Haven Hospital
- American Association of Heart Failure Nurses
- Southeast Pediatric Cardiology Society
- Midwest Pediatric Cardiology Society
- Northeast Pediatric Cardiology Nurses Association
- Westchester Cardiovascular Symposium
- American Academy of Pediatrics National Conference



THE BRUCE FAMILY

Myesha Bruce felt confused, helpless, and alone when her 7-month-old daughter, Ahsha, unexpectedly died from hypertrophic cardiomyopathy. Seeking support, Myesha turned to the Children's Cardiomyopathy Foundation (CCF).

The CCF Connect online community welcomed Myesha, and CCF's staff helped her to connect with other families who had lost a child to cardiomyopathy. The support she received helped her through her grieving process.

Today, Myesha wants to help other families who might be in the same situation. She volunteers as a CCF Ambassador and distributes literature to doctors, health care centers, schools, and community organizations to increase awareness of cardiomyopathy.

IMPACT IN ADVOCACY & AWARENESS



“FOR EVERY \$100 SPENT ON HEART
DISEASE RESEARCH, LESS THAN
\$1 GOES TOWARD CARDIOMYOPATHY.”

**CCF ADVOCATES FOR INCREASED
FUNDING THROUGH CONGRESSIONAL
LEGISLATION AND FEDERAL AGENCIES.**

IMPACT IN **ADVOCACY & AWARENESS**

ADVOCACY

At the Federal level, CCF built relationships with key Congressional leaders to elevate pediatric cardiomyopathy in their legislative agenda.

- The Committee encourages the Centers for Disease Control and Prevention (CDC) to develop educational materials about the signs, symptoms, and risk factors of pediatric cardiomyopathy and make them available and easily accessible to the public.
- Included language in the Senate appropriations bill that commends the NIH National Heart, Lung, and Blood Institute for its commitment to the Pediatric Cardiomyopathy Registry.
- Endorsed federal legislation to expand coverage of genetic testing for children through Medicaid and to develop a study to address how genetic testing can improve care.
- Joined the National Health Council and the Defense Health Research Consortium to broaden CCF's presence in the federal advocacy space.
- Participated in efforts to increase federal funding for rare disease clinical research.



“The Committee understands that pediatric cardiomyopathy is a chronic disease of the heart that may, in severe cases, lead to heart failure and sudden death. The Committee encourages the Centers for Disease Control and Prevention (CDC) to develop educational materials about the signs, symptoms, and risk factors of pediatric cardiomyopathy and make them available and easily accessible to the public.”

**—SENATE LABOR-HHS-EDUCATION
APPROPRIATIONS ACT REPORT**

IMPACT IN **ADVOCACY & AWARENESS**

AWARENESS

CCF expanded its community reach to raise awareness of pediatric cardiomyopathy during National Heart Month in February and Children's Cardiomyopathy Awareness Month in September.



FEBRUARY: NATIONAL HEART MONTH

#NATIONALHEARTMONTH

- 35 states participated in CCF's Uniting Hearts Across America Awareness Challenge to increase public awareness.
- More than 50,000 people viewed CCF's Facebook posts and shared on average 33 times each.
- Increased social media followers and interactions by 10 percent.
- CCF families and friends wore red, handed out CCF valentines, and distributed CCF materials.
- 5 Bake for a Cure events hosted by CCF families in their communities.
- 315 guests celebrated National Heart Month at CCF's Night for a Cure charity poker event in New York City.

IMPACT IN ADVOCACY & AWARENESS



Children's Cardiomyopathy
Awareness Month

SEPTEMBER: CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

#KNOWYOURHEART

- 15 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 educating others on the importance of knowing one's family heart history.
- A webinar with Dr. Leigh Reardon from UCLA Mattel Children's Hospital
- *CCF Connect Expert Q&A* session with Dr. Melanie Everitt from Children's Hospital Colorado
- Podcast on Pediheart: Pediatric Cardiology Today with Dr. Robert Pass of Mount Sinai Kravis Children's Hospital

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH PARTNERS

American Academy
of Pediatrics



IMPACT IN ADVOCACY & AWARENESS



CCF AND AMERICAN CAMP ASSOCIATION: 7TH ANNUAL AED SCAVENGER HUNT

- The summer-long scavenger hunt encouraged campers to locate automated external defibrillators (AEDs) across the U.S. Cardiomyopathy is a leading cause of sudden cardiac arrest among youth, and using an AED can save a life if used quickly during a cardiac emergency.
- The awareness initiative asked campers to locate their camp AED, take a selfie, and post on social media outlets with the hashtag #ProtectKidsHearts.



Find your automatic external defibrillator (AED)



Make note of the location



Take a photo with the AED



Post to Instagram with #ProtectKidsHearts, name of camp, and location of the AED

IMPACT IN PATIENT & FAMILY SUPPORT



“AN ESTIMATED 100 CHILDREN ARE
DIAGNOSED WITH CARDIOMYOPATHY
EVERY MONTH IN THE UNITED STATES.”

**EVERYDAY, CCF PROVIDES
INFORMATION AND SUPPORT TO
NEWLY DIAGNOSED FAMILIES.**

IMPACT IN PATIENT & FAMILY SUPPORT



CCF'S REACH AND IMPACT

- Welcomed 171 new members, increasing CCF's community to 3,374 members from 76 countries
- Responded to 868 phone calls and emails for assistance
- Generated more than 133 discussion threads on CCF Connect's discussion forum
- Facebook CCF Youth Connect Group and Family Community Group grew to 1,823 members with 760 postings and 8,200 comments in the year.
- Scheduled 8 Meet the Expert Q&A sessions and webinars featuring cardiomyopathy leaders in the field.



RARE Patient Advocacy Summit,
San Diego, Ca.

IMPACT IN PATIENT & FAMILY SUPPORT



WEBINARS

- **LIVING WITH PEDIATRIC CARDIOMYOPATHY: EXERCISE & SPORTS GUIDELINES**
Danielle Burstein, M.D.
Children's Hospital of Philadelphia
- **PEDIATRIC TO ADULT CARE: TOOLS FOR TRANSITIONING**
Leigh Reardon, M.D.
UCLA Children's Hospital
- **EMOTIONAL CONSIDERATIONS FOR PEDIATRIC TRANSPLANT FAMILIES**
Melissa Cousino, Ph.D.
C.S. Mott Children's Hospital
- **BRIDGING TO TRANSPLANT: HEART FAILURE & VENTRICULAR ASSIST DEVICES**
David Peng, M.D.
C.S. Mott Children's Hospital

EXPERT Q & A

- **HEART TRANSPLANTS**
Aliessa Barnes, M.D.
Children's Mercy Hospital
- **EVALUATION AND DIAGNOSTIC SCREENING IN PEDIATRIC CARDIOMYOPATHY**
Melanie Everitt, M.D.
Children's Hospital Colorado
- **PEDIATRIC CARDIOMYOPATHY & GENETIC TESTING**
Robyn Hyland, M.S., C.G.C.
Boston Children's Hospital
- **MEDICATIONS & PEDIATRIC CARDIOMYOPATHY**
Justin Godown, M.D.
Monroe Carell Jr. Children's Hospital at Vanderbilt

IMPACT IN PATIENT & FAMILY SUPPORT

Expanded the Family Care Bag program to 15 new hospitals with funding from Global Genes.

PARTICIPATING HOSPITALS

- Children's Hospital of Philadelphia, Philadelphia, Pa.
- Columbia Presbyterian Children's Hospital, New York, N.Y.
- Riley Children's Hospital, Indianapolis, Ind.
- Rady Children's Hospital, San Diego, Calif.
- Texas Children's Hospital, Houston, Texas
- St.Louis Children's Hospital, St.Louis, Mo.
- Dallas Children's Medical Center, Dallas, Texas
- Lurie Children's Hospital, Chicago, Ill.
- Boston Children's Hospital, Boston, Mass.
- CS Mott Children's Hospital, Ann Arbor, Mich.
- Johns Hopkins Children's Center, Baltimore, Md.
- Children's Hospital Los Angeles, Los Angeles, Calif.
- Cincinnati Children's Hospital, Cincinnati, Ohio
- Lucile Packard Children's Hospital, Palo Alto, Calif.
- Mattel Children's Hospital at UCLA, Los Angeles, Calif.



April 22–26
is National Pediatric
Transplant Week



Collaborated with Transplant Families and C.S. Mott Children's Hospital in Ann Arbor, Mich. to offer two educational webinars during National Pediatric Transplant Week.

IMPACT IN PATIENT & FAMILY SUPPORT



CCF HOSTED ITS FIRST LIVING WITH CARDIOMYOPATHY FAMILY CONFERENCE ON OCTOBER 11-12 IN PHILADELPHIA

- Offered attendees the opportunity to hear from medical experts in the field and connect with other cardiomyopathy families.
- Held in partnership with the Children's Hospital of Philadelphia and Penn Medicine
- 135 individuals from 12 states attended to hear from medical experts in the cardiac field and connect with others living with the disease.



THE PIÑA FAMILY

When six-year-old, Maddox Piña was diagnosed with hypertrophic cardiomyopathy, his parents, Gilberto and Tara were devastated and didn't know where to turn for help.

Fortunately, their pediatrician referred them to Dr. Steve Colan, a pediatric cardiologist at Boston Children's Hospital. Dr. Colan developed a treatment plan for Maddox and recommended that they reach out to CCF for support. The Piña's joined CCF's online community, CCF Connect, and ordered CCF's educational materials to learn more about the disease. They discovered that other parents on the forum had similar questions.

Gilberto considers Maddox's early diagnosis and intervention a "stroke of luck" and is thankful that they were introduced to CCF. They plan on staying connected with the many CCF families they have met.

IMPACT IN PATIENT & FAMILY SUPPORT



FINANCIAL IMPACT



“CARDIOMYOPATHIES HAVE AN
ASSOCIATED COST OF NEARLY
\$200 MILLION PER YEAR IN THE U.S.”

**CCF IS INSPIRING PEOPLE
TO RAISE FUNDS IN THEIR
COMMUNITIES TO FIND CURES.**

FINANCIAL IMPACT

2019 FUNDRAISERS

Our events bring families and supporters together for a collective impact and to support CCF's research and education programs and family services.



NIGHT FOR A CURE

More than 315 guests, including 49 sponsors, attended Night for a Cure on February 6 held at the deco-inspired Edison Ballroom in New York City. The event raised more than \$266,000 for pediatric cardiomyopathy research and education initiatives.



GOLF FOR A CURE

CCF's annual golf classic was supported by 55 sponsors and attended by 140 players at the prestigious Ridgewood Country Club, home of several PGA tournaments. The popular July 22 event raised more than \$356,000.



WALK FOR A CURE

More than 190 people from the Tri-state area attended CCF's 5th Annual Walk for a Cure during Children's Cardiomyopathy Awareness Month. The family friendly walk was held in West Orange, N.J. in September and raised funds for CCF's family resources and support services.

FINANCIAL IMPACT

IMPACT OF FAMILY FUNDRAISERS

CCF families are raising awareness of pediatric cardiomyopathy in their communities.



FIVE BAKE FOR A CURE EVENTS took place across the U.S., raising awareness and research funding for pediatric cardiomyopathy.



Team Rylan organized a **RUNNING FOR RYLAN AND A CURE FOR CARDIOMYOPATHY FUNDRAISER** linked to the Naperville Women's Half Marathon in Illinois on April 28. Jonathan Lombardo and Heather Ory raised more than **\$11,250** for CCF in honor of their son Rylan, who has hypertrophic cardiomyopathy.



Gilberto Piña and his rock band JC & The Beakers from Bluebird Bio won the **BATTLE OF THE BIOTECH BANDS** in Boston and donated the event proceeds of **\$60,790** to CCF's research program.

FINANCIAL IMPACT



THE FARSCHT FAMILY raised **\$2,364** for CCF during the holidays at their Ugly Holiday Sweater Party in New Jersey.



NATIONAL HONOR SOCIETY OF WEST WINDSOR-PLAINSBORO HIGH SCHOOL NORTH in New Jersey hosted a student talent show on April 13 and raised **\$1,500** for CCF.



THE ELLIS ANN COSBY FOUNDATION raised **\$29,000** from their local Night for a Cure and Annual Golf Tournament. In the past 4 years, EAC has raised over \$60,000 for CCF in memory of their daughter Ellis Ann.



The Riley family hosted the **10TH ANNUAL CASEN'S CREW** at Maxwell Golf Course in Texas in memory of their son Casen. The August 24th event was supported by 100 golfers and local sponsors who contributed **\$17,000** to CCF.

FINANCIAL STATEMENT SUMMARY

FISCAL YEAR ENDING DECEMBER 31, 2019

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	\$1,108,986
Investments	\$1,358,862
Intangible Net Assets	\$54,591
TOTAL ASSETS	\$2,522,439

NET ASSETS

Unrestricted Net Assets	\$2,520,426
Restricted Net Assets	\$2,013
TOTAL NET ASSETS	\$2,522,439

STATEMENT OF ACTIVITIES

REVENUE

Contributions	\$165,914
Fundraising	\$832,378
Interest & Dividends	\$47,581
Realized & Unrealized Investment Gains	\$211,892

TOTAL REVENUE \$1,257,765

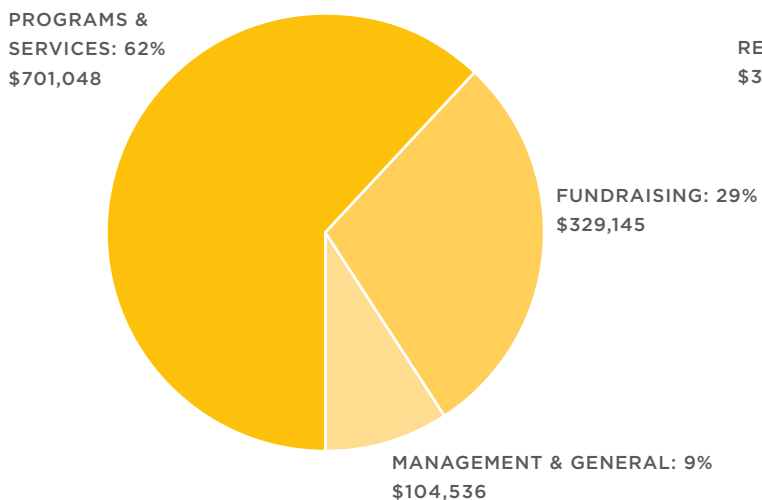
EXPENSES

Programs & Services	\$701,048
Management & General	\$104,536
Fundraising	\$329,145

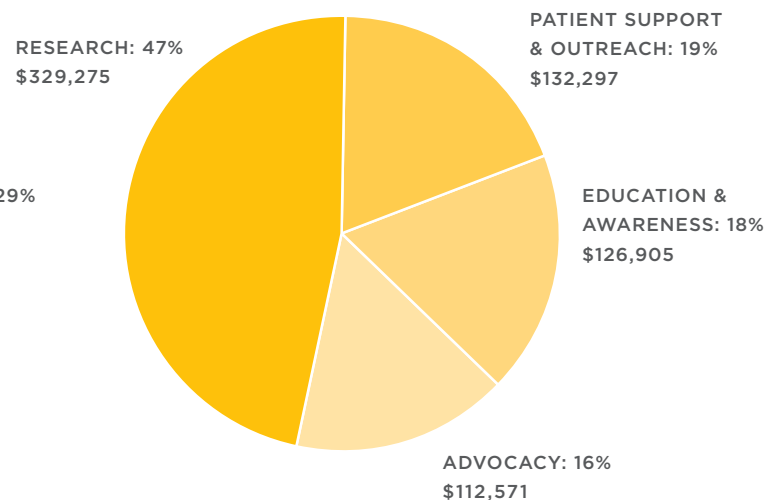
TOTAL EXPENSES \$1,134,729

NET INCOME \$123,036

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



CCF 2019 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 have made significant contributions to the Foundation in 2019.

DONORS \$10,000 AND OVER

Angel Island Capital
Arts & Business Council of Greater Boston
Bank of America Merrill Lynch
Barclays Capital
BNP Paribas
Brigade Capital Management
Children's Healthcare Associates
Deutsche Bank Securities
Ellis Ann Cosby Foundation
Houlihan Lokey
Goldman, Sachs & Co.
Jefferies
JP Morgan Chase & Co.
Kirkland & Ellis
MacKay Shields
Macquarie Group Foundation
Morgan Stanley
MyoKardia
Michael and Leslie Petrick
RBC Capital Markets
Richards Kibbe & Orbe
Senator Investment Group
Wells Fargo Securities

Benji and Susan Cheung
Colbeck Capital Management
Column Park Asset Management
David and Megan Cosby
Emil P. Costa
Vincent D'Arpino
Michael Davidson
Christopher DeLong
Lucas Detor
Gibson, Dunn & Crutcher
Global Genes
Imperial Capital
JP Morgan Platform Sales
Kathleen Lenihan
Nomura Securities International
Geoffrey and Kearby Parker
Paul, Weiss, Rifkind, Wharton & Garrison
Richards Kibbe & Orbe
Rothschild & Co
Seaport Global Holdings
Stifel Nicolaus & Company
TD Securities
UBS Investment Bank
Dick and Maggie Yue

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

Akin, Gump, Strauss, Hauer & Feld
Anchorage Capital Group
Angelo, Gordon & Co.
Bloomberg
BMO Capital Markets
Brown Rudnick
Edward Burdick
Chatham Asset Management

DONORS \$4,999-\$1,000

Abbott Medical Devices
Daniel Allen
Robert J. Barrett
Evan and Beth Bernardi
Steven Bleier
William Caggiano
Cantor Fitzgerald Relief Fund
Nicholas Casesa
Citigroup Global Markets

CCF 2019 TOP DONORS

Mark Colm
Emil Costa
Cowen
James W. Croom
Cytokinetics
David and Carol Davis
Edward Farscht and Lynn Jaeger
Patrick and Sarah Foye
Eric Friel
Robert Franz
Thomas Fuller
Patrick C. Gallagher
GLC Advisors & Co.
Richard and Anne Grissinger
Eric Guevara
Jason Handrinos
Michael Henderlong
Brian Hewitt
HG Vora Capital Management
HSBC Securities (USA)
Jet Capital Investors
Peter Joseph
Matthew Kaitz
Clint Kollar
Kristen Elise Tramm Memorial Fund
Robert Kunzweiler
La Marca Butler Group
Stephen Lehner
Pamela A. Lombardo
Si Lund
Patrick Lynch
Matthew Maggio
John Marczak
Ronald Mateo
Mike and Kristi McCluskey
Glenn McDermott
Brian McGowan
Medtronic Foundation
The Merck Foundation
MUFG Securities Americas
Donald Mullen

Jimmie Newton
Brett Nunziata
John O'Meara
William Orbe
Dan Ornstein
Heather Ory
Ronald Ory
Douglas Pardon
Gary Passavia
John Pearce
Bryan Quinlan
Andrew Quinn
Scott Rahn
Ian Rankowitz
Riva Ridge Capital Management
Anthony and Elizabeth Rosselli
Donald and Mary Lou Rossi
RW Baird
Edgar Sabounghi
Ian Sandler
Lisa Schafer
Thomas Schneider
Marc Schwartz
William Schatz
Chaney M. Sheffield
Scott and Sarah Snell
Societe Generale
David and Ranae Stewart
Robert Stobo
Chris Taliercio
Third Bridge Group
Van der Linden Family Foundation
West Windsor-Plainsboro High School North
Eddie Yu and Lisa Yue
Raymond Yue
Richard Zentko

