INSPIRING HOPE

CHILDREN'S CARDIOMYOPATHY FOUNDATION ▪ 2017 ANNUAL REPORT

FOUNDER'S LETTER

Dear Friends,

2017 was an inspiring year of hope. Through collaborative research, supportive resources, and impactful advocacy, we are ensuring that there are brighter days ahead for children with cardiomyopathy.

For the first time, a national study published in the *Journal of American College of Cardiology (JACC)*, showed that children with dilated cardiomyopathy are surviving longer without a heart transplant compared to similarly diagnosed children 20 years ago. The National Heart, Lung, and Blood Institute (NHLBI) and Children's Cardiomyopathy Foundation (CCF)–funded study indicates that twice the number of children who would have died are now living. It is validating to see how CCF's partnership with the Pediatric Cardiomyopathy Registry and increased collaboration among research centers have led to better medical management and patient outcomes.

In addition to research, it is inspiring to see achievements in advocacy as well. Due to CCF's advocacy efforts, cardiomyopathy was included in the FY18 defense appropriations bill as a covered research topic under the U.S. Department of Defense Peer Reviewed Medical Research Program. This makes an additional $4 million in federal funding available for pediatric cardiomyopathy research. CCF also worked with Congressman Frank Pallone's (NJ-06) office to introduce a more comprehensive Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act (H.R. 8330), and held an AED Hunt on the Hill event with Representative Phil Roe (TN-01) to raise awareness of cardiomyopathy, the risk of sudden cardiac death, and the importance of accessible automatic external defibrillators (AEDs) in a cardiac emergency.

CCF remains committed to awareness initiatives and continues to increase its public outreach during National Heart Month in February and Children's Cardiomyopathy Awareness Month during September. Our fundraising events continue to bring together families and supporters across the country. As we enter a new era in cardiomyopathy research and expand our awareness efforts, treatments will improve. In our collective efforts, we will continue to inspire hope within the cardiomyopathy community.

Sincerely,

Lisa Yue

Lisa Yue
Founding Executive President

OUR MISSION

The Children's Cardiomyopathy Foundation (CCF) is dedicated to finding causes and cures for pediatric cardiomyopathy through the support of research, education, and increased awareness and advocacy.

DISEASE FOCUS

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Restrictive cardiomyopathy (RCM)
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Left ventricular non-compaction cardiomyopathy (LVNC)

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Gina Peattie
Patient Outreach & Support Director

Shari Maurer
Patient Outreach & Support Coordinator

Lauren Zenreich
Executive Assistant & Bookkeeper

RESEARCH

RESEARCH

- Two research grants were awarded to investigators studying pediatric cardiomyopathy.

WENDY CHUNG, M.D., PH.D.
Impact of Genetic Testing
for Cardiomyopathies on
Children and Their Families
Columbia University, New York, NY

TERESA M. LEE, M.D., M.S.
MASAYUKI YAZAWA, PH.D.
Human Induced Pluripotent Stem Cell
Model of Hypertrophic Cardiomyopathy
Columbia University, New York, NY

> “Without CCF’s support, we could not do what needs to be done for children with cardiomyopathy.”
>
> — MELANIE EVERITT, M.D., DIRECTOR OF HEART TRANSPLANT, CHILDREN’S HOSPITAL COLORADO

RESEARCH

- Findings from CCF-funded research studies were published in six peer-reviewed medical journals and presented at four national medical meetings.

Heart Failure-Related Hyperphosphorylation in the Cardiac Troponin I C Terminus Has Divergent Effects on Cardiac Function In Vivo
Circulation: Heart Failure

Acrolein Can Cause Cardiovascular Disease
Cardiovascular Toxicology

Cardio-Oncology: Cardiovascular Complications of Cancer Therapy
Future Cardiology

New Treatments for Acute Myocardial Infarctions and Ischemic Cardiomyopathies: Human Umbilical Cord Blood Stem Cells and Chitosan Hydrogels
International Journal of Stem Cell Research and Therapy

Pilot Study Analyzing Automated ECG Screening of Hypertrophic Cardiomyopathy
HeartRhythm

Does Late Gadolinium Enhancement Identify the Patients at Risk in Childhood Hypertrophic Cardiomyopathy? A Multicenter Study
Canadian Journal of Cardiology

RESEARCH

- CCF's 4th International Conference on Cardiomyopathy in Children was held on May 18–19 in Bethesda, Md.

  60 leading researchers and clinicians convened to exchange ideas on pediatric cardiomyopathy, heart failure, and heart transplantation.

  Conference proceedings were published in a three-part series in *Progress in Pediatric Cardiology*.

  Physician interviews from the conference were posted on Facebook Live.

- CCF's partnership with the Pediatric Cardiomyopathy Registry (PCMR) resulted in four poster presentations at the American Heart Association Scientific Sessions held November 11–15 in Anaheim, Ca.

  Cardiac Biomarkers Are Associated With Death and Listing for Heart Transplantation in Pediatric Patients With Newly Diagnosed Dilated Cardiomyopathy

  Are Echocardiogram and Magnetic Resonance Imaging Comparable in Measuring Maximal Septal Thickness in Children With Hypertrophic Cardiomyopathy?

  Fibrosis and Hypertrophy Assessed by Magnetic Resonance Imaging and Serum Biomarkers in Pediatric Hypertrophic Cardiomyopathy

  Exome Sequencing in a Pediatric Cardiomyopathy Cohort

RESEARCH

- CCF's medical advisory board was expanded to include three distinguished cardiomyopathy experts.

SHELLEY D. MIYAMOTO, M.D.
Children's Hospital Colorado

JOSEPH W. ROSSANO, M.D., M.S.
Children's Hospital of Philadelphia

JAMES D. WILKINSON, M.D., M.P.H.
Monroe Carell Jr. Children's Hospital at Vanderbilt

- Findings from CCF-funded research studies were presented at six national and international medical conferences.

American Heart Association Scientific Sessions

American Society of Human Genetics Annual Meeting

Canadian Cardiovascular Congress

European Society of Cardiology Congress

International Society for Heart & Lung Transplantation Annual Meeting

Muscular Dystrophy Association Scientific Conference.

> "The report from the study, Survival Without Cardiac Transplantation Among Children With Dilated Cardiomyopathy, is the first to show improved transplant-free survival for pediatric dilated cardiomyopathy patients."
>
> — STEVEN LIPSHULTZ, M.D., CHAIR OF PEDIATRIC RESEARCH, WAYNE STATE UNIVERSITY SCHOOL OF MEDICINE


GRAND BALLROOM
Registration
7:00 - 5:00
Creating a Brighter Future for Children with Cardiomyopathy
Children's Cardiomyopathy Foundation
A Cause for Today... A Cure for Tomorrow
Registration
7:00 - 5:00
GRAND BALLROOM E
Children's

EDUCATION

EDUCATION

- Launched CCF's Accredited Centers of Care to recognize medical centers that provide high-quality cardiac care and specialized disease management to children with cardiomyopathy.

  To date, thirty-three centers have been acknowledged.

- Represented at 11 national and international medical conferences.

  Northeast Pediatric Cardiac Nurses

  Pediatric Heart Failure Summit

  Southeast Pediatric Cardiology Society Meeting

  Westchester Cardiovascular Symposium

- Sponsored a lecture on cardiomyopathy, featuring Jeff Towbin, M.D., at the Midwest Pediatric Cardiology Society meeting in September.

EDUCATION

- Sponsored the Council on Cardiovascular Disease in the Young dinner at the American Heart Association Scientific Sessions.

- Co-sponsored two ShaRe Affairs of the Heart: Living with Cardiomyopathy family conferences at University of Michigan Medical Center and Duke Heart Center.

- Distributed more than 4,954 pieces of educational materials on pediatric cardiomyopathy to families, hospitals, schools, and medical meetings throughout the U.S. and Canada.

ADVOCACY & AWARENESS

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- Included cardiomyopathy in the FY 18 defense appropriations bill as a covered research topic under the U.S. Department of Defense Peer-Reviewed Medical Research Program.
- Partnered with Congressman Frank Pallone (NJ-06) to introduce a more comprehensive Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act (H.R. 8330) during Sudden Cardiac Arrest Awareness Month.
- Worked with Representative Phil Roe (TN-01) to host the AED Hunt on the Hill in Washington D.C. on September 27 during Children's Cardiomyopathy Awareness Month.

Eleven national organizations supported the Children's Cardiomyopathy Awareness Month in September with blogs, newsletter mentions, and social media postings.

American Academy of Pediatrics

American Heart Association

Centers for Disease Control and Prevention

Eric Paredes Save A Life Foundation

National Alliance for Youth Sports

National Association of School Nurses

National Athletic Trainers' Association

National Organization for Rare Disorders

Parent Heart Watch

Sarcomeric Human Cardiomyopathy Registry (ShaRe)

Sudden Cardiac Arrest Foundation

ADVOCACY & AWARENESS

- Passed a resolution authored by Rep. Garth Everett of the Pennsylvania House of Delegates declaring September as Children's Cardiomyopathy Month in Pennsylvania.
- Organized the #MyCampAED scavenger hunt for the 5th consecutive year with the American Camp Association and One Beat CPR + AED.
- Held several awareness walks in New Jersey, Delaware, Florida, Michigan, Pennsylvania, and Virginia to highlight Children's Cardiomyopathy Awareness Month.

FAMILY & PATIENT SUPPORT

FAMILY & PATIENT SUPPORT

- Welcomed 188 new members, increasing CCF's community to 3,063 members from 74 countries.
- Responded to 705 phone calls and emails for assistance.
- Launched Family Care Bag program at four medical centers to support families coping with an extended hospital stay with their child.
- Website visited more than 65,561 times, and 103,805 pages of information viewed.
- More than 200 discussion threads generated on CCF Connect's discussion forum.
- Facebook CCF Youth Connect Group and Family Community Group grew to 1,418 members with 1,080 postings and 8,400 comments in the year.

> "CCF has been an invaluable resource for me! The forum for parents is especially helpful, and the knowledgeable and supportive CCF staff are amazing."
>
> — ERIN MAVER, MOM TO DAUGHTER WITH HCM

FAMILY & PATIENT SUPPORT

- Scheduled four Meet the Expert Q & A sessions on CCF Connect's discussion forum and four webinars featuring leading experts in the field.

MEET THE EXPERT Q&A

HELPING CHILDREN COPE WITH MEDICAL TESTS AND HOSPITALIZATIONS

Rechelle Porter, M.S.W., L.S.W., C.C.L.S. &
Alison Heffer, M.S. Ed., C.C.L.S.
Morgan Stanley Children's Hospital

HEART TRANSPLANTATION

Jeffrey Gossett, M.D.
University of California, San Francisco

NEURODEVELOPMENT DELAYS AND CARDIOMYOPATHY

Kristi Glotzbach, M.D.
Primary Children's Hospital

MEDICATIONS AND CARDIOMYOPATHY

JONDAVID MENTEER, M.D.
Children's Hospital Los Angeles

WEBINARS

GENETIC TESTING

Allison Cirino, Genetic Counselor
Brigham and Women's Hospital

LEFT VENTRICULAR NON-COMPACTION CARDIOMYOPATHY IN CHILDREN

John Jeffries, M.D.
Cincinnati Children's Hospital

DEVELOPMENTS IN RESEARCH AND TREATMENT IN PEDIATRIC CARDIOMYOPATHY

Jeffrey Towbin, M.D.
LeBonheur Children's Hospital

COPING WITH A CARDIOMYOPATHY DIAGNOSIS

Sonia Monteiro, M.D.
Texas Children's Hospital

FAMILY & PATIENT SUPPORT

HELPING FAMILIES EVERYDAY

- Connected mom of son diagnosed with LVNC to various specialists for better medical management.
- Connected a mother who lost her infant daughter to DCM with other bereaved parents for support.
- Provided educational resources and materials to assist a family with their diagnosed teenager.
- Worked with social worker to connect a newly diagnosed family to another family for emotional support.

> “The lack of a cure and the scarcity of organs are devastating. We are thankful that CCF is paving the way for awareness and education on this condition.”
>
> — BRIAN-MARIA MEDINA, MOM TO DAUGHTER LOST TO RCM

FUNDRAISING HIGHLIGHTS

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- CCF's Ninth Annual Poker Event at the Edison Ballroom in New York City was held on February 8 and attended by more than 295 guests and 49 corporate sponsors. The event raised $268,675.

- CCF Fifteenth Annual Golf Classic at Montclair Golf Club, N.J. took place on August 7 and raised $329,412 with the support of 52 sponsors.

> "CCF's commitment to spreading awareness and advocating for families affected by cardiomyopathy has given us a powerful voice in our local community and allowed us to help make a difference in the lives of those affected by this disease."
>
> — HEATHER RILEY, CASEN'S CREW

FUNDRAISING HIGHLIGHTS

- CCF's Third Annual Walk for a Cure was held September 17 in West Orange, N.J. and attracted 120 walkers. The event raised $43,680.
- Fundraisers planned by CCF families and friends brought in $41,969.
- CCF's Spring and Holiday direct mail appeals raised $74,091.

> "Your organization helped us to find answers for what would be the final chapter of our son's short life. Our donation will help CCF continue with creating a future of hope for families like ours."
>
> — DEBORAH BURT, SAM'S POSSE

2017 FINANCIAL SUMMARY STATEMENT

FISCAL YEAR ENDING DECEMBER 31, 2017

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	$1,051,085
Investments	$1,367,052
TOTAL ASSETS	$2,418,137

NET ASSETS

Unrestricted Net Assets	$2,418,137
TOTAL NET ASSETS	$2,418,137

STATEMENT OF ACTIVITIES

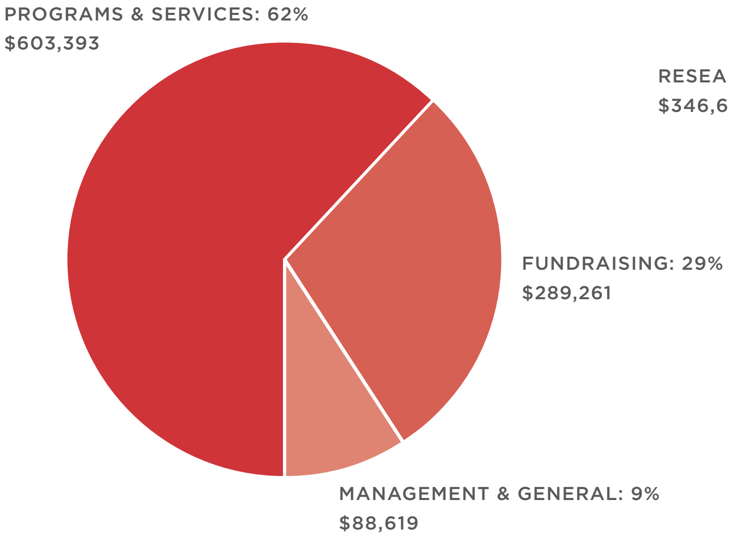
REVENUE

Contributions	$163,880
Fundraising	$764,555
Merchandise Sales	$987
Interest & Dividends	$35,776
Realized & Unrealized Investment Gains	$191,335
TOTAL REVENUE	$1,156,533

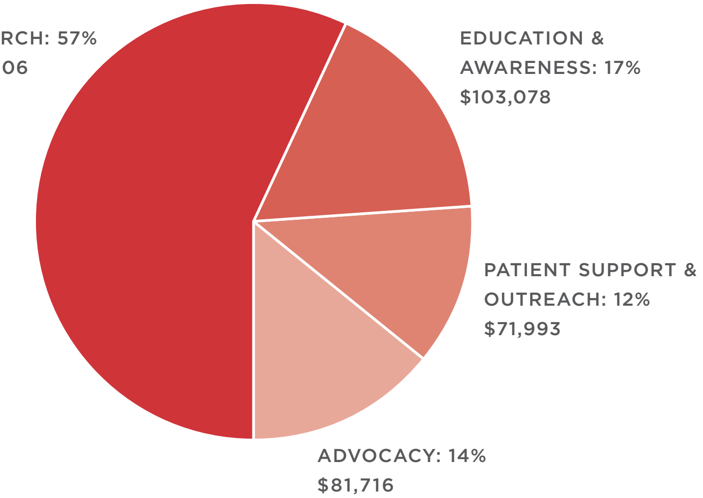
EXPENSES

Programs & Services	$603,393
Management & General	$88,619
Fundraising	$289,261
TOTAL EXPENSES	$981,273
NET INCOME	$175,260

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



2017 TOP DONORS

The following corporations, foundations, and individuals have made significant contributions to the Children's Cardiomyopathy Foundation (CCF) in 2017.

We are unable to list all our supporters but extend our heartfelt thanks to all who have contributed to CCF.

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2017 TOP DONORS

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CHILDREN'S CARDIOMYOPATHY FOUNDATION

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