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
Founding Executive President
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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  Patient Outreach & Support Director
- Shari Maurer
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- Lauren Zenreich
  Executive Assistant & Bookkeeper
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
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*

*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*
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
CCF’s medical advisory board was expanded to include three distinguished cardiomyopathy experts.

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
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.
- 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.
Sudden cardiac arrest: top cause of death at school.

Sudden cardiac arrest: seconds count.
ADVOCACY & AWARENESS

- 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

- 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
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*
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

- 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
**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: $191,335
- Investment Gains

**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 by Program & Services**
- Programs & Services: 62% ($603,393)
- Research: 57% ($346,606)
- Fundraising: 29% ($289,261)
- Education & Awareness: 17% ($103,078)
- Patient Support & Outreach: 12% ($71,993)
- Advocacy: 14% ($81,716)

**Management & General**: 9% ($88,619)
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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