



IT TAKES A TEAM



CHILDREN'S CARDIOMYOPATHY FOUNDATION
2015 ANNUAL REPORT

FOUNDER'S LETTER



Dear Friends,

What I've learned since founding the Children's Cardiomyopathy Foundation (CCF) is that it takes a team to defeat cardiomyopathy. Families, supporters and physicians have to work together if we hope to find cures in our lifetime. We have come a long way since taking our first steps in 2002. It's rewarding to see how far we've come and to know that CCF's dedication to the cause has inspired families to come forward to share their stories and raise awareness of pediatric cardiomyopathy. This was especially apparent during Children's Cardiomyopathy Awareness Month in September.

Our first Walk for a Cure was held September 27 at the South Mountain Recreation Complex in West Orange, N.J. and more than 110 CCF families and friends attended from the tristate area. Awareness walks also were held at beaches, local parks and neighborhood sidewalks across the U.S. in Indiana, Florida, Texas, Maryland, Alabama, Illinois, Ohio, Wisconsin, Louisiana, and Michigan. Not only did the walks raise awareness and funds for research, it served as a symbolic gesture for our growing cardiomyopathy community. We are all on the same journey, walking in unison towards the same goal.

In addition to the walk, we have funded seven new research studies in 2015 and continued to support the research initiatives of the North America Pediatric Cardiomyopathy Registry. We also gained ground in our legislative efforts in Washington D.C. and broadened our awareness programs to identify more at-risk children.

No family affected by cardiomyopathy should walk alone. At CCF we are a team supporting each other and making great strides. Together, we can get closer to finding cures for this devastating heart disease.

Sincerely,

A handwritten signature in black ink that reads "Lisa Yue". The signature is fluid and cursive, with the first name "Lisa" and last name "Yue" clearly distinguishable.

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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Support Coordinator*

Lauren Zenreich
*Executive Assistant
& Bookkeeper*

RESEARCH



RESEARCH



- Awarded \$323,118 to seven new pilot studies in 2015.

Automated ECG Screening for Hypertrophic Cardiomyopathy

RICHARD CZOSEK, M.D.
CINCINNATI CHILDREN'S HOSPITAL

Disease Pathways for MYBPC3 Mutations in Hypertrophic Cardiomyopathy

SHARLENE DAY, M.D.
UNIVERSITY OF MICHIGAN

Visual Proteomics for Personalized Assessment of Risk in ARVC Families

MARIO DELMAR, M.D., PH.D.
NEW YORK UNIVERSITY SCHOOL OF MEDICINE

Influence of Pediatric Cardiomyopathy on Health Related Quality of Life

KRISTI GLOTZBACH, M.D.
ALBERT EINSTEIN COLLEGE OF MEDICINE

Prevalence and Evolution of Late Gadolinium Enhancement and Myocardial Hypertrophy in Childhood Cardiomyopathy

LARS GROSSE-WORTMANN, M.D.
THE HOSPITAL FOR SICK CHILDREN

Human Cord Mesenchymal Stem Cells Decrease Cardiomyopathy Fibrosis

ROBERT HENNING, M.D.
UNIVERSITY OF SOUTH FLORIDA

Mechanism of RAF1 Mediated Pediatric Hypertrophic Cardiomyopathy

ABDUR RAZZAQUE, PH.D.
UNIVERSITY OF WISCONSIN

"I am very grateful for the support I received, and thank the Foundation for their wonderful work."

MARIO DELMAR M.D. PH.D.
NEW YORK UNIVERSITY
SCHOOL OF MEDICINE

"As a researcher looking to determine the risks and benefits of exercise for patients with a variety of cardiac conditions, working with CCF has been crucial to the success of our endeavors."

RACHEL LAMPERT, M.D.
YALE UNIVERSITY SCHOOL
OF MEDICINE

- Continued CCF's multi-year grant of \$372,000 to the North American Pediatric Cardiomyopathy Registry (PCMR), which covers multi-center study analysis, publications, a dedicated research associate, and working group meetings.

"There is little psychosocial research done to determine how cardiomyopathy affects everyday life. This CCF-funded study aims to identify areas where doctors and families can work together to better balance the medical and psychosocial needs of kids living with cardiomyopathy."

KRISTI GLOTZBACH, M.D.
ALBERT EINSTEIN COLLEGE
OF MEDICINE

RESEARCH



- Study findings from CCF-funded research studies were published in 5 peer-reviewed medical journals and presented at the American Heart Association Scientific Session.

Circulating MicroRNA as a Biomarker for Recovery in Pediatric Dilated Cardiomyopathy, *Journal of Heart Lung Transplantation*

Cardiomyopathy Phenotypes and Outcomes for Children with Left Ventricular Myocardial Non-Compaction: Results from the Pediatric Cardiomyopathy Registry, *Journal of Cardiac Failure*

Prevalence, Predictors and Outcomes of Cardiorenal Syndrome in Children with Dilated Cardiomyopathy, *Pediatric Nephrology*

Lessons Learned from the Pediatric Cardiomyopathy Registry (PCMR) Study Group, *Cardiology in the Young*

Health-Related Quality of Life and Functional Status are Associated with Cardiac Status and Clinical Outcome in Children: A Report from the Pediatric Cardiomyopathy Registry, *Journal of Pediatrics*

- Featured pediatric cardiomyopathy in a dedicated issue in *Progress in Pediatric Cardiology*, which included 12 articles from CCF's Third International Conference on Cardiomyopathy in Children.
- CCF Founding Executive Director, Lisa Yue, named as an associate editor of advocacy and family support for *Progress in Pediatric Cardiology*, an international peer-reviewed journal of scientific research, reviews and experienced opinion.

AMERICAN HEART ASSOCIATION SCIENTIFIC SESSIONS 2015 PRESENTATIONS

ARRHYTHMIA MECHANISMS
IN ARRHYTHMOGENIC
CARDIOMYOPATHY

CARDIAC MYOSIN BINDING
PROTEIN C MUTANTS
INTERACT WITH AND CAUSE
MISLOCALIZATION OF THE
HSP70 FAMILY OF CHAPERONES

IMPACT OF MALNOURISHMENT
OR OBESITY ON CLINICAL
OUTCOMES IN CHILDREN WITH
DILATED CARDIOMYOPATHY: A
REPORT FROM THE PEDIATRIC
CARDIOMYOPATHY REGISTRY
STUDY GROUP

RESULTS OF RESEARCH
GENETIC TESTING IN PEDIATRIC
CARDIOMYOPATHY PATIENTS
JUSTIFY BROADER CLINICAL
GENETIC TESTING

EDUCATION



EDUCATION

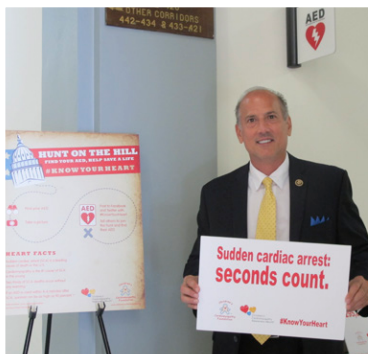


- Co-sponsored the second Sarcotonic Human Cardiomyopathy Registry (SHaRe) family conference, Affairs of the Heart: Understanding Genetic Cardiomyopathy, at the University of Michigan in Ann Arbor, Mich.
- Distributed more than 4,330 pieces of educational materials on pediatric cardiomyopathy to families, hospitals, medical meetings, and schools in the U.S. and Canada.
- Represented at more than 9 national and international medical conferences, including the Southeast Pediatric Cardiology Society Conference, Pediatric and Adult Interventional Cardiology Symposium, International Symposium on Congenital Heart Disease, and Mt. Sinai Non-Invasive Imaging for Diagnosis of The Failing Heart Meeting.
- Co-sponsored the Innovations in Pediatric Heart Failure meeting hosted by Rady's Children's Hospital in San Diego.

ADVOCACY & AWARENESS



ADVOCACY & AWARENESS



- Secured report language on cardiomyopathy in the FY 2016 Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education bill to encourage the National Heart, Lung, and Blood Institute and the Centers for Disease Control and Prevention to increase their focus on pediatric cardiomyopathy.
- Strengthened partnership with the Centers for Disease Control and Prevention (CDC), which led to their support as a national partner for the Children's Cardiomyopathy Awareness Month and developing a CDC webpage highlighting cardiomyopathy.
- Reintroduced the Supporting Athletes, Families and Educators to Protect the Lives of Athletic Youth (SAFE PLAY) Act with Senator Menendez (NJ) and Representatives Bill Pascrell (NJ-9) and Lois Capps (CA-24). The Act is the most comprehensive federal legislation on youth sports safety and includes provisions to prevent and address cardiac emergencies in youth athletes.
- Reintroduced the Cardiomyopathy Health, Education, Awareness, Risk Assessment, and Training in the Schools (HEARTS) Act in the U.S. House of Representatives with Representative Frank Pallone (NJ-6). The Act is the first cardiomyopathy-specific bill and requires the Secretary of Health and Human Services to coordinate with the Centers for Disease Control and Prevention to develop and distribute educational materials on cardiomyopathy through the public school system.

CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH

SECURED SUPPORT OF 12 NATIONAL PARTNERS INCLUDING THE AMERICAN ACADEMY OF PEDIATRICS, AMERICAN COLLEGE OF CARDIOLOGY AND AMERICAN HEART ASSOCIATION.

SECOND ANNUAL CAPITAL HILL AWARENESS CAMPAIGN, AED HUNT ON THE HILL, REACHED OUT TO 1,300 HILL STAFFERS AND GARNERED BIPARTISAN SUPPORT AT THE EVENT.

SECURED CONGRESSIONAL RECORD STATEMENTS BY REPRESENTATIVES LOIS CAPPs (CA-24), DAVID SCOTT (GA-13), ANDRE CARSON (IN-7), BILL PASCRELL (NJ-9), AND CHELLIE PINGREE (ME-1).

HELD FIRST WALK FOR A CURE ON SEPTEMBER 27 IN NEW JERSEY WITH ADDITIONAL WALK TEAMS PARTICIPATING IN INDIANA, FLORIDA, TEXAS, MARYLAND, ALABAMA, ILLINOIS, OHIO, WISCONSIN, LOUISIANA, AND MICHIGAN.

ADVOCACY & AWARENESS



- Included cardiomyopathy-specific language in the Every Child Achieves Act of 2015 (S. 1177), a bipartisan educational policy reform bill. The inclusion encourages local educational agencies to use Title IV ESEA state funding towards activities and programs that address cardiac conditions such as cardiomyopathy.
- Launched the Uniting Hearts Across America campaign during National Heart Month. The 50-state awareness challenge enabled hundreds of families and friends to come together to highlight pediatric cardiomyopathy and honor children with cardiomyopathy across the U.S.
- Passed state resolution (HJ888) in the Virginia House and Senate during National Heart Month commending the Children's Cardiomyopathy Foundation for its advocacy and education initiatives.
- Held Third Annual AED camp scavenger hunt with the American Camp Association and One Beat CPR to raise awareness of cardiomyopathy as the leading cause of sudden cardiac arrest in youth and to highlight the importance of AED accessibility in saving lives.
- Passed state resolution (H409) in the Pennsylvania House of Delegates declaring the month of September as Children's Cardiomyopathy Awareness Month in Pennsylvania.
- Named as a top-rated health organization for the fifth consecutive year by Great Nonprofits, America's leading charity evaluators.

AED CAMP SCAVENGER HUNT

"This AED initiative teaches campers what an AED looks like and how it can help save a life — a powerful tool to learn at camp and use the rest of their lives."

PEG SMITH, CEO OF AMERICAN
CAMP ASSOCIATION

"Our camp is open year round and having an AED on site helps to safeguard our participants during a cardiac emergency. We are very grateful to CCF and One Beat CPR for this award."

DAVID CROUSE, ANGELES
CREST CAMP, 2015
#MYCAMPAED HUNT WINNER

FAMILY & PATIENT SUPPORT



FAMILY & PATIENT SUPPORT



- Welcomed 244 new members to CCF's community increasing CCF's member base to 2,640 members from 73 countries.
- Handled more than 715 phone calls and emails to patients and families and exchanged more than 600 emails on CCF's Connect Listserv.
- Received more than 85,199 website visits and 130,799 viewed webpages with a viewership of 66,059.
- Connected more than 930 members and 48 teens and young adults through CCF's Facebook Group and CCF's Youth Connect Group.
- Awarded \$11,917 to five families through CCF's Family Assistance Program to cover medical and non-medical expenses related to their child's cardiomyopathy treatment.
- Scheduled five Meet the Expert Q&A sessions and webinars featuring leading experts in the field.

2015 MEET THE EXPERT SESSIONS

Pediatric Heart Transplant

MELANIE EVERITT, M.D.
COLORADO CHILDREN'S
HOSPITAL

Gastrointestinal Issues in Cardiomyopathy Patients

JENIFER LIGHTDALE, M.D.
UMASS MEMORIAL CHILDREN'S
MEDICAL CENTER

Preparing for Heart Transplant

JOSEPH ROSSANO, M.D.
CHILDREN'S HOSPITAL
OF PHILADELPHIA

Emotional and Social Issues in Cardiomyopathy

JONATHAN SLATER, M.D.
NEW YORK-PRESBYTERIAN
CHILDREN'S HOSPITAL

ICDs, Pacemakers and Rhythm Issues

MATTHEW WILLIAMS, M.D.
RADY CHILDREN'S
HOSPITAL-SAN DIEGO

FAMILY & PATIENT SUPPORT



HELPING FAMILIES, PROVIDING HOPE

- Father from overseas called in need of a U.S. specialist for his 2-year-old niece diagnosed with LVNC. Provided Spanish educational materials, sent information on specialty centers and connected him with CCF's medical advisors.
- Parent reached out for support after her infant daughter passed away from RCM. Connected her to CCF support services, including a local CCF ambassador, and shared information on genetic testing.
- Father with an infant daughter diagnosed with DCM and awaiting transplantation in the hospital contacted CCF. Provided him with heart transplant resource guide as well as transplant webinar for more information.
- Family, whose infant son was recently transplanted due to cardiomyopathy, was having difficulties paying their bills. Through CCF's family assistance program, the family received payment for medical insurance premiums.

"CCF has been an invaluable resource for me! I am beyond grateful for the work they do in raising funds for research!"

ERIN BECK MAVER,
MOM TO SEDONA, 5, HCM

"As a parent of a child who was diagnosed with DCM and eventually died as a result, I am glad I did not have to go through my journey alone."

JENNIFER COLE AYERS,
MOM TO ELEANOR
(PASSED AWAY AT AGE
OF 8 MONTHS FROM DCM)

"CCF has been a Godsend to me, and it has helped me to keep my sanity. I would like to say thank you to CCF and all the families that are on the listserv. You have all blessed my life in more ways than I can count."

FAITH PATTON SETTLES,
MOM TO RYAN, 13, HCM

FUNDRAISING



2015 FUNDRAISING HIGHLIGHTS



- CCF's Seventh Annual Poker Event at the Edison Ballroom in New York City was held on February 11 and attended by 300 guests and 52 corporate sponsors. The event raised \$271,285.
- CCF's Thirteenth Annual Golf Classic at Montclair Golf Club, N.J. took place on July 20 with more than 220 guests and 64 sponsors attending to raise \$384,108.
- CCF's First Annual Walk for a Cure, held during Children's Cardiomyopathy Awareness Month, raised \$40,734.
- CCF's Spring and Holiday direct mail appeals raised \$58,447 in 2015.
- Fundraisers planned by CCF families and friends brought in \$29,093.

"We are very happy to be a part of the organization and want to continue to be constructive members of the community. This is a marathon, not a sprint, and we are in it for the long haul!"

CHRIS AND AMANDA
PASSAVIA, TEAM BO KNOWS
HEART WALK TEAM

"I am excited and honored to help an organization that means so much to me. I am so thankful for your organization in raising awareness, searching for a cure and pushing for further research."

CORINNE MCLAUGHLIN,
NOLAN HEART OF STEEL
FUNDRAISER

2015 FINANCIAL SUMMARY STATEMENT

FISCAL YEAR ENDING DECEMBER 31, 2015

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	\$1,024,130
Investments	\$1,116,824
Property & Equipment	—
TOTAL ASSETS	\$2,140,954

LIABILITIES & NET ASSETS

Current Liabilities	—
Net Assets — Unrestricted	\$2,073,054
Net Assets — Temporary Restricted	\$67,900
Net Assets — Permanently Restricted	—
TOTAL NET ASSETS	\$2,140,954
TOTAL LIABILITIES & NET ASSETS	\$2,140,954

STATEMENT OF ACTIVITIES

PUBLIC SUPPORT & REVENUE

Contributions	\$242,450
Grants	\$67,900
Fundraising	\$781,943
Interest & Dividends	\$39,408
Unrealized Gains	(\$74,669)

TOTAL PUBLIC SUPPORT & REVENUE \$1,058,757

OPERATING COSTS

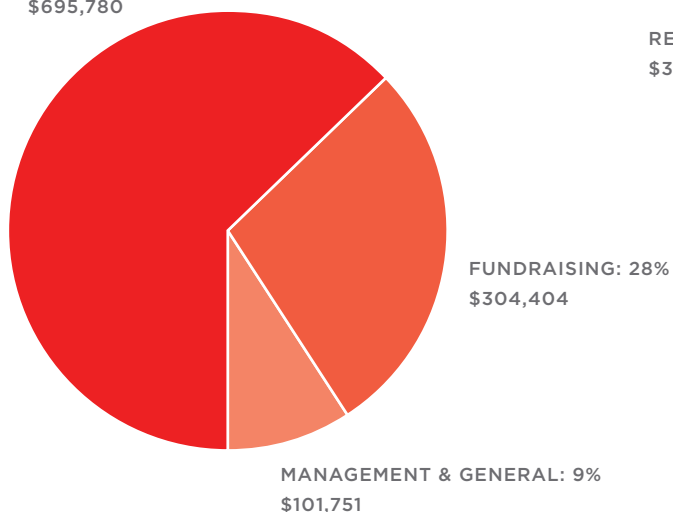
Programs & Services	\$695,780
Management & General	\$101,751
Fundraising	\$304,404

TOTAL OPERATING COSTS \$1,101,935

NET INCOME (\$43,178)

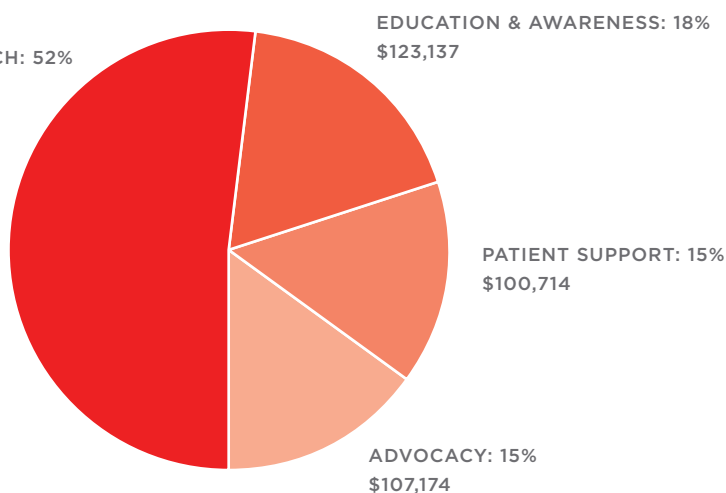
TOTAL EXPENSES

PROGRAMS & SERVICES: 63%
\$695,780



EXPENSES BY PROGRAM & SERVICES

RESEARCH: 52%
\$364,755



CIRCLE OF HEARTS 2015 TOP DONORS

The following corporations, foundations and individuals have made significant contributions to the Children's Cardiomyopathy Foundation in 2015, and we gratefully acknowledge their generosity. Due to space limitations we are unable to list all our supporters but extend our heartfelt thanks to all who have contributed during the year.

DONORS \$10,000 AND OVER

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

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CIRCLE OF HEARTS 2015 TOP DONORS

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

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