

2014 ANNUAL REPORT



Everyone Has A Story



Founder's Letter



Dear Friends,

Families affected by cardiomyopathy all have unique stories shaped by their own struggles and blessings. When I attended the Affairs of the Heart: Understanding Genetic Cardiomyopathies meeting in Boston, I had the privilege of meeting many families affected by cardiomyopathy, each with a different experience but united by the hope of improving their child's quality of life.

This year's theme is "Everyone Has a Story," which is a tribute to the program created by TODAY show hosts Kathie Lee and Hoda. During National Heart Month, I was invited on their program to share my family's story. I feel fortunate to have had the opportunity to talk about a heart disease that receives little attention. After the segment, there were numerous postings on social media from families who saw the show and wanted to share their stories of cardiomyopathy.

Their stories are a reminder that behind the disease statistics are children whose lives have been profoundly affected. This was highlighted at our Third International Scientific Conference on Children's Cardiomyopathy held in Bethesda, MD. More than 60 leading researchers and clinicians convened to discuss the future research direction for the disease. At the meeting, it was clear that research and education are critical to finding novel therapies and instituting better care.

This year we achieved another milestone by launching the first Children's Cardiomyopathy Awareness Month to educate the public about the signs, symptoms and risk factors associated with cardiomyopathy. Thirteen national partners joined us on this month-long initiative. During September, we held an AED Hunt on the Hill inviting members of Congress to participate and an Action Day on the Hill giving families an opportunity to share their stories with congressional leaders. Awareness month was a great success, and we know this is just the beginning for what will become an ongoing effort to educate others on pediatric cardiomyopathy.

Our strongest advocates for change are the families touched by cardiomyopathy. By giving them a platform to share their experiences, we can increase public awareness of the disease and hopefully save more lives. Through their rich and varied stories, we can give a public face to pediatric cardiomyopathy and continue to move forward towards finding cures.

Sincerely,

A handwritten signature in black ink that reads "Lisa Yue". The signature is fluid and cursive.

Lisa Yue

Founding Executive Director

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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Research



Research



- The Third International Scientific Conference on Cardiomyopathy in Children took place on May 15-16 in Bethesda, Md. and brought together more than 60 leading researchers and clinicians from across the U.S., Canada, Europe, and Australia to exchange ideas and discuss research direction on cardiomyopathies in children. Hosted by CCF and co-chaired by Steven Lipshultz, M.D. and James Wilkinson, M.D., M.P.H. of Wayne State University School of Medicine, the conference covered a wide range of topics on cardiomyopathy, heart failure and heart transplantation in children.
- The conference proceedings will be published in three dedicated issues of *Progress in Pediatric Cardiology*. The first issue, published December 2014, featured 12 articles on pediatric cardiomyopathy.

ARRHYTHMOGENIC
CARDIOMYOPATHY – NEW INSIGHTS
INTO DISEASE MECHANISMS AND
DRUG DISCOVERY

CHILDREN WITH MYOCARDITIS
AND NEW ONSET DILATED
CARDIOMYOPATHY HAVE EVIDENCE
OF AUTOIMMUNITY AND VIREMIA AT
PRESENTATION

DO SELECTION CRITERIA FOR
CHILDREN WITH DILATED
CARDIOMYOPATHY ENROLLED IN
NATIONAL REGISTRIES EXPLAIN
DIFFERENCES IN OUTCOMES?

FIBRILLIN-1 GENE MUTATIONS
IN LEFT VENTRICULAR NON-
COMPACTION CARDIOMYOPATHY

GENETIC CAUSES OF DILATED
CARDIOMYOPATHY

IMAGING FOR CORONARY
ALLOGRAFT VASCULOPATHY IN
CHILDREN AND ADOLESCENTS

MECHANICAL CIRCULATORY
SUPPORT STRATEGIES FOR
MYOCARDIAL RECOVERY

PATIENT-SPECIFIC PLURIPOTENT
STEM CELLS IN DOXORUBICIN
CARDIOTOXICITY:

A NEW WINDOW INTO
PERSONALIZED MEDICINE

PEDIATRIC VERSUS ADULT
CARDIOMYOPATHY AND
HEART FAILURE RELATED
HOSPITALIZATIONS: A VALUE-
BASED ANALYSIS

SUPPRESSION OF PATHOLOGICAL
CARDIAC FIBROSIS BY HISTONE
DEACETYLASE INHIBITORS

THE EVOLUTION OF MODERN
THEORY AND THERAPY FOR HEART
FAILURE

THE IMPLICATION OF CORONARY
ARTERY MALFORMATIONS AND
CONGENITAL HEART DISEASE ON
CARDIOMYOPATHY

“The medical issues and the research discussed here were extremely valuable, but the bottom line for all of us is finding ways to answer, how do we get to the best quality of life for children with cardiomyopathy and for their families?”

DR. STEVEN LIPSHULTZ
CONFERENCE CHAIR
AND CHAIR OF THE
DEPARTMENT OF PEDIATRICS,
WAYNE STATE UNIVERSITY
SCHOOL OF MEDICINE

“What an honor it was to attend and to witness first-hand CCF’s heartfelt commitment to making a difference for patients and their families.”

AIMÉE COWHER
CONFERENCE SPONSOR
AND EXECUTIVE DIRECTOR
OF THE KYLE JOHN
RYMISZEWSKI FOUNDATION

Research



- A three-year grant of \$372,000 was awarded to the North American Pediatric Cardiomyopathy Registry (PCMR) to cover 12 new studies and proposed publications, six working group meetings, and a dedicated PCMR senior research associate. An additional \$75,000 was awarded to the PCMR to assist with patient recruitment fees for the Genotype-Phenotype Associations in Pediatric Cardiomyopathy study. As result of CCF's support, over 900 patients, parents and affected relatives have been enrolled in the multi-center study.
- The Children's Cardiomyopathy Foundation committed \$200,000 to four new studies for 2014.

IPSC-derived cardiomyocytes in left ventricular non-compaction cardiomyopathy (LVNC)

DANIEL BERNSTEIN, M.D.
STANFORD UNIVERSITY

Late INa contributes to diastolic dysfunction in hypertrophic cardiomyopathy

DAVID FEDIDA, PH.D.
UNIVERSITY OF BRITISH COLUMBIA

Translational proteomics in hypertrophic cardiomyopathy

ANNE MURPHY, M.D.
JOHNS HOPKINS UNIVERSITY

Pak1 as a target for new treatment of hypertrophic cardiomyopathy

BEATA WOLSKA, PH.D.
UNIVERSITY OF ILLINOIS

Research



- The Children's Cardiomyopathy Foundation and American Heart Association Pediatric Cardiomyopathy Joint Research Award was given to Tim Wong, M.D., director of the University of Pittsburgh Medical Center's Hypertrophic Cardiomyopathy Center for his study, Cardiovascular magnetic resonance assessment of diffuse myocardial fibrosis in hypertrophic cardiomyopathy. A total of \$308,000 will be awarded over four years.
- Study findings from CCF-funded research studies were published in five peer-reviewed medical journals and presented at the American Heart Association Scientific Sessions in November.

RECOVERY OF ECHOCARDIOGRAPHIC FUNCTION IN CHILDREN
WITH IDIOPATHIC DILATED CARDIOMYOPATHY: RESULTS FROM
THE PEDIATRIC CARDIOMYOPATHY REGISTRY
JOURNAL OF AMERICAN COLLEGE OF CARDIOLOGY

ISSUES IN SOLID-ORGAN TRANSPLANTATION IN CHILDREN:
TRANSLATIONAL RESEARCH FROM BENCH TO BEDSIDE
CLINICS

CARDIAC FIBROBLASTS MEDIATE IL-17A-DRIVEN INFLAMMATORY
DILATED CARDIOMYOPATHY
JOURNAL OF EXPERIMENTAL MEDICINE

CLASSIC-PATTERN DYSSYNCHRONY AND ELECTRICAL
ACTIVATION DELAYS IN PEDIATRIC DILATED CARDIOMYOPATHY
JOURNAL OF THE AMERICAN SOCIETY OF ECHOCARDIOGRAPHY

CARDIOVASCULAR MAGNETIC RESONANCE IMAGING OF
MYOCARDIAL INTERSTITIAL EXPANSION IN HYPERTROPHIC
CARDIOMYOPATHY
CURRENT CARDIOVASCULAR IMAGING REPORTS

IMPROVED TRANSPLANT-FREE SURVIVAL OF CHILDREN WITH
DILATED CARDIOMYOPATHY: ANALYSIS OF TWO DECADES FROM
THE PEDIATRIC CARDIOMYOPATHY REGISTRY
ORAL PRESENTATION AT THE AMERICAN HEART ASSOCIATION
SCIENTIFIC SESSIONS, CHICAGO, IL. ABSTRACT PUBLISHED IN
CIRCULATION

Education



Education



- Co-sponsored with the SHaRe Cardiomyopathy Registry the Affairs of the Heart: Understanding Genetic Cardiomyopathy Family Conference in November, which was held at Brigham & Women's Hospital in Boston, Mass.
- Represented at more than 10 national and international medical conferences, including the American Heart Association, Pediatric Heart Failure Summit, World Transplant Congress, and Society of Pediatric Cardiovascular Nurses.
- Distributed more than 3,250 pieces of educational materials on pediatric cardiomyopathy to families, hospitals and schools in the U.S. and Canada.
- Developed new printed and web-based educational materials:
 - Left ventricular non-compaction cardiomyopathy insert
 - Transitioning to adult care toolkit for teens
 - Pediatric cardiomyopathy school presentation
 - AED grant and discount programs resource list
- Translated into Spanish CCF's pamphlet, Understanding Pediatric Cardiomyopathy, and inserts on Dilated Cardiomyopathy, Hypertrophic Cardiomyopathy, Restrictive Cardiomyopathy and Left Ventricular Non-Compaction Cardiomyopathy.
- Worked with the Centers for Disease Control and Prevention (CDC) to have cardiomyopathy listed on the CDC's A-Z disease index page and created a dedicated page on cardiomyopathy with the CDC Division of Heart Disease and Stroke Prevention.

Advocacy & Awareness



Advocacy & Awareness



- During National Heart Month in February, Founding Executive Director, Lisa Yue, was selected for the TODAY show's Everyone Has A Story segment with Kathie Lee and Hoda.
- The Children's Cardiomyopathy Foundation was the winning organization in the Education Hero category at the NJBIZ 8th Annual Healthcare Heroes Awards Ceremony in June.
- Named as a top-rated health organization for the fourth consecutive year by one of America's leading charity evaluators, Great Nonprofits.

SPEARHEADING LIFE-SAVING LEGISLATION

- Worked with Senator Menendez (NJ) and Representatives Bill Pascrell (NJ-9) and Lois Capps (CA-24) to introduce the Supporting Athletes, Families and Educators to Protect the Lives of Athletic Youth (SAFE PLAY) Act. The bill is the most comprehensive federal legislation on youth sports safety, and it encourages the development of best practices to prevent, document, and address youth athlete cardiac emergencies and injuries.
- Reintroduced the Cardiomyopathy Health, Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act in partnership with Senators Robert Menendez (NJ) and Frank Lautenberg (NJ) and Representative Frank Pallone (NJ-6). The bill requires the Secretary of Health and Human Services to coordinate with the Centers for Disease Control (CDC) to develop educational materials on cardiomyopathy and resources to prevent sudden cardiac death, to disseminate them to schools and families, and to post them on the CDC website.

Advocacy & Awareness



- Secured report language on cardiomyopathy in the Senate FY 2015 Labor-Health and Human Services-Education Appropriations report to encourage the National Heart, Lung, and Blood Institute to implement the proposed research agenda on pediatric cardiomyopathy and the Centers for Disease Control and Prevention to launch a pediatric cardiomyopathy awareness campaign.
- Worked closely with Representative Lois Capps (CA-24) to reintroduce the Teaching Children To Save Lives Act, legislation that provides schools with resources to teach students cardiopulmonary resuscitation (CPR) and how to use an automated external defibrillator (AED).
- Initiated a grassroots advocacy campaign to support the Cardiomyopathy HEARTS Act, SAFE PLAY Act, and Teaching Children to Save Lives Act, which generated more than 223 letters to lawmakers.
- Garnered the support of 29 legislative cosponsors and 37 organizations on the Cardiomyopathy HEARTS Act by year-end.
- Held the Second Annual AED camp scavenger hunt with the American Camp Association and One Beat CPR + AED to highlight cardiomyopathy as the leading cause of sudden cardiac arrest in the young and to emphasize the importance of AED accessibility in saving lives.

#MYCAMPAED 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, CHIEF EXECUTIVE
OFFICER OF AMERICAN CAMP
ASSOCIATION

“Clearly, we hope a camp never has to use it, but knowing everyone who visits the camp will have an AED readily available in the event of a cardiac emergency makes this an invaluable opportunity for everyone.”

LON ROSEN, CHIEF
EXECUTIVE OFFICER OF
ONE BEAT CPR + AED

Advocacy & Awareness



- Launched the inaugural Children's Cardiomyopathy Awareness Month in September.
 - Secured support of 13 national partners, including the American Academy of Pediatrics, American College of Cardiology and American Heart Association
 - Received national media coverage, including Time Warner Cable news, NY1, Arise news, Fios1 news and NBC news
 - Organized a Capital Hill Awareness Campaign, AED Hunt on the Hill, with bipartisan support from representatives Lois Capps (CA-24); William Lacy Clay, Jr. (MO-1); Frank Pallone (NJ-6); Ileana Ros-Lehtinen (FL-27); and Charles B. Rangel (NY-13)
 - Secured a floor speech by representative Capps and a congressional record statement by representative Pascrell
 - Organized a day of action on the hill with CCF family members



Children's
Cardiomyopathy
Awareness Month™

Family & Patient Support



Family & Patient Support



- Welcomed 250 new members to CCF's community this year, increasing CCF's member base to 2,395 members from 70 countries.
- Handled more than 1,175 phone calls and emails to patients and families in need, representing a 44 percent increase from last year. Exchanged more than 680 emails on CCF Connect, the Foundation's email discussion group.

HELPING FAMILIES, PROVIDING HOPE

CCF is assisting families from around the world on a daily basis.

- Father called for support for his two teen daughters with HCM who are having a difficult time coping with their diagnosis. The Foundation provided information about CCF's youth ambassadors, Facebook teen group, heart buddy program, and Secrets of the Heart DVD profiling four teenagers.
- Parents with infant daughter, who passed away from DCM, reached out to CCF to meet other cardiomyopathy parents. The Foundation connected them to a CCF ambassador and introduced them to CCF's private discussion forum and Facebook group.
- Mother of 7-year-old son with DCM awaiting a heart transplant contacted CCF for financial support to cover relocation expenses. Through CCF's Financial Assistance Program, the Foundation covered two months of their hospitality housing expenses.
- Mother of newly diagnosed teenage son called for information on LVNC and specialty treatment centers. The Foundation provided hospital listings, LVNC insert and pediatric cardiomyopathy educational materials.

Family & Patient Support



- Received more than 82,732 website visits and 139,091 viewed webpages with a viewership of 65,051.
- Grew Facebook family group page by more than 830 members and Youth Connect Group to 40 teen and young adult members.
- Provided financial assistance to six families through CCF's Family Assistance Program, which covers medical- and non-medical expenses related to a child's treatment.
- Scheduled seven Meet the Expert question and answer sessions on CCF's email discussion group, CCF Connect, and launched a webinar program that invites experts in the field to present.

Pediatric Cardiovascular Anesthesiology

COURTNEY HARDY, M.D., ANN
AND ROBERT LURIE CHILDREN'S
HOSPITAL OF CHICAGO

Ventricular Assist Devices

SCOTT AUERBACH, M.D.,
CHILDREN'S HOSPITAL COLORADO

Medication Management

TERESA LEE, M.D., MORGAN
STANLEY CHILDREN'S HOSPITAL

Exercise and Nutrition

GABRIEL SOMARRIBA, DPT,
UNIVERSITY OF MIAMI HOSPITAL

Pediatric Cardiovascular Genetics and Pediatric Genetic Testing

AMY ROBERTS, M.D.,
BOSTON CHILDREN'S HOSPITAL

Familial Forms of Cardiomyopathy

J CARTER RALPHE, M.D., UNIVERSITY
OF WISCONSIN

Psychosocial Adjustment to Medical Illness

ANNE FARRAR-ANTON, PH.D.,
HACKENSACK UNIVERSITY
MEDICAL CENTER

Living with Chronic Illness

ANNE FARRAR-ANTON, PH.D.,
HACKENSACK UNIVERSITY
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Pediatric Cardiomyopathy 101

JOHN LYNN JEFFERIES, M.D.,
CINCINNATI CHILDREN'S
HOSPITAL MEDICAL CENTER

Exploring Medical Imaging

TIMOTHY WONG, M.D. AND BRIAN
FEINGOLD, M.D., UNIVERSITY
OF PITTSBURGH MEDICAL CENTER
CHILDREN'S CARDIOMYOPATHY
FOUNDATION

Fundraising



Fundraising Highlights



- The Sixth Annual Poker Event at Providence in New York City was held on February 12 and attended by 265 guests and 42 sponsors. The event raised \$249,545.
- The Twelfth Annual Golf Classic at Montclair Golf Club, NJ, held on July 21, was attended by more than 240 guests and 61 sponsors raising \$360,405.
- CCF's Spring and Holiday appeals raised \$87,314 in total.
- Fundraisers planned by CCF families and friends brought in more than \$59,778.

"This was such a great way for us to have a fundraiser in honor of my son, Chase, who has HCM. We appreciate all the support from everyone in our town."

MICHELLE NOWAK
BIG HEART BAKE SALE
SAN ANTONIO, TEXAS

"This was an amazing experience for Cristina, who had a starring role in the school play. Thank you CCF for all you do in supporting kids and keeping the search for a cure alive."

HEATHER CINCA
WILLY WONKA SCHOOL FUNDRAISER
COCOA BEACH, FLA.

Financial Summary Statement

FISCAL YEAR ENDING DECEMBER 31, 2014

STATEMENT OF FINANCIAL POSITION

ASSETS

| | |
|-------------------------|--------------------|
| Cash & Cash Equivalents | \$639,994 |
| Investments | \$1,543,986 |
| Property & Equipment | — |
| TOTAL ASSETS | \$2,183,980 |

LIABILITIES & NET ASSETS

| | |
|---|--------------------|
| Current Liabilities | — |
| Net Assets — Unrestricted | \$2,123,980 |
| Net Assets — Temporary Restricted | \$60,000 |
| Net Assets — Permanently Restricted | — |
| TOTAL NET ASSETS | \$2,183,980 |
| TOTAL LIABILITIES & NET ASSETS | \$2,183,980 |

STATEMENT OF ACTIVITIES

PUBLIC SUPPORT & REVENUE

| | |
|---|--------------------|
| Contributions | \$166,861 |
| Grants | \$60,000 |
| Fundraising | \$761,042 |
| Interest & Dividends | \$23,963 |
| Unrealized Gains | \$149,608 |
| TOTAL PUBLIC SUPPORT & REVENUE | \$1,161,474 |

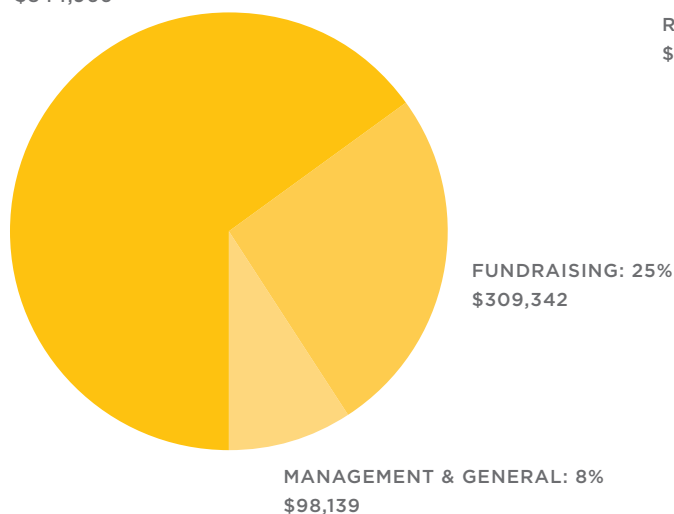
OPERATING COSTS

| | |
|------------------------------|--------------------|
| Programs & Services | \$844,966 |
| Management & General | \$98,139 |
| Fundraising | \$309,342 |
| TOTAL OPERATING COSTS | \$1,252,477 |

NET INCOME \$(90,973)

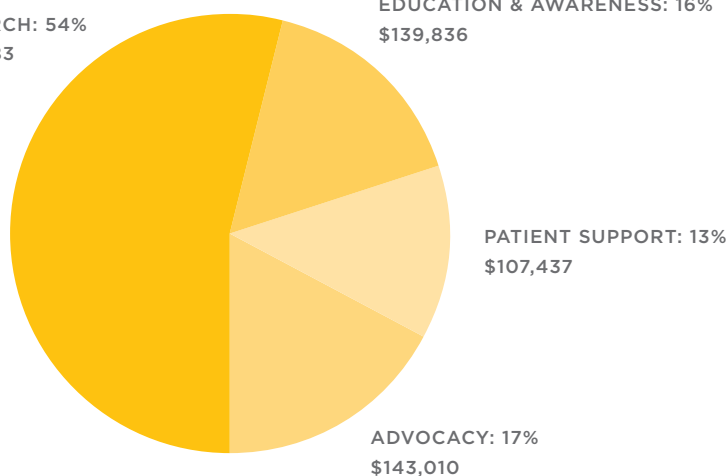
TOTAL EXPENSES

PROGRAMS & SERVICES: 67%
\$844,966



EXPENSES BY PROGRAM & SERVICES

RESEARCH: 54%
\$454,683



2014 Top Donors

The following corporations, foundations and individuals have made significant contributions to CCF in 2014, and we gratefully acknowledge their generosity. Due to space limitations we are unable to list all our donors but extend our heartfelt thanks to all who have contributed.

\$10,000 AND OVER

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Jordan Teramo
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US Cellular
Parag Vora
Spencer Wells

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Dustin Cappelletto
Matthew Carter

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Jodi Costa
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Solomon Noh
Joseph Norman
Michelle Nowak
Jennifer Parker
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Mark Rambler
Brian Reid
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