



# A BRIGHTER FUTURE

CHILDREN'S CARDIOMYOPATHY FOUNDATION

2016 ANNUAL REPORT

## FOUNDER'S LETTER



Dear Friends,

There is a brighter future for kids with cardiomyopathy, and we need to continue working towards better outcomes and ultimately cures. While scientific research may appear to not be moving fast enough, the reality is we are making progress slowly and steadily.

When the biopharmaceutical firm MyoKardia announced in 2016 they were working on a small molecule drug to target the underlying genetic cause for inherited cardiomyopathies, I was extremely excited. We have finally reached a stage where clinical trials on a therapy for children with cardiomyopathy may be a possibility. I am proud to work with MyoKardia on several patient initiatives as we continue to focus on accelerating research and education on the disease.

Making advancements in research truly is a collaborative effort, and I am thrilled that in 2016 we joined forces with the Kyle John Rymiszewski Foundation to establish a pediatric cardiomyopathy research scholar program. We also continued our multi-center research partnership with the Pediatric Cardiomyopathy Registry (PCMR) and funded four studies on genetics and patient management.

It has been encouraging to see friends and families come together to support these initiatives at our Golf for a Cure, Night for a Cure during National Heart Month, and Walk for a Cure during Children's Cardiomyopathy Awareness Month. In addition, Bake for a Cure is gaining momentum as kids, families, and CCF supporters get creative in raising awareness of pediatric cardiomyopathy in their community.

What we hope to achieve may still seem far on the horizon, but if we continue working together towards that goal we will eventually get to our destination.

Sincerely,

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

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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*Children's Hospital of Michigan*

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## CCF STAFF

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*Patient Outreach & Support Director*

Shari Maurer  
*Patient Outreach & Support Coordinator*

Lauren Zenreich  
*Executive Assistant & Bookkeeper*



RESEARCH

# RESEARCH

- Awarded research grants to five new investigators studying various forms of cardiomyopathy affecting children.

JUAN ALEJOS, M.D. AND  
PATRICIA LESTER, M.D.

Integrated Family-Centered  
Behavioral Health Screening &  
Preventive Intervention for  
Pediatric Cardiomyopathy

UNIVERSITY OF CALIFORNIA, LOS ANGELES

ANGELIKI ASIMAKI, PH.D.

The Role of GSK3 in the Pathogenesis  
of Arrhythmogenic Cardiomyopathy

BETH ISRAEL DEACONESS MEDICAL CENTER

BAHIG SHEHATA, M.D.

Genetic Analysis to Identify Inheritance  
Patterns in Histiocytoid Cardiomyopathy

EMORY UNIVERSITY SCHOOL OF MEDICINE

NOAH WEISLEDER, PH.D.

Targeting Membrane Repair to Treat  
Pediatric Dilated Cardiomyopathy

OHIO STATE UNIVERSITY

- Joined force with the Kyle John Rymiszewski Foundation to establish a pediatric cardiomyopathy research scholar program.

**“Innovation is best designed by listening to those on the front lines of healthcare delivery—patients and clinicians.”**

—PEDIATRIC CARDIOMYOPATHY RESEARCH  
SCHOLAR, PAUL BARACH, M.D., M.P.H.,  
WAYNE STATE UNIVERSITY



- Pediatric Cardiomyopathy Research Scholar, Paul Barach, M.D., M.P.H., delivered five invited talks and keynote presentations on findings from the Pediatric Cardiomyopathy Registry.
- Published a special cardiomyopathy series in *Progress in Pediatric Cardiology* consisting of 12 manuscripts from CCF's International Conference on Cardiomyopathy in Children.
- CCF Founding Executive Director, Lisa Yue, published “From Partnership to Progress in the Field of Pediatric Cardiomyopathy,” in *Progress in Pediatric Cardiology*.

# RESEARCH

- Funded the Pediatric Cardiomyopathy Registry working group session at the Children's Hospital of Michigan.
- Published findings from several CCF-funded research studies in eight peer-reviewed medical journals.

Nanoscale Visualization of Functional Adhesion/Excitability Nodes at the Intercalated Disc

*NATURE COMMUNICATIONS*

Genotype-Dependent Calcium Signaling Dysfunction in Human Hypertrophic Cardiomyopathy

*CIRCULATION*

Deficient cMyBP-C protein expression during cardiomyocyte differentiation underlies human hypertrophic cardiomyopathy cellular phenotypes in disease specific human ES cell derived cardiomyocytes

*JOURNAL OF MOLECULAR AND CELLULAR CARDIOLOGY*

Electrocardiography Screening for Hypertrophic Cardiomyopathy

*CLINICAL ELECTROPHYSIOLOGY*

**“We are entering a new era in cardiomyopathy research and moving the field from observation to intervention.”**

—CCF-FUNDED INVESTIGATOR,  
SHARLENE DAY, M.D.,  
UNIVERSITY OF MICHIGAN



Improving Communication with Families of Patients Undergoing Pediatric Cardiac Surgery

*PROGRESS IN PEDIATRIC CARDIOLOGY*

The Benefits and Hazards of Publicly Reporting Quality Outcomes

*PROGRESS IN PEDIATRIC CARDIOLOGY*

Readmitting Children with Heart Failure: The Importance of Communication, Coordination, and Continuity of Care

*JOURNAL OF PEDIATRICS*

- Presented CCF-funded research findings at six national and international medical conferences, including the American Heart Association Scientific Sessions.



EDUCATION



# EDUCATION

- Collaborated with the American Academy of Pediatrics to include an overview on pediatric cardiomyopathy on their [healthychildren.org](http://healthychildren.org) website.
- Represented at nine medical conferences, including the International Pediatric Heart Failure Summit, Children's Hospital of Philadelphia's Update on Pediatric and Congenital Heart Disease, Southeast Pediatric Cardiology Society Meeting, and International Conference on Pediatric Mechanical Circulatory Support Systems and Cardiopulmonary Perfusion.
- Co-sponsored and presented at two Sarcomeric Human Cardiomyopathy Registry (SHaRe) family conferences at Stanford University Center for Inherited Cardiovascular Disease and Yale New Haven Hospital Heart and Vascular Center.
- Co-sponsored the American Academy of Pediatrics Specialty Review in Pediatric Cardiology in Chicago, which covered both basic science and clinical applications.



- Developed an educational video, “Know Your Heart: Genetic Testing for Cardiomyopathy Families” as an additional resource for families.
- Distributed more than 2,262 pieces of educational materials on pediatric cardiomyopathy to families, hospitals, medical meetings, and schools in the U.S. and Canada.
- Created Spanish versions of the “Cardiowhat?” booklet and other support materials for CCF’s online resource library.





# ADVOCACY & AWARENESS

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- Named as a top-rated health organization for the 6th consecutive year by one of America's leading charity evaluators, Great Nonprofits.
- Secured report language in the President's FY 2017 Budget highlighting cardiomyopathy and requesting the National Institutes of Health and the Centers for Disease Control and Prevention to direct more resources to pediatric cardiomyopathy.
- Former Miss Ohio, Lindsay Davis, who was diagnosed with hypertrophic cardiomyopathy, joins CCF in advocating for automatic external defibrillator (AED) preparedness.



## **Children's Cardiomyopathy Awareness Month September Celebration**

Thirteen national organizations supported the month-long initiative 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*

*School-Based Health Alliance*

*The Society of Thoracic Surgeons*

*Sudden Cardiac Arrest Foundation*

## ADVOCACY & AWARENESS

- CCF's 2nd Walk for a Cure was held on September 18 in West Orange, New Jersey and attracted 120 walkers. Additional awareness walks took place in Ohio, Pennsylvania, and Virginia.
- An informational webinar, "An Overview of Pediatric Cardiomyopathy," was offered in partnership with the National Association of School Nurses.
- Held the #MyCampAED scavenger hunt for the 4th consecutive year with One Beat CPR + AED and the American Camp Association.
- The Pennsylvania House of Delegates passed a resolution authored by Rep. Garth Everett declaring September as Children's Cardiomyopathy Month in Pennsylvania.



**"Safety is an important component to running a successful camp, and this generous donation of an AED to our facility means we can better serve our youth and guests."**

—2016 #MYCAMPAED HUNT WINNER,  
JULIE PETTY, CAMP FIRE



**"The road to healing is a long one, but volunteering and raising awareness have helped my family cope with an unimaginable loss."**

—JULIE SKINNER, MOM TO NOAH  
WHO LOST HIS LIFE TO HCM





# FAMILY & PATIENT SUPPORT

# FAMILY & PATIENT SUPPORT

- With more than 2,875 members from 74 countries, CCF responded to more than 1,300 phone calls and emails for assistance.
- Website was visited more than 89,097 times, and 135,113 pages of information were viewed by visitors.
- Partnered with the New York Mid-Atlantic Consortium for Genetic and Newborn Screening Services to develop an emergency card for pediatric cardiomyopathy patients.
- Launched new online community, CCF Connect, to engage more members and offer additional family resources including medical center profiles, Meet the Expert Q&A transcripts, fact sheets, heart camp listings, and webinar links.
- Launched Coffee & A Chat, an online chat for CCF members via the CCF Connect online community.
- Grew the Facebook CCF Youth Connect Group and Family Community Group to 1,200 members, resulting in more than 1,200 postings and 9,000 comments in the year.

## Extending a Helping Hand

- Provided Spanish educational materials and information on specialty centers to a father from Columbia for his 2-year-old diagnosed niece.
- Shared our heart transplant resource guide and transplant webinar for more information and resources to a father with a newly diagnosed infant daughter in the hospital waiting for a heart transplant.
- Provided bereavement support for a mom who lost her infant daughter to cardiomyopathy, including connecting her with a local parent ambassador and sharing genetic testing information and screening guidelines.
- Gave financial aid through our Financial Assistance Program to a family whose infant son was transplanted due to cardiomyopathy, including covering medical insurance premiums due to financial hardships from their child's prolonged hospitalization.



# FAMILY & PATIENT SUPPORT

- Scheduled four Meet the Expert Q & A sessions on CCF's email discussion group and three webinar programs featuring leading experts in the field.

## GENETICS AND CARDIOMYOPATHY

Stephanie Ware, M.D., Ph.D. professor of pediatrics and medical and molecular genetics, Indiana University School of Medicine

## MEDICATIONS

Heather Henderson, M.D., assistant professor of pediatrics, Duke University

## TRANSITION TO ADULT CARE FOR TEENS

Jason Hopper Cruz, R.N., heart failure and transplant nurse, Seattle Children's Hospital

## SURGICAL PROCEDURES — TRANSPLANT, LVAD AND ICD PLACEMENTS

Iki Adachi, M.D., co-director of the mechanical circulatory support program, Texas Children's Hospital

## COPING WITH LOSS

Dr. Donna Schuurman, senior director of advocacy & training, The Dougy Center

## OVERVIEW OF PEDIATRIC CARDIOMYOPATHY

Dr. Elfriede Pahl, medical director of heart transplant program, Ann and Robert Lurie Children's Hospital

## NAVIGATING DISABILITY BENEFITS

Deanna Power, director of outreach, Disability Benefits Help

“Being able to connect with others who are going through a similar terrifying experience helps to alleviate isolation. CCF also helps to keep me informed on the latest innovations in treatment and research.”

—CINDY LONG



“When a cardiologist tells you they don't know enough to answer your questions, what are you to do? CCF assisted us in dealing with the educational impact of this disease and was a place to turn to for additional medical help. Without CCF I would be lost.”

—KRISTA KONING WOODWORTH





# FUNDRAISING



## 2016 FUNDRAISING HIGHLIGHTS

- CCF's Eighth Annual Poker Event at the Edison Ballroom in New York City was held on February 10 and attended by more than 220 guests and 42 sponsors. The event raised \$202,940.
- CCF's Fourteenth Annual Golf Classic at Montclair Golf Club, N.J. took place on July 18 with 200 guests and 55 sponsors attending to raise \$329,880.
- CCF's Second Annual Walk for a Cure, held during Children's Cardiomyopathy Awareness Month, raised \$33,081.
- CCF's Spring and Holiday direct mail appeals raised \$96,454 in 2016.
- Fundraisers planned by CCF families and friends brought in \$40,332.

**"Our firm has been privileged to become involved in supporting CCF's mission."**

—PAUL HASKEL,  
RICHARDS KIBBE & ORBE



# 2016 FINANCIAL SUMMARY STATEMENT

FISCAL YEAR ENDING DECEMBER 31, 2016

## STATEMENT OF FINANCIAL POSITION

### ASSETS

Cash & Cash Equivalents	\$703,740
Investments	\$1,539,137
Property & Equipment	—
<b>TOTAL ASSETS</b>	<b>\$2,242,877</b>

### LIABILITIES & NET ASSETS

Current Liabilities	—
Net Assets: Unrestricted	\$2,209,903
Net Assets: Temporary Restricted	\$32,974
Net Assets: Permanently Restricted	—
<b>TOTAL NET ASSETS</b>	<b>\$2,242,877</b>
<b>TOTAL LIABILITIES &amp; NET ASSETS</b>	<b>\$2,242,877</b>

## STATEMENT OF ACTIVITIES

### PUBLIC SUPPORT & REVENUE

Contributions	\$154,407
Grants	\$32,974
Fundraising	\$712,175
Interest & Dividends	\$47,556
Unrealized Gains	\$116,480

<b>TOTAL PUBLIC SUPPORT &amp; REVENUE</b>	<b>\$1,063,592</b>
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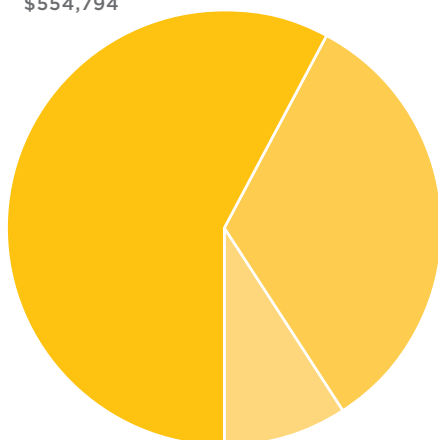
### OPERATING COSTS

Programs & Services	\$554,794
Management & General	\$90,276
Fundraising	\$316,743

<b>TOTAL OPERATING COSTS</b>	<b>\$961,813</b>
<b>NET INCOME</b>	<b>\$101,779</b>

## TOTAL EXPENSES

PROGRAMS & SERVICES: 58%  
\$554,794

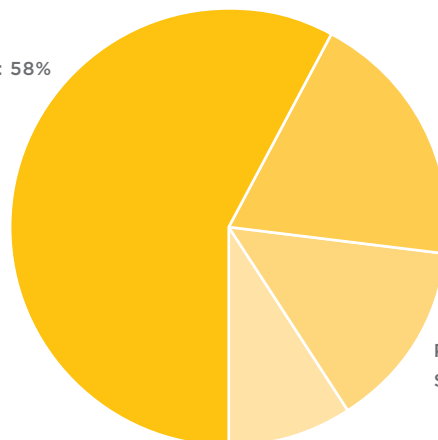


MANAGEMENT & GENERAL: 9%  
\$90,276

RESEARCH: 58%  
\$320,861

FUNDRAISING: 33%  
\$316,743

## EXPENSES BY PROGRAM & SERVICES



ADVOCACY: 9%  
\$48,344

# CIRCLE OF HEARTS HONORING 2016 TOP DONORS

The following corporations, foundations, and individuals have made significant contributions to CCF, and we gratefully acknowledge their support. Due to space limitations we are unable to list all our 2016 supporters but extend our heartfelt thanks to all who have contributed.

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# CIRCLE OF HEARTS HONORING 2016 TOP DONORS

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