

Progress by the Numbers

2018
Annual Report

**CHILDREN'S
CARDIOMYOPATHY
FOUNDATION**





Dear Friends,

Last year, the Children's Cardiomyopathy Foundation (CCF) embarked on a plan to increase its visibility and elevate its profile within the medical, patient, and legislative communities. Building upon strategic partnerships, community alliances, and research collaborations, CCF has broadened its reach to serve more families, patients, and doctors. While the numbers speak for themselves, I'd like to share a few highlights from 2018.

Two funding opportunities were offered to support young investigators pursuing research on pediatric cardiomyopathy. The first, CCF's inaugural early career research grant, was established through a partnership with the American Academy of Pediatrics. The second, a pediatric cardiomyopathy research scholar award, was renewed through a collaboration with the Kyle John Rymiszewski Foundation. In addition, five new centers qualified to be CCF Accredited Care Centers, bringing the total number to 38 centers that offer high quality and specialized pediatric cardiomyopathy care.

Advocacy and awareness efforts related to sudden cardiac arrest awareness, prevention, and survival included CCF's AED Hunt on the Hill and Children's Cardiomyopathy Awareness Month activities. At the Federal level, getting cardiomyopathy added to the congressionally directed Peer Reviewed Medical Research Program with the Department of Defense was a significant achievement that opened up millions of dollars for cardiomyopathy research.

Lastly, our signature fundraisers and family-led community events continue to unite more people in raising awareness and funds for cardiomyopathy research. In the coming year, I am confident that we can multiply our impact exponentially as we embark on new initiatives to improve the quality of life for children with cardiomyopathy.

Sincerely,

A handwritten signature in black ink that reads "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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Janine Burke
Medical Outreach Manager

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Research





4 CCF Research Grants

Four new pilot studies were funded through CCF's research grant program. This initiative provides investigators with seed funding for the testing of research hypotheses and the collection of preliminary data to secure long-term funding from the National Institutes of Health.

- **STEVEN GREENWAY, M.D.**
Modeling Novel Therapeutics for DCMA:
A Mitochondrial Cardiomyopathy
University of Calgary
Alberta, Canada
- **AMY KONTOROVICH, M.D., PH.D.**
Elucidating the Genetics of Myocarditis-
Related Cardiomyopathy
Icahn School of Medicine at Mount Sinai
New York, N.Y.
- **SHELLEY MIYAMOTO, M.D., CAROLYN HO, M.D., KIKI SUCHAROV, PH.D.**
Circulating MicroRNA in Genotype-Positive Hypertrophic Cardiomyopathy
University of Colorado
Denver, Colo.
- **KATHLEEN SIMPSON, M.D.**
Distinction of Serum Biomarkers in Heart Failure Between Children and Adults with Dilated Cardiomyopathy
University of Washington
St. Louis, Mo.



- “Lessons and Results from the Late Gadolinium Enhancement (LGE) in Hypertrophic Cardiomyopathy Study”
Society for Cardiovascular Magnetic Resonance Scientific Sessions
Barcelona, Spain
- “Strengthening Resilience in Children with Cardiomyopathy and their Families: The FOCUS-PAC Model”
American Psychological Association
San Francisco, Calif.



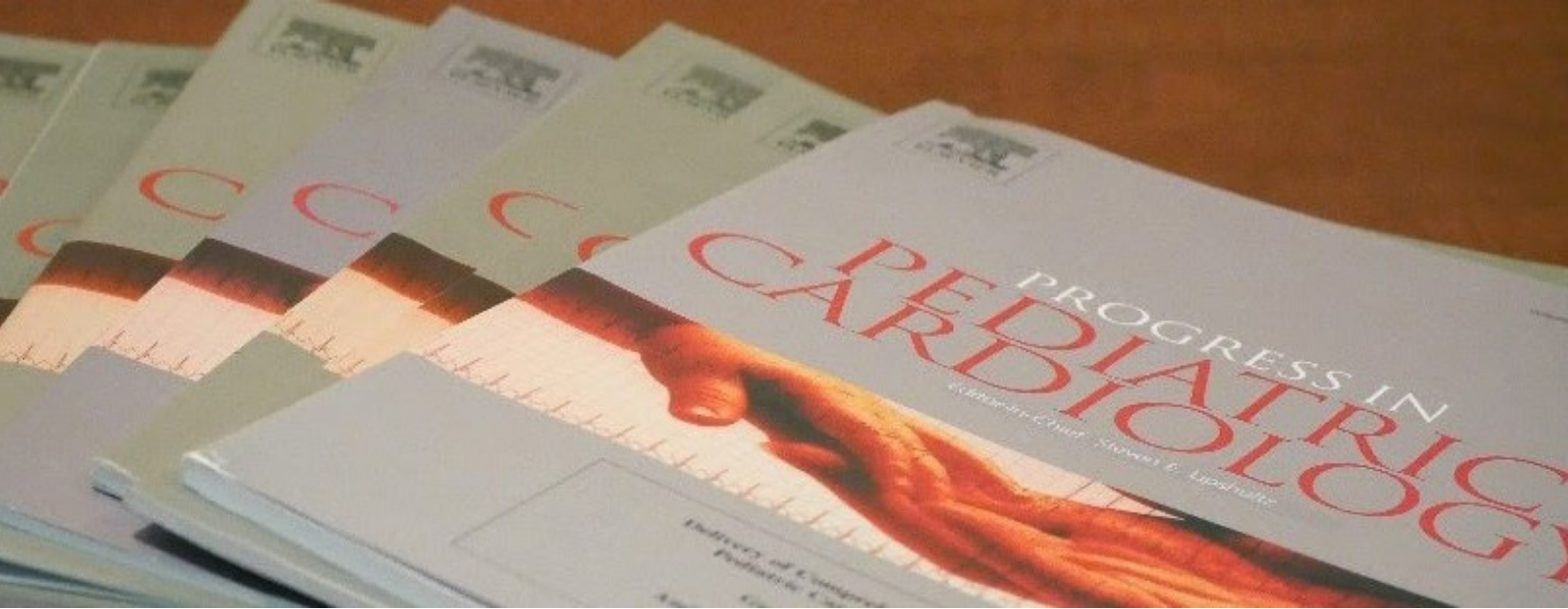
- “HSC70 is a Chaperone for Wild-Type and Mutant Cardiac Myosin Binding Protein C”
JCI Insight



6 Pediatric Cardiomyopathy Registry Presentations

CCF continues to fund multi-center studies with the Pediatric Cardiomyopathy Registry (PCMR) to understand regional, ethnic, gender, and age differences in cardiomyopathy and identify clinical factors to predict mortality, congestive heart failure, and the likelihood for heart transplantation. Study findings were presented at medical meetings in the U.S. and Canada.

- “Phenotype, but Not Genotype Determines Survival in Pediatric Dilated Cardiomyopathy”
American Heart Association Scientific Sessions
Chicago, Ill.
- “Cardiac Biomarkers Are Associated with Death and Listing for Heart Transplantation in Pediatric Patients with Newly Diagnosed Dilated Cardiomyopathy”
Pediatric Academic Societies Meeting
Toronto, Canada
- “Fibrosis and Hypertrophy Assessed by Magnetic Resonance Imaging (MRI) and Serum Biomarkers in Pediatric Hypertrophic Cardiomyopathy”
Pediatric Academic Societies Meeting
Toronto, Canada
- “Clinical Genetic Panel Test Results for Pediatric Cardiomyopathy After Exome Sequencing”
Pediatric Academic Societies Meeting
Toronto, Canada
- “The Frequency of Mutations in Known Cardiomyopathy Genes Among Children with Hypertrophic Cardiomyopathy”
American College of Cardiology
Orlando, Fla.
- “Are Echocardiogram and Magnetic Resonance Imaging Comparable in Measuring Maximal Septal Thickness in Children with Hypertrophic Cardiomyopathy”
Pediatric Academic Societies Meeting
Toronto, Canada



1

**PCMR MANUSCRIPT
PUBLISHED IN
WELL-REGARDED
MEDICAL JOURNAL**

“No Obesity Paradox in Pediatric Patients with Dilated Cardiomyopathy” was published in *Journal of the American College of Cardiology: Heart Failure*

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**PCMR RESEARCHERS
ATTEND CCF-SPONSORED
WORKING GROUP
MEETING**

Cardiomyopathy specialists convened in Metairie, La. to determine research priorities, review study findings, and discuss new manuscript and research partnerships.



“CCF continues to be an active supporter of the National Institutes of Health-funded Pediatric Cardiomyopathy Registry and has been instrumental in accelerating multi-center studies on the disease.”

—Steven Lipshultz, M.D., Chair of Pediatrics,
University of Buffalo, N.Y.



1 Pediatric Cardiomyopathy Early Career Research Award

A partnership was established with the American Academy of Pediatrics Section on Cardiology and Cardiac Surgery to create a new award for early career researchers interested in advancing medical knowledge of pediatric cardiomyopathy and developing diagnostic guidelines and targeted therapies.

- **MEGHNA D. PATEL, M.D.**
DANIEL BERNSTEIN, M.D.
GREGORY HAMMER, M.D.

Immunologic Profiling Correlated to Outcomes
in Pediatric Heart Failure Patients After Left
Ventricular Assist Device Placement
Stanford University
Palo Alto, Calif.

American Academy
of Pediatrics



12

ARTICLES PUBLISHED IN *PROGRESS IN PEDIATRIC CARDIOLOGY*

Special issue in June included proceedings from CCF's International Scientific Conference on Cardiomyopathy in Children.

- "Obstacles to prediction of outcome in pediatric cardiomyopathy."
- "A dynamic risk management approach to reduce harm in hypertrophic cardiomyopathy."
- "Genetics of pediatric cardiomyopathies."
- "Towards a learning system for pediatric outcomes: Harvesting meaning from evidence."
- "Differential response to heart failure medications in children."
- "Risk stratification in pediatric hypertrophic cardiomyopathy: Insights for bridging the evidence gap?"
- "Implantable cardioverter defibrillators and biventricular pacing in pediatric dilated cardiomyopathy: Preventing death and delaying heart transplant."
- "Cardiac rehabilitation in pediatric cardiomyopathy."
- "Utilization of VADs in children with restrictive and hypertrophic cardiomyopathy: Are we there yet?"
- "Circulating microRNAs as biomarkers in pediatric heart diseases."
- "Targeting protein kinase C: A novel paradigm for heart failure therapy."
- "Neurohormonal targets in the treatment of pediatric heart failure."

Other Research Achievements

- Special issue on "Delivery of Comprehensive Care in Pediatric Cardiac Disease" consisting of 13 articles published in *Progress in Pediatric Cardiology*.
- Partnered with the Kyle John Rymiszewski Foundation to fund the second Pediatric Cardiomyopathy Research Scholar Award.
- "When is Early Septal Myectomy in Children with Hypertrophic Cardiomyopathy Justified?" in *Translational Pediatrics* is third article by CCF-sponsored Pediatric Cardiomyopathy Research Scholars.



Neha Bansal, M.D. and Paul Barach, M.D.

Education





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HOSPITALS AND MEDICAL CENTERS

The CCF Accredited Centers of Care program recognizes centers for providing high-quality cardiac care and specialized disease management to children with cardiomyopathy.

2

NEW PATIENT FACT SHEETS

In 2018 CCF published the following educational materials: “Transition to College Tips and Checklist” and “Glossary of Common Terms Related to Cardiomyopathy.”



3,682

PIECES OF EDUCATIONAL MATERIALS DISTRIBUTED

CCF literature reached families, hospitals, medical meetings, and schools in the U.S. and Canada.

1

NATIONAL PEDIATRIC TRANSPLANT WEEK

CCF partnered with the United Network for Organ Sharing, Transplant Families, and other national transplant societies for the inaugural awareness week in April.

Advocacy & Awareness





Federal Advocacy

- Included cardiomyopathy in the FY18 Senate defense appropriations bill as an approved disease topic for federal funding under the U.S. Department of Defense Peer-Reviewed Medical Research Program, which provided additional federal funding options for cardiomyopathy researchers.
- Nominated 4 CCF advocates to serve as consumer reviewers on cardiomyopathy for the Department of Defense Peer Review Medical Research Program.

“CCF is one of the reasons our grandson just celebrated his 20th birthday.”

—Dale & Imogene Davis



Awareness Initiatives

5

MEMBERS OF CONGRESS ISSUED
CONGRESSIONAL RECORD
STATEMENTS DURING CHILDREN'S
CARDIOMYOPATHY AWARENESS MONTH.

34

STATES PARTICIPATED IN CCF'S UNITING
HEARTS ACROSS AMERICA CAMPAIGN
DURING NATIONAL HEART MONTH, SHARING
DISEASE FACTS ON SOCIAL MEDIA,
SENDING CCF VALENTINE CARDS, AND
HOSTING BAKE FOR A CURE EVENTS.



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NATIONAL ORGANIZATIONS SUPPORTED THE CHILDREN'S CARDIOMYOPATHY AWARENESS MONTH IN SEPTEMBER

Partners supported the month-long initiative with blogs, newsletter articles, website mentions, and social media postings.

- American Academy of Pediatrics
- American College of Cardiology
- American Heart Association
- American Public Health Association
- EAC Foundation
- George F. Jefferson Foundation
- Harboring Hearts
- Joseph Middlemiss Big Heart Foundation
- National Alliance for Youth Sports
- National Association of School Nurses
- National Athletic Trainers' Association
- Parent Heart Watch
- Phosphorus
- Sarcomeric Human Cardiomyopathy Registry
- School-Based Health Alliance
- Society of Thoracic Surgeons
- Sudden Cardiac Arrest Foundation

Patient & Family Support





4 Meet the Expert Q&A Sessions on CCF Connect Discussion Forum

- **TRANSITION FROM PEDIATRIC TO ADULT CARE**

Megan Zakrzewski, N.P. and
Robert Winchester, N.P.
Joe DiMaggio Children's Hospital
Hollywood, Fla.

- **GENETIC TESTING CONSIDERATIONS**

Erin Miller, M.S.
Cincinnati Children's Hospital Medical Center
Cincinnati, Ohio

- **CARDIAC ELECTROPHYSIOLOGY**

Jennifer Avari Silva, M.D.
St. Louis Children's Hospital
St. Louis, Mo.

- **PROVIDING EMOTIONAL SUPPORT TO CARDIOMYOPATHY PATIENTS**

Melissa Cousino, M.D.
C.S. Mott Children's Hospital
Ann Arbor, Mich.

7 Webinars Featuring Leading Experts in the Field

- **DEVELOPMENTS IN RESEARCH AND TREATMENT IN PEDIATRIC CARDIOMYOPATHY**

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

- **OVERVIEW OF PEDIATRIC HEART TRANSPLANTS**

Betsy Blume, M.D.
Boston Children's Hospital

- **CHILD LIFE: SERVICES AND BENEFITS TO PATIENTS AND FAMILIES**

Brittany Smith, M.A., CCLS
Ann & Robert H. Lurie Children's Hospital

- **ADHERENCE AND TRANSITION CONSIDERATIONS**

Diana Shellmer, Ph.D.
Children's Hospital of Pittsburgh at UPMC

- **EXERCISE AND SPORTS IN THE CARDIOMYOPATHY PATIENT**

Rachel Lampert, M.D., Sharlene Day, M.D.
Yale School of Medicine and
University of Michigan

- **INTRODUCTION TO CCF CONNECT**

Gina Peattie, M.P.A.
Children's Cardiomyopathy Foundation

- **OVERVIEW OF THE PANORAMA-HEART FAILURE RESEARCH STUDY**

Robert Shaddy, M.D.
Children's Hospital Los Angeles

"The Children's Cardiomyopathy Foundation is a great resource and source of strength for families dealing with pediatric cardiomyopathy."

—Jennifer Maria K.



Betsy Blume, M.D., Director of Heart Failure & Transplant Program, Boston Children's Hospital

140

NEW MEMBERS INCREASED
CCF'S COMMUNITY TO

3,203

MEMBERS FROM

77

COUNTRIES

41,218

WEBSITE VISITS AND

84,282

PAGES OF INFORMATION
VIEWED BY VISITORS

815

PHONE CALLS AND
EMAILS FOR ASSISTANCE

1,636

FACEBOOK MEMBERS GENERATED

810

POSTINGS AND

8,500

COMMENTS IN THE YEAR

274

DISCUSSION THREADS GENERATED ON
CCF CONNECT'S DISCUSSION FORUM



12 International Medical Conferences

The Children's Cardiomyopathy Foundation expanded its public presence by supporting or participating in scientific and medical conferences worldwide and through sponsorship of key events hosted by professional organizations focused on pediatric cardiology.

- 24th Annual Cardiologists Conference
- American Academy of Pediatrics Specialty Review on Pediatric Cardiology
- American Heart Association Scientific Sessions
- Children's Hospital of Philadelphia Pediatric Cardiology Conference
- 25th Congress on Cardiology and Medical Intervention
- SHaRe Registry Affairs of the Heart Family Conferences

"With CCF's ongoing research support, I hope to identify medical and psychosocial factors that positively and negatively impact patients and families."

—Kristi Glotzbach, M.D.,
Assistant Professor, University of Utah



“I would be lost without CCF and all the heart moms and dads that I have met from the support group.”

—Erin Noonan, parent

“I met a mother who lost a child to cardiomyopathy. She is immensely grateful for CCF; she felt so supported by other parents who understand where she is coming from.”

—Kimberly Y. Lin, M.D., Assistant Professor,
Children’s Hospital of Philadelphia



“CCF’s ongoing effort to provide education, family support, and research funding is something to be proud of.”

—Sarah Foye, parent

2018 Fundraisers





10TH ANNUAL POKER EVENT
FEBRUARY 7, 2018
EDISON BALLROOM, NEW YORK CITY

300

GUESTS

50

CORPORATE SPONSORS

\$259,495

RAISED



16TH ANNUAL GOLF CLASSIC
AUGUST 6, 2018
MONTCLAIR GOLF CLUB, NEW JERSEY

190

ATTENDEES

60

CORPORATE SPONSORS

\$334,135

RAISED



4TH ANNUAL WALK FOR A CURE
SEPTEMBER 30, 2018
SOUTH MOUNTAIN RECREATION COMPLEX, NEW JERSEY

150

WALKERS

\$44,240

RAISED



\$74,584

COMMUNITY & FAMILY FUNDRAISERS

\$23,645

FACEBOOK FUNDRAISERS

\$57,965

SPRING & HOLIDAY APPEALS

2018 Financial Summary Statement

Fiscal year ending December 31, 2018

STATEMENT OF FINANCIAL POSITION

ASSETS

Cash & Cash Equivalents	\$951,109
Investments	\$1,386,450
TOTAL ASSETS	\$2,399,403

NET ASSETS

Unrestricted Net Assets	\$2,399,403
TOTAL NET ASSETS	\$2,399,403

STATEMENT OF ACTIVITIES

REVENUE

Contributions	\$128,070
Fundraising	\$803,199
Interest & Dividends	\$39,300
Realized & Unrealized Investment Gains	(\$136,640)

TOTAL REVENUE	\$833,929
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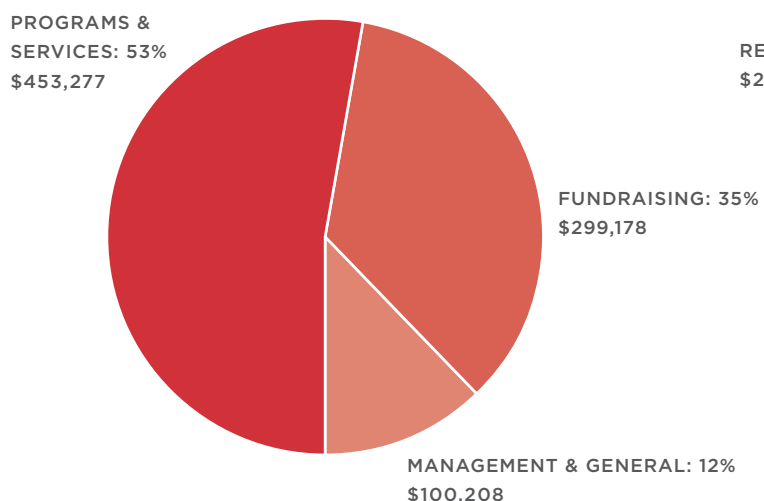
EXPENSES

Programs & Services	\$453,277
Management & General	\$100,208
Fundraising	\$299,178

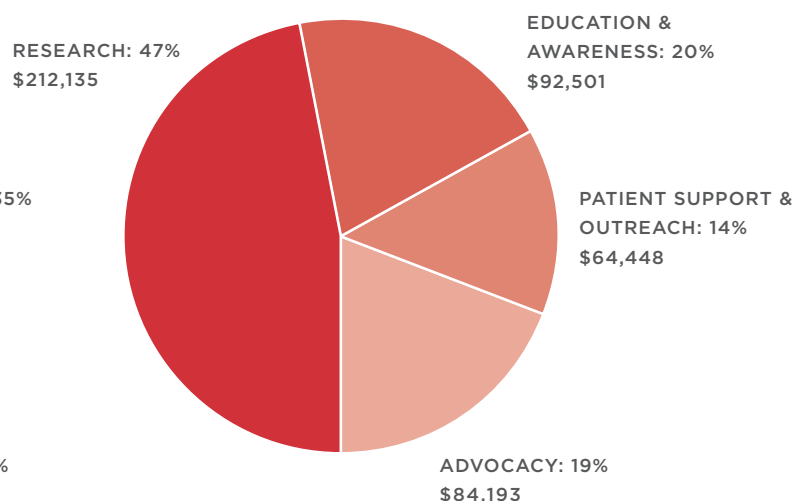
TOTAL EXPENSES	\$852,663
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NET INCOME	(\$18,734)
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TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



2018

Circle of Hearts CCF Top Donors

We extend our heartfelt thanks to all who have contributed to the Children's Cardiomyopathy Foundation this year. The following corporations, foundations, and individuals have made significant contributions to the Foundation in 2018.

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