Children's Cardiomyopathy Foundation

2012 ANNUAL REPORT

YEARS

Helping Kids with Cardiomyopathy

Ten Years of Helping Children with Cardiomyopathy and their Families

Dear Friends,

It is hard to believe that ten years have past since CCF was established. A decade ago, outcomes for children with cardiomyopathy were dismal with little research being conducted and no existing support services for those living with this chronic heart disease. Now CCF is a worldwide community, with nearly 2,000 members from more than 60 countries, focused on accelerating research and providing resources to affected families. This year has special meaning in that it marks ten years of progress in honor of children with cardiomyopathy.

2012 was a remarkable anniversary year for CCF. The year started off with the introduction of the Cardiomyopathy HEARTS bill to the Senate and being named a top-rated health organization for the second consecutive year. Three new research grants were funded, findings from four CCF-funded studies were published and a CCF supported investigator was awarded multi-year funding from the National Institutes of Health (NIH). Receiving a coveted NIH grant during these challenging economic times is a great victory for the cardiomyopathy community, and it underscores the importance of CCF's research grant program.

These achievements would not have happened without the steadfast support of our CCF community. In this report, we feature photos of the children and their families living with cardiomyopathy as a tribute to the people who inspire us everyday in our work. We hope it warms your heart to see the children you are helping and to read the positive comments that others have shared with CCF.

Thank you for being a part of CCF through the years. The next decade holds great promise as we work together towards a brighter future for children with cardiomyopathy and their families.

Sincerely,

Lisa Yue

Lisa Yue
President and Founder

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)
- Hypertropic cardiomyopathy (HCM)
- Restrictive cardiomyopathy (RCM)
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Left ventricular non-compaction cardiomyopathy (LVNC)

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RESEARCH

- Carmelo Milano, M.D., associate professor of surgery at Duke University was awarded $500,000 from the National Heart, Lung, and Blood Institute (NIHLBI), a division of the National Institutes of Health, following his CCF–funded study "Expanding the Donor Pool for Pediatric Heart Transplant."
- The Pediatric Cardiomyopathy Registry, with support from CCF, received $14.2 million in grants from the National Heart, Lung, and Blood Institute for two multi-center studies, "Genotype-Phenotype Associations in Pediatric Cardiomyopathy" and "Cardiac Biomarkers in Pediatric Cardiomyopathy."

"These studies are game changers for physicians, surgeons and parents as they point the way to improve transplant outcomes."

—STEVE E. LIPSHULTZ, M.D.,
PROFESSOR OF PEDIATRICS,
UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE

"Over nearly a decade, CCF's support of the Pediatric Cardiomyopathy Registry has resulted in dozens of publications in medical research journals, whose findings positively affect the lives of children with cardiomyopathy and their families."

—JAMES WILKINSON, M.D., M.P.H.,
DIRECTOR OF THE PCMR ADMINISTRATIVE COORDINATING CENTER,
UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE

RESEARCH

DANIELA CIHAKOVA, M.D., Ph.D.

"Drivers of pediatric dilated cardiomyopathy"

JOHNS HOPKINS UNIVERSITY

MARK FRIEDBERG, M.D.

"Patterns and clinical significance of electro-mechanical dyssynchrony in pediatric dilated cardiomyopathy"

TORONTO HOSPITAL FOR SICK CHILDREN

CARMEN SUCHAROV, Ph.D.

"MicroRNA expression in children with heart failure"

UNIVERSITY OF COLORADO AT DENVER

CCF RESEARCH GRANTS

- Awarded $144,550 in research grants in 2012 to new investigators Daniela Cihakova, M.D., Ph.D. of Johns Hopkins University; Mark Friedberg, M.D. of Toronto Hospital for Sick Children; and Carmen Sucharov, Ph.D. of University of Colorado in Denver.
- To date, the number of publications and presentations resulting from CCF research grants total 57.

CCF SUPPORTED PEDIATRIC CARDIOMYOPATHY REGISTRY STUDIES

- Committed $75,000 to the National Heart, Lung, and Blood Institute Pediatric Cardiomyopathy Registry to assist with patient recruitment on a multi-center genotype-phenotype study.
- Resulted in four published manuscripts and abstract in leading peer-reviewed medical journals: *Circulation, American Heart Journal* and *Journal of the American College of Cardiology.*
- To date, the number of publications and presentations resulting from CCF-funded PCMR studies total 19.

> "Since CCF was formed, there has been much progress in the field of pediatric cardiomyopathy. As a CCF grant recipient, I know the impact CCF's support can have. To finally have answers for parents is incredibly rewarding, and this would not have been possible without funding from CCF."
>
> STEPHANIE WARE, M.D., Ph.D.,
> CO-DIRECTOR OF THE DIAGNOSTIC CARDIOMYOPATHY CLINIC,
> CINCINNATI CHILDREN'S HOSPITAL

EDUCATION

EDUCATION

- Distributed more than 2,000 pieces of literature to families, hospitals and schools.
- Represented at more than 10 national and international medical conferences including the American Academy of Pediatrics Annual Conference, American Heart Association Scientific Sessions, Canadian Association of Genetic Counselors and Parent Heart Watch Annual Meeting.
- Sponsored the Pediatric Heart Failure Group meeting in Los Angeles, C.A. to focus on improving heart failure care in children.
- Presented at the Winthrop University Hospital Hypertrophic Cardiomyopathy Conference in Mineola, NY.
- Partnered with the Children's Heart Foundation to sponsor a PBS documentary on congenital heart disease titled, *The Heart of the Matter*.

> "As a healthcare provider, CCF has helped me have a better understanding of the cardiomyopathy journey. Each story I read makes me more passionate about what I do for these special children and their families."

—JENNY NOVA, R.N.,
TRANSPLANT COORDINATOR,
CHILDREN'S HOSPITAL AT MONTEFIORE

> "We are very grateful to have the genuine support from such important organizations as CCF to advance the field of pediatric heart failure, as there is currently enormous interest in advancing this critical field."

—YUK MING LAW, M.D.,
DIRECTOR OF CARDIAC TRANSPLANT AND HEART FAILURE,
SEATTLE CHILDREN'S HOSPITAL

ADVOCACY & AWARENESS

ADVOCACY & AWARENESS

- Named as a top-rated health organization for the second consecutive year by American's leading charity evaluators Great Nonprofits, Charity Navigator, GuideStar and Global Giving.

- Introduced the first-ever cardiomyopathy legislation to the Senate during National Heart Month in February. The Cardiomyopathy Health Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act was introduced by Senators Frank R. Lautenberg and Robert Menendez.

- Grassroots initiative for support of the Cardiomyopathy HEARTS Act resulted in more than 874 letters to lawmakers in 37 states. Under CCF's leadership, the bill garnered the support of 19 cosponsors and 36 organizations by year-end.

- Presented testimony to the New Jersey Senate Health and Human Services and Senior Citizens Committee to support bill S.1911, the Children's Sudden Cardiac Events Reporting Act.

> "When I first met with the Children's Cardiomyopathy Foundation, I was shocked to learn about the lack of federal efforts in educating parents and school administrators about this devastating disease."
>
> —U.S. SENATOR ROBERT MENENDEZ

ADVOCACY & AWARENESS

- Joined U.S. Representatives Charles Rangel, Jerrold Nadler, Carolyn Maloney and members of the Associated Medical Schools of New York at a press conference at Columbia University Medical Center to urge Congress to reject 2013 budget cuts to the National Institutes of Health, Medicare and Title VII health professions programs.
- Worked alongside 46 organizations of the Sudden Cardiac Arrest Coalition as a steering committee member to obtain 10,000 petition signatures to raise awareness of sudden cardiac arrest and ask the U.S. Secretary of Education and U.S. Secretary of Health and Human Services to increase automatic external defibrillators in schools and public places.
- Worked on the planning committee with the American Heart Association to welcome the newly appointed director of the National, Heart, Lung, and Blood Institute, Gary H. Gibbons, M.D.
- Partnered with the Sudden Cardiac Arrest Foundation on the higher education "You can Save a Life" campaign to generate awareness of sudden cardiac arrest among college students.

> I want to personally thank the staff at CCF who dedicate every day of their lives to helping children and their families with cardiomyopathy. They are doing great work for all of us.
>
> MATT PROTAS, 21, HCM DIAGNOSED AT AGE 15

> Nobody else knows exactly what is it like to live with cardiomyopathy, but for the families that live it, CCF connects those families and gives us the strength we need to move forward.
>
> JENNIFER AYERS, MOM TO ELEANOR, DCM, DECEASED

FAMILY & PATIENT SUPPORT

FAMILY & PATIENT SUPPORT

- Welcomed 212 new members to CCF's community this year. Currently CCF has more than 1,936 members from 61 countries.
- CCF's website was visited more than 48,000 times and visitors viewed 91,000 pages of information in 2012. This represents an average of more than 4,000 visits each month and a 39 percent increase from last year.
- Handled more than 680 phone calls and emails to patients and families in need — a 36 percent increase from last year.
- Through the Family Assistance Program, CCF awarded $14,061 to six families in need.
- The CCF Youth Connect Group on Facebook grew to 27 teen and young adult members.
- The Ambassador Program now includes 13 adult and three youth ambassadors who are trained to provide information and support to cardiomyopathy families in their area.
- Expanded CCF's support meeting format to include online meetings, which enables parents to chat with one another online in real time.
- Scheduled six "meet the expert" question and answer sessions on CCF's international member listserv, *CCF Connect.*
- Developed a treatment resource of Hypertrophic Cardiomyopathy programs in the U.S. to assist those with a family history of HCM or have multiple family members with the disease.

> "We never felt alone because there was always a link to someone in CCF's supportive community who could help. When I needed a heart transplant, instead of being scared, we had a level of understanding and comfort that we never would have had without CCF."
>
> —JOE DISANTO, 17, HCM DIAGNOSED AT AGE 11

FAMILY & PATIENT SUPPORT

WHAT CCF HAS MEANT TO FAMILIES

When my daughter was 3½ months old, she was in heart failure and we were given little hope for her future. I have received priceless advice, support and love from the caring people who work at CCF, as well as from the parents who I connect with on CCF's forum.

HEATHER TUCKER, MOM TO EVANGELINE, 5, DCM

I discovered CCF soon after my son was diagnosed, and it has changed my life. Not only has CCF been an invaluable source of information and resources, it has connected me with other families. I now have a worldwide network of friends who understand my fears and my hopes.

CAROL DAVIS, MOM TO NATHAN, 13, DCM

After my son was diagnosed with hypertrophic obstruction cardiomyopathy, I found CCF online and it gave me a reason to hope. Without CCF and the many families I have met through its forum I might not have known to look for a specialist and better facility.

ANDI COFFMAN, MOM TO JAXSON, 3, HCM

CCF is my safe harbor, my port in a storm. No matter how lost and confused I am there is always someone there to lend a hand and point out a new direction.

SHARON BELLEVILLE, MOM TO LUKE, 15, DCM/LVNC

"When I found out we had been awarded a grant from the Family Assistance Program, I just sat down at the kitchen table and cried. Thank you so much to CCF and to all the wonderful families who have donated to the fund."

LINSEY RIPPY, MOM TO MADISON AND SYDNEY, 7 AND 4, DCM

FUNDRAISING

2012 FUNDRAISING HIGHLIGHTS

- CCF's Fourth Annual Poker Event at Crimson in New York City was held on February 8 and attended by 235 guests and 30 corporate sponsors. The event raised more than $209,000.
- CCF's 10th Annual Golf Classic at Montclair Golf Club, N.J., held on July 16, was attended by a sold-out crowd of more than 225 guests raising $385,510 for cardiomyopathy research and education programs.
- CCF's spring and holiday direct mail appeals raised $77,706.
- Fundraisers planned by CCF families and friends brought in more than $73,716.

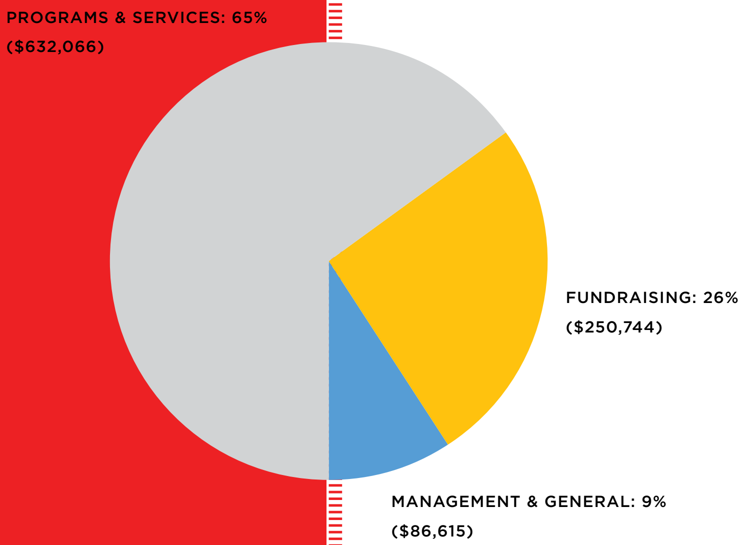
> "I'm glad that I was able to do something for CCF because the Foundation has helped me enormously in my journey."
>
> —KAVITHA BARATAKKE,
> CCF PARENT & HALF-MARATHON FUNDRAISER,
> SAN ANTONIO, TEXAS

> "I was so impressed by the supporters, who didn't know anything about cardiomyopathy but who were willing to show their support to a family who has been through a lot."
>
> —JENNIFER KIRKHAM,
> CCF PARENT AMBASSADOR & SPEAKER AT FAMILY FUNDRAISER,
> LAKE ZURICH, ILL.

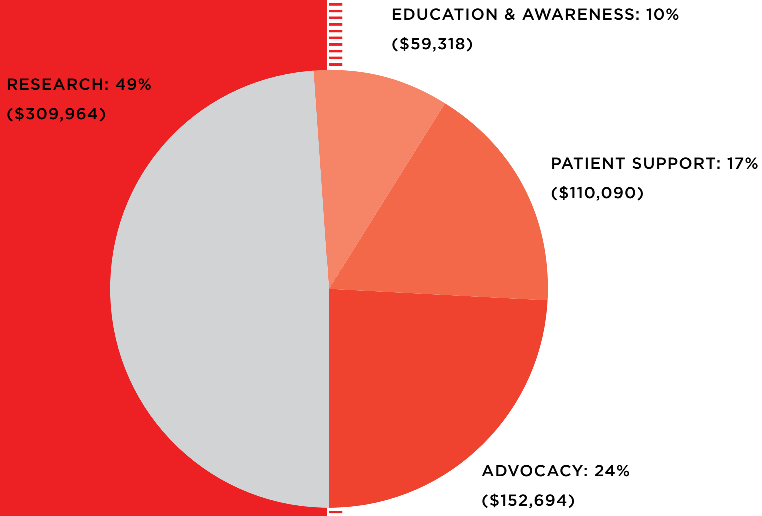
STATEMENT OF ACTIVITIES

FISCAL YEAR ENDING DECEMBER 31, 2012

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



PUBLIC SUPPORT & OTHER REVENUE

Corporations & Foundations	$103,218
Individuals	24,673
Fundraising Appeals	90,183
Fundraising Events	668,437
Grants	1,000
Interest & Dividends	25,275
Unrealized Gains & Losses	82,953
TOTAL INCOME	**$995,739**

EXPENSES

Fundraising	$250,744
Management & General	
Bank & Credit Card Processing	$9,769
Compensation	40,632
Copying & Printing	3,224
Filing Fees	3,091
Insurance	4,314
Legal & Professional Fees	8,971
Office Expenses	1,247
Payroll Service	850
Payroll Taxes & Service Fees	4,569
Postage & Freight	807
Storage Rental	3,208
Supplies	1,971
Telephone & Internet	3,962
Subtotal	$86,615
Program & Services	$632,066
TOTAL EXPENSES	**$969,425**

MAJOR DONORS & SPONSORS

HONORING 2012 TOP DONORS

CCF expresses its deep appreciation to the friends and partners who have so generously supported our work. The individuals, corporations and organizations listed below helped advance CCF's mission by making a gift of $250 or more in 2012.

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> “CCF has built strong bridges between patients, physicians and scientists so that they can work together to improve the lives of children with cardiomyopathy.”
>
> —SEEMA MITAL, M.D.,
> PEDIATRIC CARDIOLOGIST,
> TORONTO HOSPITAL FOR SICK CHILDREN

> “I am immensely grateful for CCF’s support, which gave me the resources to collect critical data and jump-start my research.”
>
> —J. CARTER RALPHE, M.D.,
> ASSISTANT PROFESSOR OF PEDIATRICS,
> UNIVERSITY OF WISCONSIN SCHOOL OF MEDICINE

Children's Cardiomyopathy Foundation™

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