Dear Friends,

More than twelve years ago, my husband Eddie and I set out to find answers as to why our two sons died from cardiomyopathy at such a young age. There were no answers to why cardiomyopathy affected them so severely or why their heart condition seemed different from adults with cardiomyopathy. We were determined to find answers and even more so after hearing the stories of other cardiomyopathy families.

From the start, CCF has been committed to accelerating research that improves the survival rate and quality of life for children with cardiomyopathy. The multi-center studies that we have been supporting are yielding important results after a decade-long search for answers. In a 2013 published paper, “Risk Stratification at diagnosis for children with hypertrophic cardiomyopathy: an analysis of data from the Pediatric Cardiomyopathy Registry,” identified risk factors will aid cardiologists in determining which children with hypertrophic cardiomyopathy are at greatest risk of death and who should be evaluated for earlier heart transplant. Before this study, there was no indication of which clinical signs could predict a child’s outcome. These findings will have a significant impact on patient care worldwide.

The search for answers never ceases, and we keep moving forward with our work. In 2013, we awarded three research grants and provided additional funding to the Pediatric Cardiomyopathy Registry to cover patient recruitment for a new genotype and phenotype study. We raised our voices in Washington to lobby for increased research funding and educational awareness programs. Throughout 2013, we strengthened our patient support services and resources. Based on positive family reviews, CCF was named top-rated health organization for the third consecutive year.

These achievements give our cardiomyopathy families hope for a brighter future—one where children with cardiomyopathy are diagnosed earlier and there is a promise of a cure. In honor of our two sons and all cardiomyopathy heart kids, we will keep seeking answers and finding hope.

Sincerely,

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)

---

**BOARD OF DIRECTORS**

Lisa Yue  
*President*

Brian Nold  
*Treasurer*

Raymond Yue  
*Secretary*

Carney Hawks  

Carolyn Kong  

Ian Sandler  

Eddie Yu  

---

**MEDICAL ADVISORS**

Wendy Chung, MD, PhD  
*Columbia University Medical Center*

Steve Colan, MD  
*Boston Children’s Hospital*

Daphne Hsu, MD  
*Children’s Hospital at Montefiore*

Steve Lipshultz, MD  
*Wayne State University School of Medicine*

Jeff Towbin, MD  
*Cincinnati Children’s Hospital Medical Center*

---

**CCF STAFF**

Lisa Yue  
*Founding Executive Director*

Sheila Gibbons  
*Development & Communication Senior Manager*

Jennifer Hivry  
*Development & Communication Coordinator*

Gina Peattie  
*Patient Outreach & Support Manager*

Dara Schwam  
*Patient Outreach & Support Coordinator*

Lauren Zenreich  
*Executive Assistant & Bookkeeper*
Research
• CCF-Funded Research with the North American Pediatric Cardiomyopathy Registry (PCMR) Identifies Risk Factors of Death and Heart Transplant in Children with Cardiomyopathy.

• Publications from three CCF-supported Pediatric Cardiomyopathy Registry research studies are recognized among most read articles in Circulation, the top-ranked journal on the cardiac and cardiovascular systems.

• CCF awarded $286,720 in research funds and committed $145,000 to support three new studies in 2013:

  Leslie A. Leinwand, Ph.D.
  Pediatric Hypertrophic Cardiomyopathy Caused by Myosin Mutations
  University of Colorado, Boulder, Biofrontiers Institute

  John Carter Ralphe, M.D.
  Human iPS cells and ECT in the Study of Hypertrophic Cardiomyopathy
  University of Wisconsin, Madison, School of Medicine and Public Health

  Maria I. Kontaridis, Ph.D.
  Developmental Effects of PTPN11 Mutations on Pediatric Hypertrophic Cardiomyopathy
  Beth Israel Deaconess Medical Center, Harvard Medical School

“Before this study, nobody knew which factors were more or less important in predicting outcomes. Based on our experience with adults, we do not think of HCM as a cause for heart transplant. Yet for a select group of high-risk children with HCM, transplant is key for survival.”

Steve E. Lipshultz, M.D., PCMR Principal Investigator
• CCF awarded $75,000 to the Pediatric Cardiomyopathy Registry to assist with patient recruitment on a nationwide National Health Institutes sponsored study, “Genotype-Phenotype Associations in Pediatric Cardiomyopathy.”

• Two CCF-supported researchers secured multi-year funding from the National Heart, Lung, and Blood Institute (NHLBI) to expand their studies.

  Carmelo Milano, M.D.
  Expanding the Donor Pool for Pediatric Heart Transplant
  Duke University, Durham, N.C.

  Maria Kontaridis, Ph.D.
  Developmental Effects of PTPN11 Mutations on Pediatric Hypertrophic Cardiomyopathy
  Beth Israel Deaconess Medical Center, Boston, Mass.

• Study findings from CCF-funded research studies were presented at nine national medical meetings and published in six peer-reviewed medical journals in 2013. To date, the number of publications and presentations resulting from CCF-funded research initiatives total 161.

“CCF’s support has been essential to two new NHLBI research grants which will study 600 children with cardiomyopathy over the next 4 years to identify the genetic causes of this disease as well as identify the best way to care for these children in pediatric cardiology centers in the U.S. and Canada.”

James Wilkinson, M.D., M.P.H., Professor of Pediatrics and Epidemiology, University of Miami Miller School of Medicine, Fla.
Education
Education

- Sponsored the inaugural Pediatric Heart Failure Group meeting in Los Angeles, C.A. to focus on improving heart failure care in children.
- Represented at more than 10 national and international medical conferences including the American Academy of Pediatrics Annual Conference, American Heart Association Scientific Sessions, International Society of Heart and Lung Transplantation, 4th Summit on Youth Sports Safety, and Parent Heart Watch Annual Meeting.
- Collaborated with the Pediatric Heart Transplant Foundation (PHTF) to develop a new educational resource, *Pediatric Heart Transplants: A Guide for Patients and Families*. The comprehensive guidebook was developed with the top pediatric heart transplant centers across the U.S. and Canada.
- Distributed more than 3,700 pieces of educational materials on pediatric cardiomyopathy to families, hospitals and schools.

“The meeting proved that there is enormous interest in advancing the field of pediatric heart failure. This is becoming very clear as we have support from important organizations such as American Heart Association and the International Society for Heart and Lung Transplantation.”

Yuk Ming Law, M.D., Director of Cardiac Transplant and Heart Failure at Seattle Children’s Hospital, Wash.
Advocacy & Awareness
• Named as a top-rated health organization for the third consecutive year by one of America’s leading charity evaluators, Great Nonprofits.

• Partnered with Senators Robert Menendez (NJ) and Frank Lautenberg (NJ) and Representative Frank Pallone (NJ-6) to reintroduce the Cardiomyopathy Health, Education, Awareness, Risk Assessment and Training in the Schools (HEARTs) Act. CCF garnered the support of 26 legislative cosponsors and 37 organizations for the Cardiomyopathy HEARTs Act by year-end.

• Joined Representative Frank Pallone Jr. (NJ-6) and Assemblyman Patrick Diegnan at South Plainfield Middle School, N.J., to raise awareness of the Cardiomyopathy HEARTs bill and to call attention to sudden cardiac arrest in the young.

• Initiated grassroots advocacy campaign to support the Cardiomyopathy HEARTs Act and Teaching Children to Save Lives Act, which generated letters from 28 states to lawmakers.

• Secured report language on cardiomyopathy in the Senate Labor, Health, and Human Services appropriations bill, which was approved by the full Senate Appropriations Committee.

• Worked closely with Representative Lois Capps (CA-24) to reintroduce the Teaching Children To Save Lives Act, legislation that would provide schools with resources to teach students cardiopulmonary resuscitation (CPR) and how to use an automated external defibrillator (AED).

• Worked with the National Heart, Lung, and Blood Institute, Centers for Disease Control and congressional leaders to establish a Sudden Death in the Young Registry. The national registry will collect population-based information on sudden unexpected death in youths up to age 24.

• Launched an AED camp scavenger hunt to raise awareness of cardiomyopathy, the leading cause of sudden cardiac arrest in youth and to highlight the importance of AED accessibility in saving lives.
Family & Patient Support
Family & Patient Support

HELPING FAMILIES, PROVIDING HOPE

• Welcomed 212 new members to CCF’s community this year. Currently, CCF has more than 2,140 members from 70 countries.

• Handled more than 815 phone calls and emails to patients and families in need.

• Received more than 71,700 website visits and 121,624 webpages of information was viewed—a 15 percent increase from last year.

• Grew CCF Facebook group to more than 400 members and generated more than 100 posts and 500 comments per month.

• Introduced new support meeting format to include online meetings, enabling parents to chat with one another online in real time.

• Awarded $12,053 to seven families through CCF’s Family Assistance Program to cover medical and non-medical expenses related to their child’s treatment.

• Enhanced the Ambassador Program by offering a variety of opportunities for families to be involved in physician outreach, family support, grassroots advocacy, school education and community awareness.

• Parent whose daughter (age 13) has DCM called for resources to work with her school on accommodations and 504 education plans. CCF provided the Ensuring a Good Learning Environment resource to support the family through the process and to help the school personnel understand the disease and how to best support the student.

• Worried parent of a teenage son (age 16) just diagnosed with LVNC reached out for help. Her son, a competitive athlete, was told he is no longer able to play sports. CCF offered various family and teen support services to connect the parents and son to other affected families and teens in a similar situation.

• Parent looking for information and guidance for her son (age 10) diagnosed with RCM and listed for transplant. CCF shared the Pediatric Heart Transplants Guide for Patients and Families and connected her with a heart failure expert via the CCF Meet the Expert Program and other parents who have been through the transplant process.

• Single mother of two children (ages 16 and 7) affected by HCM called for support and information about the Family Assistance Program. CCF provided financial assistance to the family during child’s treatment.
Family & Patient Support

• Expanded support services for preteens and teens to include a youth blogger of the month program on CCF’s Youth Connect Group and Heart Buddy Program, which encourages support and friendship among CCF youth members.

• Exchanged more than 1,130 emails on CCF’s Connect Listserv.

• Scheduled six Meet the Expert question and answer sessions on CCF’s email discussion group, CCF Connect.

Pediatric Cardiac Social Work
Rachel Justus, LMSW &
Anna Zelig, LMSW

Left Ventricular
Non-Compaction (LVNC)
Stephanie Ware, M.D., Ph.D., FACMG

Cardiomyopathy Evaluation
and Diagnostic Screening
Irene Lytrivi, M.D.

Cardiac Electrophysiology
Robert H. Pass, M.D.

Heart Transplant:
Before, During and After
Yuk Law, M.D.

Gastrointestinal Issues
Relating to Cardiomyopathy
Philip Kazlow, M.D.
“CCF was there for me less than one day after I found out that my son had hypertrophic obstructive cardiomyopathy. From that point on, CCF has been my lifeline. The CCF forum has given me the help and hope that I need to go on with my life knowing that I’m not alone on this tough, unpredictable journey.”

Janell Gregerson, mom to Chase, 2, HCM

“CCF is the only place I can talk to someone who truly knows the ups and downs, the struggles, and the times of perseverance when dealing with this disease our children live with.”

Aimee White, mom to Tyler, 4, DCM

“CCF has brought me close to life-long friends who I know are always there for me when we receive good and not-so-good news about Annabelle’s diagnosis and disease. We are a close group who offer unconditional love and support to each other.”

Jessica & Rick Marshall, parents to Annabelle, 4, DCM

“I joined CCF in 2008 while my son was being worked up for a heart transplant at 3 weeks old and then admitted into hospice. The CCF community was there for us the entire time. I found a place I could lean on others for support and knowledge. I even found information for treatments that probably contributed to his dramatic improvement leading to hospice discharge. After more than 4 years, I am still a part of this community.”

Kristi, mom to Christopher, 4, DCM/LVNC
2013 Fundraising Highlights

- CCF’s Fifth Annual Poker Event at Crimson in New York City was held on February 6 and attended by 262 guests and 42 corporate sponsors. The event raised $241,105.

- CCF’s 11th Annual Golf Classic at Montclair Golf Club, N.J., held on July 22, was attended by more than 230 guests and 60 sponsors raising $403,540.

- CCF’s spring and holiday direct mail appeals raised $90,313 in total.

- Fundraisers planned by CCF families and friends brought in more than $54,977.

“After registering with CCF, they called me at least twice to check on us and always remembered my son’s name. How many foundations know your child’s name? This is why I am raising money for CCF.”

Brenda Pressler Sprague
Online Shopping Fundraiser
Daphne, Ala.

“It warms my heart to think that a child, my son Casen, who was alive for only 6 months can make a difference in the lives of so many.”

Heather Riley
5th Annual Casen’s Crew for CCF Fundraiser
Abilene, Texas
STATEMENT OF FINANCIAL POSITION

ASSETS
Cash & Cash Equivalents $981,278
Investments $1,293,671
Property & Equipment —
TOTAL ASSETS $2,274,949

LIABILITIES & NET ASSETS
Current Liabilities —
Net Assets — Unrestricted $2,266,823
Net Assets — Temporary Restricted $8,126
Net Assets — Permanently Restricted —
TOTAL NET ASSETS $2,274,949

TOTAL LIABILITIES & NET ASSETS $2,274,949

STATEMENT OF ACTIVITIES

PUBLIC SUPPORT & REVENUE
Contributions $168,028
Fundraising $775,523
Interest & Dividends $16,526
Unrealized Gains $108,505
TOTAL PUBLIC SUPPORT & REVENUE $1,068,582

OPERATING COSTS
Programs & Services $602,969
Management & General $80,701
Fundraising $272,423
TOTAL OPERATING COSTS $956,093

NET INCOME $112,489

EXPENSES BY PROGRAM & SERVICES

Programs & Services: 63%
$602,969
Education & Awareness: 10%
$62,432
Research: 48%
$286,720
Advocacy: 24%
$144,523
Patient Support: 18%
$109,294
Fundraising: 29%
$272,423
Management & General: 8%
$80,701
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 2013.

**DONORS $10,000 AND OVER**
- Bank of America Merrill Lynch
- Casen’s Crew
- Emil P. Costa
- Kevin Eng & Un Hae Song
- Robert Gallivan
- Goldman Sachs & Co.
- Houlihan Lokey
- Katten Muchin Rosenman
- Kirkland & Ellis
- Kramer Levin Naftalis & Frankel
- Patrick & Kelly Lynch
- Macquarie Group Foundation
- Nomura Securities International
- Richards Kibbe & Orbe
- Edgar Sabounghi
- Ian Sandler
- Shearman & Sterling
- Eddie Yu & Lisa Yue
- Dick & Maggie Yue

**DONORS $4,999 – $1,000**
- Imperial Capital
- JP Morgan Securities
- MacKay Shields
- Lee Milstein
- Eric Needleman
- Lucille Protas
- Steven Saggi
- Simpson Thacher & Bartlett
- Stone Lion Capital Partners
- Sullivan & Cromwell
- Taconic Capital Advisors
- Wachtell, Lipton, Rosen & Katz
- Daniel Allen
- Jason Alpin
- Todd Arden
- David Austen
- Barclays Bank
- Randall Beil
- Evan & Beth Bernardi
- Chris Berry
- David Bersh
- Geoffrey Bilcer
- Michael & Susan Brennan
- Richard Brennan
- Andrew Brenner
- Eric Brezina
- Nancy Broadbent
- Kenneth Brody
- Edward Burdick
- Camulos Foundation
- Stephen Carbone
- Chatham Asset Management
- Benji Cheung
- Won Choi
- David Chou
- Tom & Christine Chun
- Colbeck Capital Management
- Eric Cole

**DONORS $9,999 – $5000**
- Anchorage Capital Group
- Angelo Gordon & Co.
- Balyasny Asset Management
- Bank of America Foundation
- Robert Barrett
- BNP Paribas
- Brigade Capital Management
- Citigroup Global Markets
- Credit Suisse Securities
- Michael Cyran
- Christopher DeLong
- Lucas Detor
- Deutsche Bank Securities
- Oliver Elkareh & Linda Yu
- Fried, Frank, Harris, Shriver & Jacobson
- Richard & Anne Grissinger
- Carney Hawks
- ICAP High Yield
- Mark Colm
- Jason Colodne
- Harry & Dawn Cresser
- James Croom
- Cyrus Capital Partners
- John Decker
- Deutsche Bank
- Robert Dishner
- Drinker Biddle & Reath
- Catherine Duffy
- Jon Eckert
- Edward Farsch & Lynn Jaeger
- Rick Feinstein
- David & Nicole Fisch
- James Fitzpatrick
- John Florio
- Robert Frahm
- Robert Franz
- Eric & Monica Friel
- Gavin George
- Gibson, Dunn & Crutcher
- Liam Gilmore
- Bill Goebelbecker
- Kevin Golden
- Grandstand Sports & Memorabilia
- Shelley Greenhaus
- Eric Guevara
- Andrew Hain
- Harmil Foundation
- Karen Haycox
- Keith B. Hayes Foundation
- Jeremy Hedberg
- Frank Heller
- Brian Hewitt
- Hunton & Williams
- IBM Employees
- Independent Health Association
- Brian Jarmain
- Jefferies
- Sarah & David Johnson
Mike Karras
Jed Kelly
Keybanc Capital Markets
Danielle Schaefer Klyap
Knight Capital Group
Jonathan Kolatch
Clint Kollar
Devi Koya
Daniel Krueger
Matthew Lambert
Colin Lancaster
Robert Lentini
Douglas Logigian
Jay Lupo
James Malley
Jeffrey Manton
Craig Martone
Clinton Matter
Mike & Kristi McCluskey
Christopher McGrath
Michael Miller
Russel Miron
Morgan Stanley & Co.
Thomas Mullarkey
Gilbert Nathan
Genevieve Nestor
Lawrence and Jillian Neubauer
Michael & Beth Neumann
Jed Nussbaum
Kevin & Vanessa O’Malley
John O’Meara
Dan Ornstein
Mark O’Shaughnessy
Gene Pagnozzi
John Matt Philo
Dan Ponder
Benjamin Pratt
Purnima Puri
RBS Securities
Darren Richman
Riva Ridge Capital Management
Robert W. Baird & Co.
Donald & Mary Lou Rossi
Dan Ryan
Joseph Salerno
Ron & Becky Sampson
Tom Saxton
Elizabeth Schaal

Bill Schatz
Irwin Schuster
Michael Schwartz
Senator Investment Group
Daniel Shatz
Charles Short
Kristi Snyderman
Southpaw Asset Management
Gary Stanco
Andrew Stock
Jack Thekkekara
Gerard Uzzi
Van der Linden Family Foundation
Vanderbilt Appraisal Company
Todd Vannucci
Verizon Foundation
Stephen Wallace
Katrina Willis
Andrew Wise

DONORS $999 - $500
Sunil Aggarwal
John & Julie Baldo
Charles Bartels
Marc Berg
Matthew & Angela Bickel
Steven Bleier
David Breazzano
Michael & Maureen Brennan
Tim Brennan
Charles Brody
Frank Brosens
Alisa & Tom Bullard
Brendan Burke
Clay Calhoun
Barbara & Jack Callahan
Vincent & Eileen Campbell
Cantor Fitzgerald Relief Fund
Dustin Cappelletto
Sheree Chiou
David & Patricia Choi
Jerome Connolly, Jr.
Gayle Cook
Krista & Craig DeSensi
Rosario Diminni
Amanda diMonda
Doug Dodge
Adam M Dohler

Michael Doniger & Jeanne Manischewitz
Daniel Driscoll
Michael & Amy Egan
Chris Farmer
Anthony & Karen Ferraro
Robert Fitzpatrick
Stephen Flynn
Joshua Glassman
GMP Securities
David Haake
Scott Haberman
Arthur Hahn
Sandor Hau
James Higgins
Harry & Mary Hintlian
L.G. Jamar
James Jerabek
Peter Joseph
George Khouri
Kyle Kliegerman
Andrew Kronenberg
Nancy Lascurettes
Stephen Lehner
Keith Luh
Andrew & Maria Lund
Marianne Manzoillus
James Martin
Justin McEvily
Drew McKnight
David Miller
Xavier Mimaud
Murray Devine & Co.
Faraz Naseer
National Philanthropic Trust
Robert Newman
Emilie Ng
Brian & Susan Nold
Michael & Ellen O’Hare
Heather Ory
Caroline Parisi
Brian & Robin Potash
Brian Reid
Marc & Robin Rollo
Kristine Rotelli
Alexander Rupert
Thomas Schneider
Adam Schwartz
Marc Schwartz
Ken Senior
Adam Shane
Seth Shapiro
Chaney Sheffield
Eraj & Celeste Shirvani
Rich Siegel
Scott & Sarah Snell
Andrew Susser
Nirav Thakker
Alison & Joseph Thomas
Laura Torrado
Matthew Tuck
US Cellular
Arang Varadhachary
Dixon Yee
Raymond Yue
Terry Yun

DONORS $499 – $250
American Express Charitable Fund
Puneet Singh Arora
Joe Beggans, Jr.
Mary Bianchi
David Bicking
Brian & Diane Bilcer
John & Deborah Bowman, III
Dana Brandt
Charles and Elizabeth Bridge
Robert Britton
Matthew Carter
Christopher Chang
George Chris
Kevin and Lisa Coleman
Evelyn Combest
David & Carol Davis
Sharlene Day
Dell Matching Gifts Fund
Robert Depiro
Eric & Marilyn Drobinko
Thomas Fitzgerald
Gladys Golden
Goldman Sachs & Co. Matching Gift Program
Robert & Lori Hamilton
Hunton & Williams
Matthew & Lauren Jacobson
Dianne Jenett
Matt Kaitz
Paula Laliberte
Pamela Lawrence
Kent & Stephanie Leung
Michelle Lincoln
Debra MacClennan
Matthew Maggio
John Maher
Vikram Natarajan
Jennifer Parker
Michael Petrick
Judith Raiskin
Todd Reynders
Sean Sauler
Frank & Kristi Schippers
Barry & Karen Schnur
Christine Seidman
Frederic & Jean Sharf
Gregory Steele
David and Carole Stewart
John Suarino
Bradford & Missy Sutherlin
Kelly & Will Taylor
Rowan & Julie Taylor
Bryan Trowbridge
Tyngsborough Elementary School
UTLX Manufacturing
Rehana Wijenayake

We would like to thank our CCF families, Alana Harris Photography, Memorial Blood Centers of MN, Michael Seto Photography, and University of Miami Miller School of Medicine for the use of their photographs.