

# Seeking Answers



# Finding Hope

Children's Cardiomyopathy Foundation

2013 ANNUAL REPORT

# Founder's letter



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,

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)

### 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*

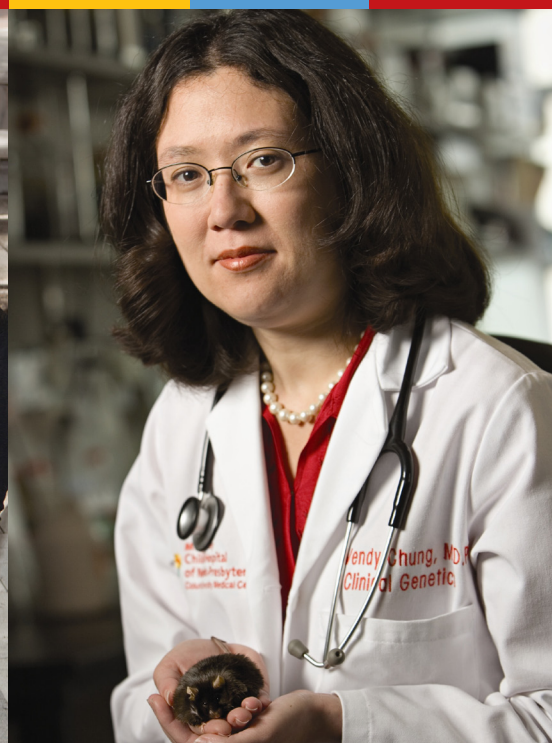
Gina Peattie  
*Patient Outreach & Support  
Manager*

Dara Schwam  
*Patient Outreach & Support  
Coordinator*

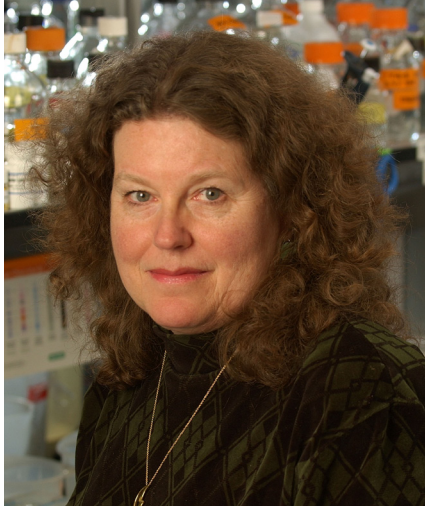
Lauren Zenreich  
*Executive Assistant &  
Bookkeeper*



# Research



# 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

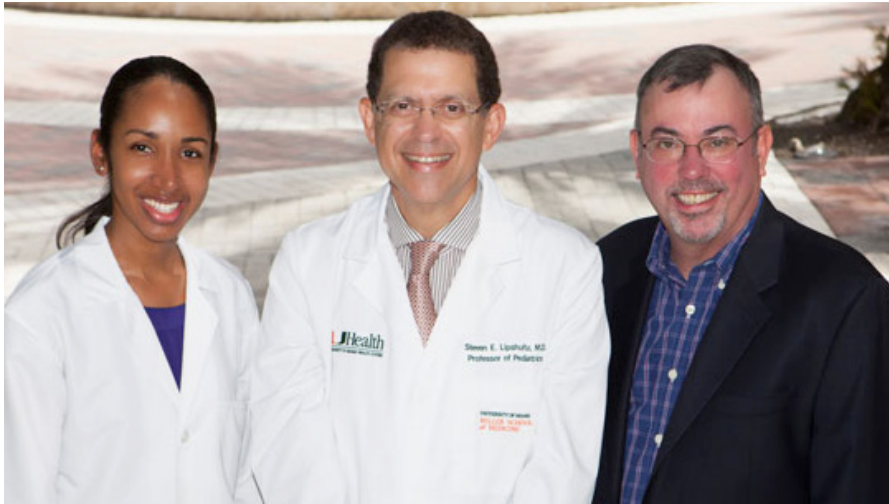
John Carter Ralphe, M.D.  
Human iPS cells and ECT in the Study  
of Hypertrophic Cardiomyopathy  
University of Wisconsin, Madison, School of Medicine  
and Public Health

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**

# Research



- 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



# 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



- 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.

## HELPING FAMILIES, PROVIDING HOPE

- 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.

# Family & Patient Support



“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**



# Financial Summary Statement

FISCAL YEAR ENDING DECEMBER 31, 2013

## STATEMENT OF FINANCIAL POSITION

### ASSETS

Cash & Cash Equivalents	\$981,278
Investments	\$1,293,671
Property & Equipment	—
<b>TOTAL ASSETS</b>	<b>\$2,274,949</b>

### LIABILITIES & NET ASSETS

Current Liabilities	—
Net Assets — Unrestricted	\$2,266,823
Net Assets — Temporary Restricted	\$8,126
Net Assets — Permanently Restricted	—
<b>TOTAL NET ASSETS</b>	<b>\$2,274,949</b>

**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

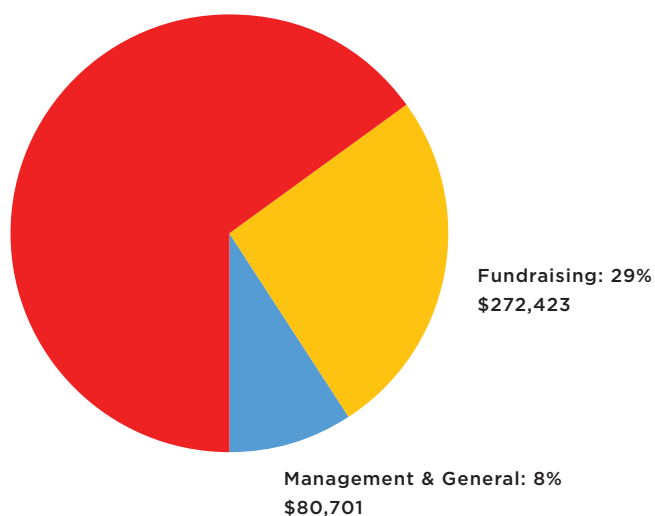
Programs & Services	\$602,969
Management & General	\$80,701
Fundraising	\$272,423

**TOTAL OPERATING COSTS \$956,093**

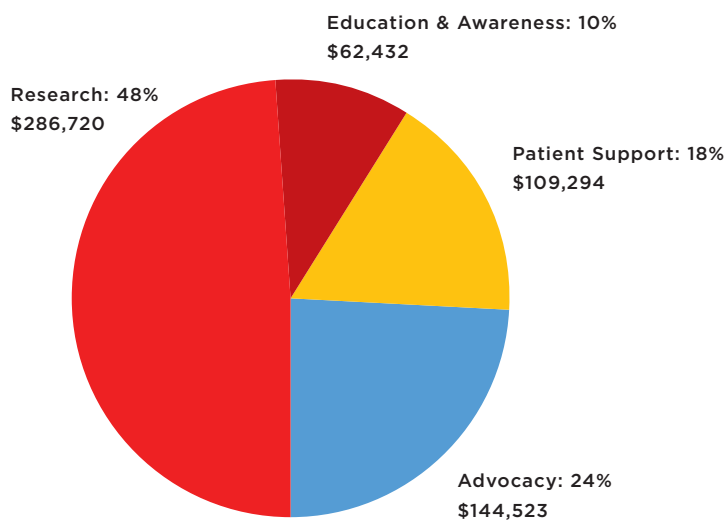
**NET INCOME \$112,489**

## TOTAL EXPENSES

Programs & Services: 63%  
\$602,969



## EXPENSES BY PROGRAM & SERVICES



# Major Donors & Partners

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 \$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

Imperial Capital  
JP Morgan Securities  
MacKay Shields  
Lee Millstein  
Eric Needleman  
Lucille Protas  
Steven Saggese  
Simpson Thacher & Bartlett  
Stone Lion Capital Partners  
Sullivan & Cromwell  
Taconic Capital Advisors  
Wachtell, Lipton, Rosen & Katz

## DONORS \$4,999 - \$1,000

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

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 Farscht & 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 Calhoon  
 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 Manzolillo  
 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 & Laurie 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 Raikin  
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.*



P.O. Box 547, Tenafly, NJ 07670  
Tel 866.808.CURE • Fax 201.227.7016  
[www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org)