



DEFINING MOMENTS

Children's
Cardiomyopathy
Foundation

2011 Annual Report

Defining Moment—an act that results
in significant change or a particular point in time
in which change is clearly seen.



Dear Friends,

2011 was a year of defining moments for the Children's Cardiomyopathy Foundation (CCF), one in which our commitment to the health and well-being of children with cardiomyopathy was strengthened. Most notably, we reached \$1 million in gross revenues. This milestone puts us in an excellent position to fund more research and invest in advocacy efforts that will lead to improvements for families affected by pediatric cardiomyopathy.

I would like to give my sincerest thanks to our donors, sponsors, families and friends for helping us reach this pivotal point.

There were several defining moments for CCF in 2011. We were named a top-rated health organization. We funded three new research grants, initiated a multi-center hypertrophic cardiomyopathy study and partnered with the National Institutes of Health Pediatric Cardiomyopathy Registry to support 10 auxiliary studies. And perhaps our most significant moment of 2011 was our entry into the realm of Congressional advocacy.

CCF's decision to develop a federal public policy and advocacy program has already had an enormous impact. In a very short amount of time, through our hard work and perseverance, the first-ever cardiomyopathy bill was introduced to the U.S. House of Representatives. This is a great victory for the cardiomyopathy community.

Even with these accomplishments, our job is far from done. Cardiomyopathy remains a leading cause of sudden cardiac arrest and heart transplants in children. If we are to change the course of this heart disease and ensure that more at-risk children are diagnosed and properly treated, we must strive for more defining moments. We must continue our efforts on Capital Hill to educate legislators about pediatric cardiomyopathy and impassion them to take action on behalf of children with cardiomyopathy.

Our true defining moment is on the horizon—the moment when all children with cardiomyopathy can live a full and active life. Together, we will get there.

Sincerely,

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

Lisa Yue

President and Founder

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, *Children's Hospital Boston*

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

Steve Lipshultz, MD, *University of Miami Medical Center*

Jeff Towbin, MD, *Cincinnati Children's Hospital*

CCF STAFF

Lisa Yue, *Executive Director*

Sheila Gibbons, *Development & Communication Senior Manager*

Renee Thekkekara, *Development & Communication Coordinator*

Chris Colón, *Patient Outreach & Support Manager*

Harriet Salk, *Patient Outreach & Support Coordinator*

Becky Delgado, *Administrative Assistant*

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

Pediatric Cardiomyopathy covers five basic forms:

- Dilated cardiomyopathy (DCM)
- Hypertrophic cardiomyopathy (HCM)
- Restrictive cardiomyopathy (RCM)
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Left ventricular non-compaction cardiomyopathy (LVNC)





RESEARCH

- Awarded nearly \$250,000 in research grants to new investigators Wendy Chung, MD, PhD, Columbia University Medical Center; Kathy Hodgkinson, PhD, Memorial University of Newfoundland; Carmelo Milano, MD, Duke University; and Jill Tardiff, MD, PhD, Albert Einstein College of Medicine.

2010 CCF-funded researcher **J. Carter Ralphe, MD** received a \$1.9 million grant from the National Institutes of Health to expand his research on engineered cardiac tissue as a model for hypertrophic cardiomyopathy.

**2011 CCF-FUNDED
RESEARCH STUDIES**

WENDY CHUNG, MD, PHD

“Identification of New Genes for Infantile Cardiomyopathy”

COLUMBIA UNIVERSITY,
NEW YORK, NY

KATHY HODGKINSON, PHD

“Informing Diagnostic and Prognostic Information for Arrhythmogenic Right Ventricular Cardiomyopathy Type 5 (ARVD5) in Children by Comprehensive Clinical and Genetic Analysis”

MEMORIAL UNIVERSITY OF
NEWFOUNDLAND, NL, CANADA

CARMELO MILANO, MD

“Expanding the Donor Pool for Pediatric Heart Transplant”

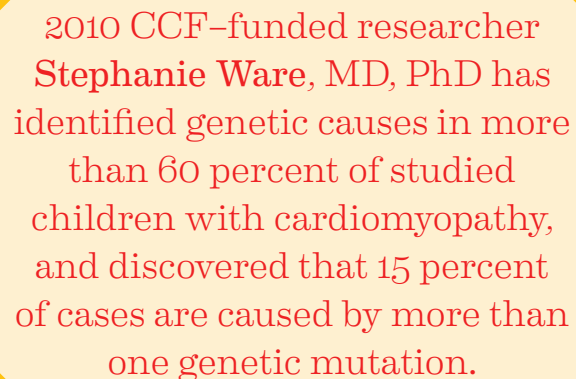
DUKE UNIVERSITY, DURHAM, NC

JIL TARDIFF, MD, PHD

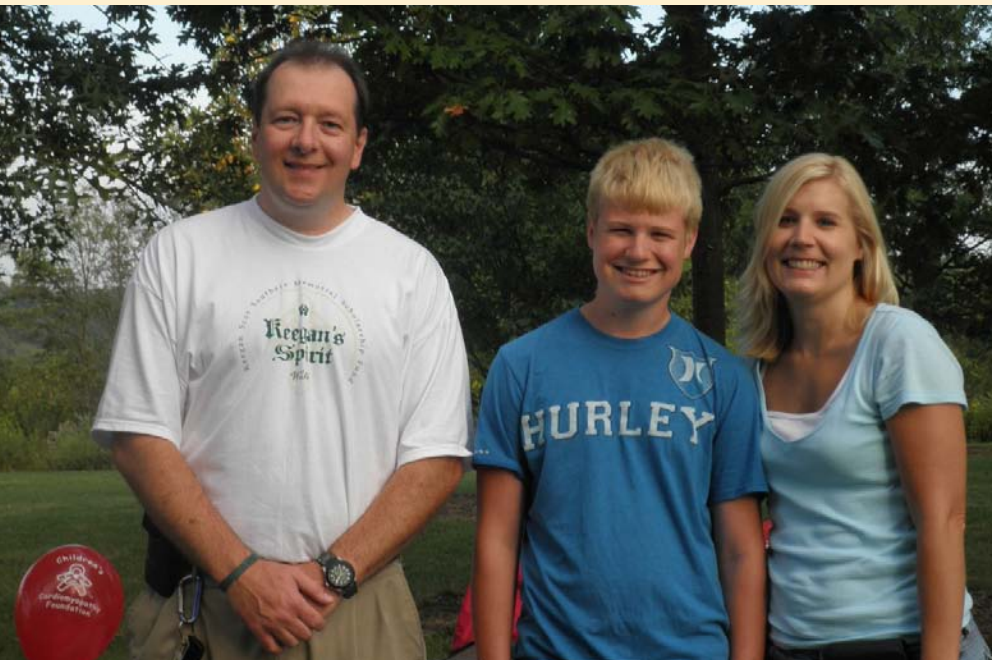
“Development of a Model System for Tropomyosin-linked Early Onset Dilated Cardiomyopathy”

ALBERT EINSTEIN COLLEGE
OF MEDICINE, BRONX, NY

- Distributed an additional \$46,481 in research funding to ongoing pediatric cardiomyopathy studies.
- Committed \$250,000 to the National Heart Lung and Blood Institute Pediatric Cardiomyopathy Registry to fund working group sessions and complete ten epidemiologic and clinical studies.
- Initiated a multi-center research study, “Exome Sequencing to Identify Novel Causes of Infantile Hypertrophic Cardiomyopathy.”
- Findings from CCF-funded studies highlighted at three medical conference presentations and in four new publications in *Circulation Research*, *Circulation* and *Journal of Heart and Lung Transplantation*.
- Additional 36 articles on pediatric cardiomyopathy published in three dedicated issues of *Progress in Pediatric Cardiology*.



2010 CCF-funded researcher
Stephanie Ware, MD, PhD has
identified genetic causes in more
than 60 percent of studied
children with cardiomyopathy,
and discovered that 15 percent
of cases are caused by more than
one genetic mutation.



EDUCATION

- Updated content of *Understanding Pediatric Cardiomyopathy* booklet and disease inserts. Distributed more than 2,041 pieces of literature to families, hospitals and schools.
- Represented at 14 national medical conferences, including the American Heart Association Cardiovascular Council for the Young, American Academy of Pediatrics, American Society of Transplantation, Child Life Council, and American College of Medical Genetics.
- Participated as a panelist at the Genetic Diseases of Children: Advancing Research and Care Conference hosted by the New York State Department of Health.

“I am forever grateful for CCF!
Words cannot adequately describe
how vital this organization
is to the families affected
by pediatric cardiomyopathy.”

—Heather, mom to daughter with DCM



ADVOCACY & AWARENESS

- Named as a top-rated health organization by American's leading charity evaluators Great Nonprofits, Charity Navigator, Guidestar and Global Giving.
- Developed a two-year government relations strategic plan and public policy and advocacy agenda following a comprehensive public policy audit, environmental scan and needs assessment.
- Worked closely with Congressman Frank Pallone to introduce the first ever cardiomyopathy legislation, the Cardiomyopathy Health Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act, to increase awareness of cardiomyopathy and the risk of sudden cardiac arrest among parents, schools and health professionals.
- As a steering committee member of the Sudden Cardiac Arrest Coalition, worked in cooperation with the Congressional Heart & Stroke Caucus to host the Take a Stand Against Sudden Cardiac Arrest briefing on Capital Hill.

“It’s time to raise awareness of this disease and provide parents, schools, and health departments with the tools to respond quickly and effectively when heart conditions strike.”

—Senator Frank Lautenberg



FAMILY & PATIENT SUPPORT

- Welcomed 230 new members to CCF's community this year. Currently CCF has more than 1,700 members from 52 countries.
- CCF's website visited more than 34,500 times with 76,500 pages of information accessed, which represents a 20 percent increase from last year.
- Established CCF's Family Assistance Program to assist low-income families with cardiomyopathy-related medical and non-medical needs when insurance and other financial resources have been exhausted.
- Introduced CCF Youth Connect, a private Facebook group created for teens and young adults. Also expanded the CCF Ambassador Program to include our first teen and young adult ambassadors.
- Trained seven new ambassadors, increasing the total number to 13 ambassadors. CCF's Ambassador Program offers personal support to newly diagnosed families. Parents in similar situations are trained to listen to concerns and questions, share tips, and provide information about CCF's resources.
- Assisted families with more than 500 phone calls and emails in 2011.
- Organized four "meet the expert" question and answer sessions on CCF's popular member listserv, CCF Forum.
- Scheduled eight phone group sessions and 12 support group meetings. Currently there are 11 support groups established throughout the U.S.



FUNDRAISING HIGHLIGHTS

- CCF's Third Annual Poker Event at Crimson in New York City was held on February 9 and attended by 250 guests. There were 28 sponsors this year and more than \$209,091 was raised.
- CCF's Ninth Annual Golf Classic at Montclair Golf Club in NJ took place on July 18 and was attended by a sold-out crowd of nearly 250 guests. 69 sponsors supported the event and \$424,797 was raised.
- CCF's spring and holiday direct mail appeals raised \$78,773.
- Fundraisers planned by CCF families and friends brought in more than \$24,391.

STATEMENT OF ACTIVITIES

FISCAL YEAR ENDING DECEMBER 31, 2011

PUBLIC SUPPORT & OTHER REVENUE

Corporations & Foundations	\$291,230
Individuals	32,005
Fundraising Appeals	78,773
Fundraising Events	658,280
Grants	35,000
Interest & Dividends	11,720
Unrealized Gains & Losses	(33,781)
Total Income	\$1,073,227

EXPENSES

Fundraising \$241,452

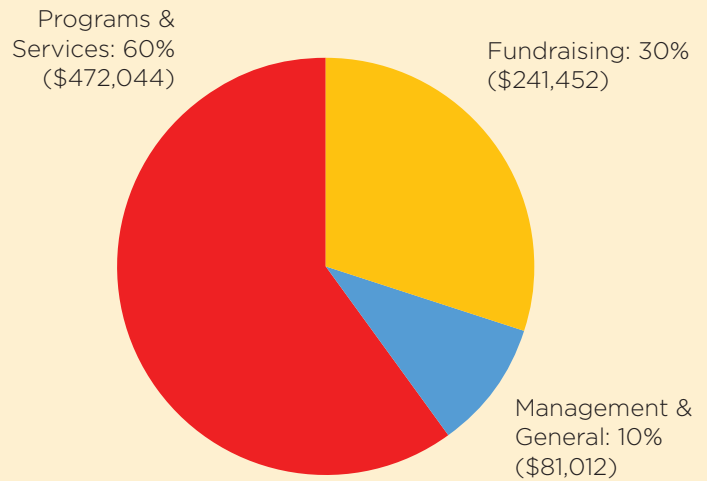
Management & General

Bank & Credit Card Processing	\$9,968
Compensation	39,463
Copying & Printing	711
Filing Fees	2,284
Insurance	3,958
Legal & Professional Fees	7,171
Office Expenses	1,787
Payroll Service	1,446
Payroll Taxes & Service Fees	4,614
Postage & Freight	881
Storage Rental	2,656
Supplies	1,710
Telephone & Internet	4,363
Subtotal	\$81,012

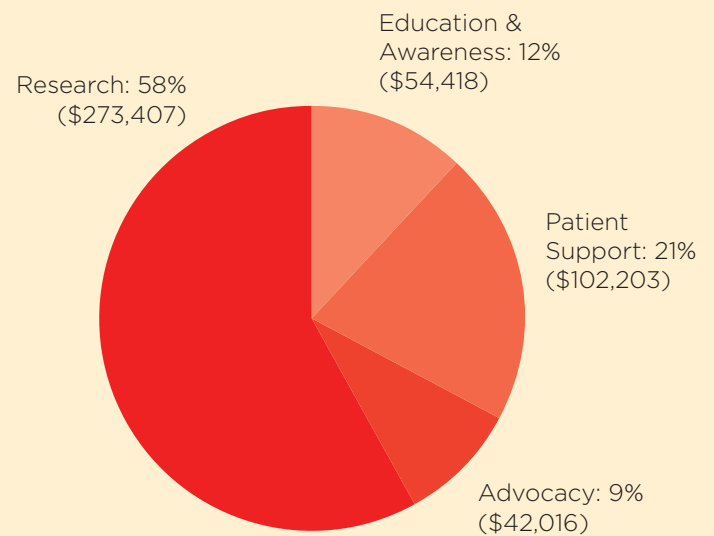
Program & Services \$472,044

Total Expenses \$794,508

TOTAL EXPENSES



EXPENSES BY PROGRAM & SERVICES



MAJOR DONORS & SPONSORS

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 CCF fulfill its mission by making a gift of \$500 or more in FY 2011.

DONORS \$10,000 & ABOVE

Bank of America
Emil Costa
Rob Gallivan
Goldman Sachs & Co.
Carney & Melissa Hawks
ICAP Services
Katten Muchin Rosenman
Patrick Lynch
Macquarie Group Foundation
Medtronic Foundation
RBS Securities
Richard Kibbe & Orbe
Edgar Sabounghi
Tamgem Corp.
Tullett Prebon
Eddie & Lisa Yu

DONORS \$9,999-5,000

Anchorage Advisors
Angelo Gordon & Co.
Barclays Bank
Evan & Beth Bernardi
BNP Paribas
Andrew Brenner
Brigade Capital Management
Robert Burke
Benji Cheung
Citigroup
Christopher DeLong

Lucas Detor
Deutsche Bank
Robert Dishner
Jon Eckert
Robert Franz
Fried, Frank, Harris,
Shriver & Jacobson
James Geregthy
Bill Goebelbecker
Gladys Golden
Jose Bacardi Gonzalez
Imperial Capital
Jefferies & Co.
Jeffrey Altman Foundation
JP Morgan Chase
Robert Langer
Norm Louie
Mackay Shields
Lee Millstein
Morgan Stanley
Kevin O'Malley
Gene Pagnozzi
Doug Pardon
Heather Riley
Ian Sandler
Adam Savarese
Simpson Thacher & Bartlett
Stone Lion Capital Partners
Taconic Capital Advisors
Vanessa's Big Heart Foundation

DONORS \$4,999-1,000

Dan Allen
Rob Ambriano
Bacardi USA
Richard Barrera & Purnima Puri
Joe Beggans, Jr.
Steven Bleier
Richard Brennan
Allen Brilliant
Ted Burdick
Chatham Asset Management
Thomas & Christine Chun
Heather Cinca
Jorge Cinca
Mark Colm
Jason Colodne
Credit Suisse
James Croom, Jr.
Brian Devaney
George Dimitri
DLF Real Estate Corp.
Patrick Dooley
Catherine Duffy
Daniel Elkaim
Edward & Lynn Farscht
David Feldman
Robert Ferguson
Anthony & Karen Ferraro
David & Nicole Fisch
Florida Metal Trading

John Florio
Robert Frahm
Eric Frank
Mark Frank
Eric Friel
Gibson, Dunn & Crutcher
Gleacher & Company
Kevin Golden
Bill Green
Scott Haberman
Brian Hewitt
Hunton & Williams
Jed Kelly
George Khouri
Thomas Kinnally
Knight Capital Americas
Marti & Martha Knoblock
Jeff & Julie Kobold
Kolatch Family Foundation
Stuart & Nicole Kovensky
Kramer Levin Naftalis & Frankel
Daniel Krueger
Stephen Lehner
Robert Lentini
Al Lhota
John Lugano
Michael Mansdorf
Jared Markiewicz
Clinton Matter
James McGinley
Andrew McKnight
Michael McLaughlin
James McMahan
Thomas Mullarkey
Vikram Natarajan
Gil Nathan
Lawrence & Jillian Neubauer
Neubauer Family Foundation
Emilie Ng

Nomura Securities
John O'Meara
Dan Ornstein
Michael Petrick
Brian Potash
Christopher Pucillo
Darren Richman
Riva Ridge Capital Management
Steve Rosen
Donald & Mary Lou Rossi
Richard Rossi
Joseph Salerno
Ron & Becky Sampson
Peter Schellbach
David & Carrie Schulman
Senator Investment Group
Chaney Sheffield, Jr.
Robert Sherman &
Barbara Bradford
Charles Short
James Shim
Timothy & Lisa Siefert
Southpaw Asset Mangement
Dave & Ranae Stewart
Andy Stock
Andrew Susser
TD Securities
Tillman Family Trust
Pedro Urquidi
Vanderbilt Appraisal Company
Van der Linden Family
Foundation
Todd Vannucci
Michael Weir
Matthew Whitcomb
John & Jessica Winthrow
Chris Yanney
Yolanda Cinca Trust
Dick & Maggie Yue

DONORS \$999-500

Sunil Aggarwal
Jason Alpin
Paul Arrouet
Robert Barrett
Carolyn Beckedorff
James Book
John & Deborah Bowman
Thomas Boyce
David Breazzano
Robert Brullo
Tom & Alisa Bullard
John Callahan
Dustin Cappelletto
Courtney Carson
Daniel Chandra
Christopher Chang
Vito Chiarello
Sheree Chiou
David Choi
Won Choi
Peter Chung
Eric Cole
Kevin Coleman
Jeff Enslin
Stephen Flynn
Michael Forrester
Stephen Golden
George Goudelias
Carson & Kelly Green
Robert & Lori Hamilton
Karen Haycox
Michael Henderlong
Gerard Hickey
James Higgins
Matthew Howard
Nunzio Innucci
Eileen Jacobs

L.G. Jamar
David & Sarah Johnson
Jeff Jones
Peter Joseph
Sam Kim
Bryan & Jennifer Kirkham
Michael Kirkpatrick
Jon Kline
Clint Kollar
Richard Lee
Douglas Logigian
Andrew Lund
Jolene Madden
Leah Maloney
James Martin
Mike & Kristi McCluskey

Donald McManus
Michael Miller
New Age Transportation
Jed & Carrie Nussbaum
Michael & Ellen O'Hare
Stephen Older
Caroline Parisi
Marc & Laurie Rollo
Jeff Resnick
Joel Sandler
Marc Santo Domingo
Tom Saxton
Bill Schatz
Thomas Schneider
Marc Schwartz
Michael Schwartz

John Sette
Scott Setzler
Adam Shane
Douglas Silverman
Josh Sock
Bruce Southers
Gregory Steele
Betsy Sutter
Kevin Tan
UBS
Michael Vargas
Robert Voreyer
Mark Warner
James Wolf
Daniel Yarsky



We would like to thank the Chatman-Royce, Cinca, Davis, Gupta, Keegan, Riley, and Siefert Families; Michael Seto Photography; and the Sudden Cardiac Arrest Coalition for the use of their photographs.



P.O. Box 547, Tenafly, NJ 07670
Tel 866.808.CURE • Fax 201.227.7016
www.childrenscardiomyopathy.org