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,

Lisa Yue
President and Founder
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Ian Sandler
Eddie Yu

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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

KA THY 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.
### PUBLIC SUPPORT & OTHER REVENUE

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<thead>
<tr>
<th>Source</th>
<th>Revenue</th>
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<tbody>
<tr>
<td>Corporations &amp; Foundations</td>
<td>$291,230</td>
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<tr>
<td>Individuals</td>
<td>32,005</td>
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<td>Fundraising Appeals</td>
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<td>Fundraising Events</td>
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<td>Grants</td>
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<td>Interest &amp; Dividends</td>
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<td>Total Income</td>
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### EXPENSES

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<tr>
<th>Category</th>
<th>Expenses</th>
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<tbody>
<tr>
<td>Fundraising</td>
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<tr>
<td>Management &amp; General</td>
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<tr>
<td>Bank &amp; Credit Card Processing</td>
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<td>Legal &amp; Professional Fees</td>
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<td>Supplies</td>
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<td>Telephone &amp; Internet</td>
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<td>Subtotal</td>
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<tr>
<td>Program &amp; Services</td>
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<tr>
<td>Total Expenses</td>
<td>$794,508</td>
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### TOTAL EXPENSES

- **Fundraising**: 30% ($241,452)
- **Management & General**: 10% ($81,012)
- **Advocacy**: 9% ($42,016)
- **Patient Support**: 21% ($102,203)
- **Research**: 58% ($273,407)
- **Education & Awareness**: 12% ($54,418)

### 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.

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