Dear Friends,

It is always a pleasure to report on the year’s accomplishments for the Children’s Cardiomyopathy Foundation. It allows me to reflect on the progress we have made and to focus on the needs that remain. When CCF began in 2002, we had a vision to call attention to a chronic heart disease with little awareness. Now in our eighth year with more than 1,500 families strong and close to reaching $1 million in gross revenues, we are steadily moving closer to our goal of making cardiomyopathy a recognized heart disease in communities around the world. We have the momentum to truly make a difference — to ensure more children are properly diagnosed, to empower more affected families to get the best treatment and to accelerate research that will lead to an eventual cure.

In 2010 we spent more than $250,000 in the research area and made great strides in disease education, patient support and awareness of cardiac arrest related to cardiomyopathy. The many accomplishments of the past year, which are highlighted in the following pages, were made possible by the continued and generous support of our donors, sponsors, family members and friends. I am especially proud of our CCF families who are getting more involved in raising funds and awareness of cardiomyopathy. Their involvement is so important to advancing our mission and giving pediatric cardiomyopathy a personal dimension that is beyond the flat statistics.

I hope you enjoy reading about what we have done in 2010, and I thank you for your unfailing support. For the year ahead, we will set our sights on what still needs to be done to bring pediatric cardiomyopathy to the forefront of pediatric care and medicine.

Sincerely,

Lisa Yue
President & Founder

A Cause for Today... A Cure for Tomorrow
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)

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CCF Staff:
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Sheila Gibbons, Development & Communications Senior Manager
Renee Thekkekara, Development & Communications Coordinator
Kella Boyer, Patient Outreach & Support Manager
Harriet Salk, Patient Outreach & Support Coordinator
Becky Delgado, Administrative Assistant
RESEARCH

• Awarded \$186,735 in research grants to new investigators Bernhard Kuhn, M.D., Children’s Hospital Boston; J. Carter Ralphe, M.D., University of Wisconsin-Madison; and extended funding to Stephanie Ware, M.D., Ph.D., Cincinnati Children’s Hospital to continue her genetic study, which CCF initially funded in 2009.

• An additional \$21,828 in research funding was distributed to ongoing pediatric cardiomyopathy studies. The number of CCF acknowledgements has increased to 59 medical publications and 27 presentations at key medical conferences.

• Sponsored and hosted the Second International Scientific Conference on Cardiomyopathy in Children in Bethesda, Md. in which 60 of the top clinicians and researchers from the U.S., United Kingdom, Canada and Australia convened to identify key research areas, share best practice models, and review new research data and findings on pediatric cardiomyopathy. The conference was co-sponsored by the National Heart, Lung, and Blood Institute and the University of Miami Miller School of Medicine. GeneDX and the Myocarditis Foundation were additional supporters.

EDUCATION

• Created and distributed Ensuring a Good Learning Environment: A Cardiomyopathy School Resource Kit to hundreds of hospitals and schools across the country. It was developed to inform school staff about the disease and guide parents in working with their child’s school to obtain appropriate accommodations and modifications.

“CCF is such an important organization to all of us families dealing with this disease day in and day out.”

- Courtney Smith, mother of Charlotte (2-year-old with DCM)
• Began sending **monthly announcements to CCF’s email discussion group, CCF Forum**, on recently released pediatric cardiomyopathy and heart failure/heart transplant studies.

• Developed additional **fact sheets** for CCF’s growing library of patient resources.

• Distributed more than **1,200 pieces of literature** to 18 national medical conferences, including annual meetings of the American Heart Association Council for the Young, Children’s Hospital of Philadelphia Pediatric Cardiovascular Disease, International Society for Heart and Lung Transplantation, and the National Society of Genetic Counselors.

**ADVOCACY AND AWARENESS**

• Invited to be on the **steering committee for the Sudden Cardiac Arrest Coalition**, an advocacy group of 40 cardiac organizations focused on raising awareness of sudden cardiac arrest, and organized a briefing at Capitol Hill to commemorate Sudden Cardiac Arrest Month and educate congressional members on the importance of cardiopulmonary resuscitation (CPR) and automatic external defibrillators (AED) in saving lives.

• Participated in the **“Cure the Process” campaign**, which focuses on creating new science-driven public policy that will improve the Food and Drug Administration (FDA) regulatory process related to the development of rare disease therapies.

• Developed two new **volunteer guidebooks** *Partnership in A Cause: A Guide to Raising Funds and Awareness* and *Reaching out the Media: A Guide for Increasing Public Awareness of Pediatric Cardiomyopathy* to provide more guidance and resources for those interested in planning a community fundraiser and getting local media coverage.

**FAMILY & PATIENT SUPPORT**

• Welcomed **263 new members** to CCF’s community this year. Currently CCF has more than 1,500 members from 49 countries.

• CCF’s **website visited more than 28,600 times** in 2010 and visitors accessed more than 73,000 pages of information. This represents more than 2,300 visits each month.

• Distributed more than **4,660 pieces of literature** to more than 117 families and hospitals in the U.S. and Canada.

• Formed **three new local support groups**, increasing the total number to 12 local support groups.

• Started **phone groups** to focus on specialized topics of interest such as pediatric heart transplant, coping with a new diagnosis, parents of teens with cardiomyopathy.

• Launched the **Ambassador Program**, which matches newly registered members with trained long-time members in similar situations. The ambassadors share tips, listen and provide information about CCF’s resources to new members.

• Scheduled **seven “meet the expert” guests sessions** on CCF’s popular member listserv, *CCF Forum*. The sessions from 2006-2010 were then compiled into Q&A documents for easy patient reference.
# Statement of Activities

Fiscal year ending December 31, 2010

## PUBLIC SUPPORT & OTHER REVENUE

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<th>Source</th>
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**Total Income:** $990,317

## EXPENSES

### Fundraising
- $239,198

### Management & General

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</table>

**Subtotal**: $75,369

### Program & Services
- $437,702

### Total Expenses
- $752,269

### Pie Charts

- **Fundraising** - 32%
- **Management & General** - 10%
- **Programs & Services** - 58%
- **Education & Awareness** - 14%
- **Patient Support** - 22%
- **Research** - 62%

**Legend:**
- Fundraising ($239,198)
- Management & General ($75,369)
- Programs & Services ($437,702)
- Advocacy ($6,772)
- Education & Awareness ($61,391)
- Patient Support ($99,653)
- Research ($269,886)
2010 Fundraising Highlights

2010 CCF FUNDRAISERS

- CCF’s Second Annual Poker Event at Crimson in New York City on February 3 was attended by 200 guests and raised more than $207,845, an increase of more than 67 percent from 2009.

- CCF’s Eighth Annual Golf Classic at Montclair Golf Club in NJ took place on July 19 and was attended by a sold-out crowd of nearly 200 guests raising $409,957 surpassing 2009’s total by 23 percent.

- CCF’s holiday and spring direct mail appeals raised $78,155, an increase of 4 percent from the previous year.

- Fundraising planned by CCF families brought in more than $45,000, an increase of 29.5 percent over 2009.
2010 TOP CONTRIBUTORS
The following corporations, foundations and individuals have made significant contributions to CCF, and we gratefully acknowledge their generosity.

Due to space limitations we are unable to list all our 2010 supporters but extend our heartfelt thanks to all who have contributed.

$10,000 and above
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Circle of Hearts, continued

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Spencer Wells
Christopher Yanney
Dwight Yoo
Terry Yun

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Eugene Berman
David Bersh
David Brooks
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Douglas Callahan
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