

# Heart to Heart

Volume 9, Number 1 • Spring • Summer 2012

## CCF Announces its 2012 Research Grant Recipients



Daniela Cihakova, M.D., Ph.D., Mark Friedberg, M.D., Carmen Sucharov, Ph.D.

### Identifying Molecular Mechanisms of Inflammation in the Development of DCM

**Daniela Cihakova, M.D., Ph.D.**  
Assistant Professor, Department of Pathology and Director of the Immunologic Disorders Laboratory, Johns Hopkins University

Dr. Cihakova's study, *Drivers of Pediatric Dilated Cardiomyopathy*, focuses on how mediators of inflammation called cytokines lead to DCM. Using a mouse model of DCM, Dr. Cihakova and her colleagues recently discovered that an immune product, cytokine IL17A, is essential to the development of the disease. The proposed study will determine if another cytokine (granulocyte-macrophage colony-stimulating factor or GM-CSF) is a partner of IL17A in the development of DCM.

The second part of the project concentrates on possible treatment options. Because inflammation of the heart (myocarditis) often precedes DCM, the study will neutralize cytokine IL17A in mouse models with myocarditis. If the strategy succeeds in

*continued, page 4*

The Children's Cardiomyopathy Foundation (CCF) is pleased to announce that \$144,550 in seed funding will be awarded in 2012 to three pediatric cardiomyopathy studies proposed by **Daniela Cihakova, M.D., Ph.D.** of Johns Hopkins University; **Mark Friedberg, M.D.** of Toronto Hospital for Sick Children; and **Carmen Sucharov, Ph.D.** of University of Colorado in Denver.

Each study will focus on an aspect of dilated cardiomyopathy (DCM), the leading cause of heart failure and transplantation in infants and children. DCM accounts for approximately half of those with pediatric cardiomyopathy, and currently there are no therapies available to delay or stop the progression of the disease, decrease the need for a heart transplant or improve the long-term survival of children with DCM.

## Ben Breedlove's Message of Hope

**"Mom, Dad, come here. You have to see this!"** Deanne and Shawn Breedlove, ran to their daughter, Ally, who was in the living room. On her laptop was their beloved teenage son, Ben, who had died the day before on Christmas day. He appeared alive and smiling, sharing his story of struggling with hypertrophic cardiomyopathy (HCM), surviving three cardiac arrests and seeing the bright light that had comforted him each time his heart had given out.

Little did they know that Ben's two-part video using simple, handwritten note cards would go viral on **YouTube**—viewed more than 11.5 million times and covered by international media outlets. His video, **"This is my story,"** called attention to the uncertainties of living with cardiomyopathy, but it was Ben's underlying message of faith and hope that touched

*continued, page 10*



**Children's  
Cardiomyopathy  
Foundation**

**A Cause for Today... A Cure for Tomorrow**

### Highlights...

#### RESEARCH BRIEFINGS

- CCF's 2012 Research Grant Recipients .....pg. 1
- Findings from CCF-Funded Studies Published and Presented .....pg. 3
- Pediatric Cardiomyopathy Registry Receives Multi-Million Dollar Grant....pg. 5

#### CCF UPDATES

- 4th Annual Poker Event .....pg. 6
- Highlights from CCF Family Fundraisers .....pg. 7
- CCF Sponsors Documentary, The Heart of the Matter ....pg. 8
- Cardiomyopathy Bill Introduced to the Senate .....pg. 8

#### FOR FAMILIES

- Ben Breedlove's Message of Hope .....pg. 1
- Lizzy Craze: A Journey with a New Heart .....pg. 9
- CCF Family Assistance Program Grant .....pg. 11

The *Heart to Heart* newsletter is published biannually by the Children's Cardiomyopathy Foundation (CCF), a national organization dedicated to saving lives and improving the quality of life for children with cardiomyopathy. CCF's mission is to accelerate the search for a cure by supporting research, educating physicians and patients, and increasing awareness and advocacy related to the needs of children with cardiomyopathy and their families. CCF is a publicly supported tax-exempt organization as described under section 501(c)(3) of the Internal Revenue Service.

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## From Lisa Yue, CCF Founder & President

Dear Families,

In mid-April, I traveled to Washington, D.C. for a series of meetings with senators and representatives from the **American Heart Association** and **American College of Cardiology** to garner more support for the **Cardiomyopathy HEARTS Bill**. I also met with directors at the **Office of Rare Diseases Research and National Heart, Lung and Blood Institute** to thank them for their multimillion-dollar grant to the **Pediatric Cardiomyopathy Registry** (article on pg. 5), and to discuss other ways to increase research on cardiomyopathy. I returned from the trip invigorated and more committed than ever to raising the profile of pediatric cardiomyopathy.

Sharing the stories of our cardiomyopathy families was the highlight of the trip and helped policy makers understand what it is like to live with or, sadly, to lose a child to the disease. In this issue you will hear the story of two extraordinary individuals who have had to face the ultimate challenge with the disease – heart transplantation and death. 30-year-old **Lizzy Craze**, diagnosed with DCM at 13 months, was the youngest transplant recipient at the time (article on pg. 9), and **Ben Breedlove** was the courageous teen who lost his life to HCM but inspired millions with his story on **YouTube** (article on pg. 1).

As 2012 unfolds, advocacy remains a top priority for CCF. In the next few months, we will be developing an **Advocacy Toolkit** and launching our grassroots initiative to get you more involved (article on pg. 8). Making our voices heard will influence members of congress and the Administration to prioritize pediatric cardiomyopathy research, education and awareness. We have a lot to do in this area, and I look forward to hearing your story of how cardiomyopathy has impacted your life.



Lisa Yue



## SPRING APPEAL 2012 CCF Teen Making a Difference

Watch your mail for a letter from **Joe DiSanto**, CCF **teen ambassador**, who tells his story of how in less than a year he had gone from feeling fine and playing sports to being one of the sickest patients at Children's Hospital of New York.

We want to continue helping kids, like Joe, and their families have a fighting chance. Please support our efforts and contribute to our Spring Appeal.

- A heartfelt thank you to all our 2011 sponsors and donors.
- Read CCF's **2011 Annual Report** online under "About CCF/Financials."

## RESEARCH HIGHLIGHTS

### Findings from CCF-Funded Pediatric Cardiomyopathy Registry Studies Published and Presented

In 2011, CCF awarded \$250,000 to the **National Heart, Lung and Blood Institute's Pediatric Cardiomyopathy Registry (PCMR)** for multiple studies using the registry's nationwide patient data. The findings from three studies have been published in the *Journal of the American College of Cardiology and Circulation*, as well as presented at the **2012 American College of Cardiology Scientific Session**. This increases the total number of CCF-funded PCMR publications and presentations to 17 (ten manuscripts and seven presentations). The dissemination of these study results could have potentially important ramifications for the treatment of children with dilated cardiomyopathy (DCM).

#### Incidence of and Risk Factors for Sudden Cardiac Death in Children with Dilated Cardiomyopathy

Until now, the incidence of sudden cardiac death (SCD) and risk factors for sudden cardiac arrest have not been identified in children with DCM. In the absence of accurate data, infants and children have undergone placement of implantable cardioverter defibrillators (ICDs) based on recommendations from studies of adults with DCM. While implanting an ICD may protect those at risk of SCD by normalizing their heart rhythm, the use of an ICD in a child carries certain risks and complications that may offset or even exceed its benefits. Risks include lead fractures, need for lead and defibrillator replacement, implant-related complications due to body size, and the psycho-social aspects of inappropriate shocks.

In this study, **Elfriede Pahl, M.D.** and colleagues determined the incidence and risk factors of SCD in children with DCM. The study, which was published in the *Journal of the American College of Cardiology* in February 2012, analyzed the clinical data of 1,800 children enrolled in the PCMR. Researchers found that the 5-year rate of SCD in children with DCM is 2.4 percent, which is far lower than that in adults. Based on their analysis of children's echocardiography tests, they were able to identify the highest risk factors for SCD, which include age at diagnosis younger than 14 years of age, left ventricular dilation and left ventricular thinning. Gender, ethnicity, cause of DCM and family history were not risk factors for SCD. These results help to establish a criteria for determining which children would benefit most from ICD therapy.

The data from the PCMR was critical for the study's completion. "No one center sees enough children with DCM to reliably determine the rate of SCD or to assess current recommendations for ICD placement," says **Steve Lipshultz, M.D.**, PCMR principal investigator and chairman of pediatrics at the **University of Miami Miller School of Medicine**. "This study supports the concept that universal implantation of ICDs is probably not

warranted. However, risk-stratification is possible, and if a patient's condition meets all the high-risk criteria for an extended period, ICD placement should be considered for children with DCM."

#### Competing Risks for Death and Cardiac Transplantation in Children with Dilated Cardiomyopathy

The vast majority of children with DCM are diagnosed during their first year of life, and many children with DCM are in need of a heart transplant. In fact, DCM is the leading cause of pediatric heart transplants between 2 and 18 years of age. Currently, the eligibility criteria for heart transplants does not take into account the various causes of DCM. As a result, some children are not being listed for a transplant, while other children are being transplanted when there is a chance that their heart may stabilize or recover.

This study, led by **Jorge Alvarez, M.D., Ph.D.**, used a new statistical approach to identify risk factors for death and transplantation in 1,731 children with idiopathic DCM. Published in *Circulation* in August 2011, the study discovered some important criteria in children who die that had not been used previously to determine who should be listed for a heart transplant. Notably, the study found that impaired growth or short stature increased the risk of death but not transplantation. Progression to congestive heart failure and increased age (above 6 years) also lead to worse outcomes. Dilation of the left ventricle, which has been commonly used as a criteria for transplantation, was not found to be predictive of death. Other differences were discovered among children with neuromuscular disease and myocarditis.

These findings indicate that the cause of DCM should be considered when evaluating the importance of predictive factors such as ventricular dilation. As explained by a press release issued by the **National Institutes of Health**, "... the causes of DCM strongly affected which risk factors were predictive of death and/or transplantation. This suggests that establishing the cause of the disease early on is critically important."

Using risk factors identified in the study should help physicians better identify which high-risk children will likely benefit from a heart transplant. "If the findings of this study were implemented fully and used to decide which children with DCM should be listed for cardiac transplantation, we estimate that about 50 children in the U.S. annually would live who would otherwise die," explains Dr. Steve Lipshultz.

#### Progressive Left Ventricular Changes Predict the Likelihood of Survival in Pediatric Dilated Cardiomyopathy

Although it has been established that dysfunction in the heart's left pumping chamber (left ventricular dysfunction) is associated with death and heart transplantation in children

*continued, page 8*

### Research Grant Recipients *continued from page 1*

preventing DCM in these mice, the same approach using a drug to counteract the effect of IL17A will be proposed for treating humans.

According to Dr. Cihakova, "Our overall goal is to identify the cellular and molecular mechanisms by which inflammation initiates the development of DCM. We have already shown that we can prevent progression to DCM in mouse models by neutralizing the cytokine IL17A. We now want to determine whether we can arrest or even reverse already established DCM, improve cardiac function and improve survival." Wendy Chung, M.D., Ph.D., CCF medical advisor and director of clinical genetics at Columbia University Medical Center, believes that "This study could open a new avenue for the development of biologic treatments with potentially rapid application."

Dr. Cihakova has been investigating molecular and cellular processes of autoimmune diseases since 1998, and has focused specifically on autoimmune myocarditis since 2003.

### Identifying Benefits of Cardiac Resynchronization Therapy for Children with DCM

**Mark Friedberg, M.D.**

*Associate Professor in Pediatrics,  
University of Toronto and Cardiologist,  
Hospital for Sick Children*

Dr. Friedberg's study, *Patterns and Clinical Significance of Electro-Mechanical Dyssynchrony in Pediatric Dilated Cardiomyopathy*, aims to determine which children with DCM may benefit from cardiac resynchronization therapy using a specialized pacemaker to re-coordinate the heart's pumping action.

In some children with DCM, slow or abnormal electrical signals in the heart muscle may cause different regions of the heart to contract at different times (cardiac dyssynchrony), which can lead to inefficient pumping and heart failure.

Cardiac resynchronization therapy, or CRT, uses an implantable pacemaker to send electrical impulses to stimulate the left and

right chambers of the heart to squeeze at the same time. CRT has been shown to improve quality of life and life expectancy in adults with heart failure.

In spite of its success in adults, CRT is rarely used in children with DCM because limited experience has suggested that children with DCM do not always respond to this therapy. Dr. Friedberg, however, has seen dramatic improvement in some children with DCM following CRT.

"Some of our patients have been able to come off the heart transplant waiting list because their heart function improved so significantly," says Dr. Friedberg.

Because systematic studies have not been done to test the use of CRT in children with DCM, it is unclear which children with DCM may benefit from CRT and which children would show the greatest improvement with this therapy. Without further investigation, treatment guidelines cannot be developed for this therapy in children.

With CCF funding, Dr. Friedberg plans to identify patterns of cardiac contraction that may be treated by CRT in children with DCM. The research team will analyze ultrasound pictures from 150 healthy children and 60 children with DCM. This comparison will help them to better understand exactly what is abnormal in DCM and identify which patients would be most likely to benefit from CRT. They also will analyze tissue samples from 15 children undergoing heart transplant to understand the relationships between the genes associated with DCM, scarring in the tissue and abnormal cardiac contraction.

"If we can identify which patterns of cardiac dyssynchrony are associated with heart failure and death, and which can be effectively treated with CRT, this potentially lifesaving therapy could be offered to more appropriate children with DCM," says Steve Lipshultz, M.D., CCF medical advisor, and professor and chairman of pediatrics at University of Miami School of Medicine.

Dr. Friedberg is a Canadian Institute of Health Research and Canadian Heart

and Stroke Foundation-funded expert in the assessment of cardiac function by echocardiography in children. Since 2004, he has been researching mechanisms of cardiac dysfunction and dyssynchrony by echocardiography in children with cardiomyopathy and congenital heart disease.

### Predicting Outcomes and Severity of Disease with Biomarkers

**Carmen Sucharov, Ph.D.**

*Associate Professor in Cardiology,  
University of Colorado at Denver*

Dr. Carmen (Kika) Sucharov's study, *MicroRNA Expression in Children with Heart Failure*, aims to determine whether microRNAs can be used as biomarkers to predict which children with idiopathic dilated cardiomyopathy (DCM) will most

*continued, page 5*

### Request for Research Applications

#### Dilated, Hypertrophic, Restrictive, Left Ventricular Non-Compaction or Arrhythmogenic Right Ventricular Cardiomyopathy

#### Funding Opportunity:

The Children's Cardiomyopathy Foundation (CCF) is inviting investigator-initiated research applications for innovative basic, clinical, population or translational studies relevant to the cause, diagnosis or treatment of primary cardiomyopathy in children under the age of 18 years. Funding is available in the range of US\$25,000 to US\$50,000 for one year of total direct costs.

#### Eligibility Requirements:

The principal investigator must hold an M.D., Ph.D. or equivalent degree and have a faculty appointment at an accredited U.S. or Canadian medical institution.

#### Application Deadline:

The 2012 deadline for application submission is Friday, September 7. Grant guidelines and application form are available online at [childrenscardiomyopathy.org/site/grants.php](http://childrenscardiomyopathy.org/site/grants.php).

For more information, contact  
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# Pediatric Cardiomyopathy Registry Receives MULTIMILLION-DOLLAR RESEARCH GRANTS from NHLBI

The **Pediatric Cardiomyopathy Registry (PCMR)** will receive two multimillion-dollar, 5-year research grants from the **National Heart, Lung and Blood Institute (NHLBI)** to improve diagnosis and treatment for children with cardiomyopathy.

“We believe this unprecedented support from the NHLBI for pediatric cardiomyopathy research shows how important this disease is,” said CCF Medical Advisor, Steve Lipshultz, M.D. Dr. Lipshultz also is the PCMR study group leader and professor and chairman of pediatrics at the University of Miami Miller School of Medicine.

The first study will use state-of-the art technology to map every gene for 600 diagnosed children to find new gene

mutations that cause dilated, hypertrophic and restrictive cardiomyopathy, as well as identify gene mutations that explain the age at which symptoms appear and the severity of those symptoms.

The second study will look at the relationship between specific blood tests, called cardiac biomarkers, along with echocardiogram and cardiac MRI images to determine if these tests can predict short- and long-term outcomes for children with dilated cardiomyopathy. The study will determine if specific cardiac biomarkers can indicate the presence of myocardial fibrosis, a thickening of the heart, in cases of hypertrophic cardiomyopathy.

Results for these two research projects should improve the cardiologist’s ability to better diagnose and more effectively treat

children with cardiomyopathy. It also can improve screening of other family members for the disease and help in the development of new cardiomyopathy therapies for children. “We are confident that the results of this research will likely lead to better treatments, which will improve the lives of people with cardiomyopathy and their families,” adds James Wilkinson, M.D., M.P.H., professor of pediatrics and epidemiology and director of the PCMR administrative coordinating center.

The PCMR is a national database of 3,500 patients age 18 and under with selected cardiomyopathies from nearly 100 medical centers in the United States and Canada. CCF has been actively involved with the PCMR over the years funding auxiliary studies, working group meetings and the establishment of a linked DNA and tissue repository. “CCF is an important and integral partner in all that we do,” said Dr. Wilkinson. The PCMR study group meets biannually to analyze new study data, discuss updates on current PCMR manuscripts and determine how study findings should be disseminated.

## Research Grant Recipients *continued from page 4*

likely progress to heart failure and which are likely to have better outcomes.

Although many children with DCM progress to heart failure, 15 to 35 percent of children do recover from the disease. Yet reliable guidelines to predict outcomes among infants and children with DCM do not exist, and pediatric cardiologists are not always able to determine which therapeutic options are best for their patients. Because of the risks and complications associated with heart transplantation and device therapy, a criteria for risk stratification of infants and children with heart failure could improve outcomes for this high-risk population.

MicroRNAs are small nucleic acids that modulate the expression of many genes, and their presence in the blood is associated with cardiovascular disease, cancer and certain other diseases. Circulating miRNAs in adult patients with DCM can be associated with poor outcomes, but their levels have not yet been studied in children with DCM. Dr. Sucharov’s study will analyze microRNAs in the circulating blood of children with DCM to determine the feasibility of using them as biomarkers to predict pediatric outcome and disease severity.

According to Dr. Sucharov, “If we can identify which patients are likely to recover with the use of medical therapy, we can avoid

placing these children on the heart transplant waitlist. If we can predict which patients are likely to benefit from a ventricular assist device, then we may be able to achieve better outcomes for these challenging patients.”

Dr. Sucharov’s team will analyze circulating microRNAs in the blood of 28 children who are listed for heart transplantation – nine children at the time of transplantation, nine children who have received a ventricular assist device and ten control subjects. A goal of the study is to identify a “signature” of circulating microRNAs in children with DCM as a basis for future prognostic studies. This would be the initial step in defining whether microRNAs may represent a new biomarker for children suffering from heart failure.

“If microRNA profiling is found to be associated with severe disease, it would open an avenue for further research and potentially identify areas of therapeutic research,” states Daphne Hsu, M.D., CCF medical advisor and chief of pediatric cardiology at Children’s Hospital at Montefiore.

A member of the genetics and epigenetics study section of the American Heart Association peer review committee, Dr. Sucharov has studied the molecular mechanisms of pathologic cardiac growth and heart failure for the past 10 years.

# CCF POKER EVENT Deals a **WINNING HAND** Four Years in a Row



Lisa Yue and grand prize winner David Croll

It was a royal flush for CCF's **All-In For A Cure No-Limit Texas Hold 'Em Tournament**. With a sold-out crowd of 235 people and 30 corporate sponsors, the event raised more than **\$245,000**—a 15 percent increase from last year—for CCF's research and education initiatives.

CCF Board Member **Carney Hawks** kicked off the event with opening remarks. "Thank you for attending our Fourth Annual Poker Tournament during National Heart Month," said Hawks. "Your support allows us to continue our mission of helping kids with cardiomyopathy have strong, healthy hearts."

Guests and players from top law firms and financial companies in the metro area enjoyed cocktails and appetizers at the

start of the evening and moved on to a rousing game of poker that lasted well into the night.

Grand-prize winner **David Croll** of **Imperial** won a **\$10,000** entry to the **2012 World Series of Poker Main Event** in Las Vegas. David works at **Imperial Capital** with **Jason Alpin**, winner of CCF's 2009 Poker Tournament.

Second prize of an all-inclusive trip for two to Las Vegas went to **James Cullinane** of **RBS**. **Gary Lehrman** of **1798 Global Partners** won the third prize, an Atlantic City getaway for two to the Borgata. Fourth prize of golf and lunch at Hudson National Golf Club went to **Brian Potash** of **Intrade Group**. **David Yaker** was the fifth-prize winner with four tickets to a New York Giants game. **Colin Lancaster**, **Travis Hogan**, **George Goudelias**, **Bob Franz** and **Dale Stohr** won the sixth through tenth prizes, gift certificates to popular New York City restaurants.



Above: Ashley Singer, Bob Franz and Bob Frahm

Below: Participants enjoy a lively evening playing poker



## SAVE THE DATE!

Montclair Golf Club  
West Orange, New Jersey

### Monday July 16, 2012

Join CCF for this popular  
and fun-filled event!

Visit our event web page  
under "News & Events/Golf"  
for more information.

**2012 Event Sponsors:** Rob Barrett; Jay Bharadwa; Brigade Capital Management; Benji Cheung/Bob Franz/Jed Kelly; Credit Suisse; Robert & Karen Dishner; John Florio/Andy Stock; Eric Friel; Rob Gallivan; Gibson Dunn & Crutcher; Bill Goebelbecker; Imperial Capital; Katten, Muchin & Rosenman; Knight Capital Group; Kramer Levin Naftalis & Frankel; John Lugano; Chris Mikosh; Eric Needleman; Mike & Beth Neumann; Gene Pagnozzi; Richards Kibbe & Orbe; Riva Ridge Capital Management; Royal Bank of Scotland; Edgar Sabounghi; Ian Sandler; Gary Stanco; Andrew Susser; Taconic Capital Advisors; Tullett Prebon/Chris Berry/Matt Lambert; UBS; Eddie Yu.

More event photos are online under "News & Events/Poker."

## FAMILY FUNDRAISERS



Above: Heather, Cristina and Parker Cinca

Right: Parker Cinca and friend

### CINCA FAMILY FUNDRAISER KEEPS GETTING BETTER

diagnosed with hypertrophic cardiomyopathy when she was 7 years old.

Held on November 19, 2011, attendees enjoyed a day of food, shopping and fabulous entertainment courtesy of Cristina, her friends and her 7-year-old brother, Parker, who enthralled the crowd with his magic tricks. More than 26 vendors, including **31 Gifts, Avon, Jockey and Creative Memory** participated in the event. Funds were raised through a percentage of event sales, sponsors and silent auction proceeds.

"This is Cristina's favorite day of the year, and it is worth every minute I put into it just for that!" says **Heather Cinca** who is already hard at work planning the next year's Extravaganza.

The **Third Annual Cinca Shopping Extravaganza** in Cocoa Beach Fla. had another successful year, raising more than \$21,000 for CCF. More than 150 people attended the event in honor of **Cristina Cinca**, age 11, who was



### Dedicated CCF Staff Member Gives Foundation Support

CCF Patient Outreach and Support Coordinator, **Harriet Salk**, organized a fundraiser lunch at her daughters' school during **Heart Awareness Month**. Held at **J. Spencer Smith Elementary School** in Tenafly, N.J. on February 9, more than 250 students and teachers participated. The student lunchroom was decorated with red and white balloons, and students enjoyed a pizza lunch along with heart-shaped cupcakes. "It was a great day in honor of CCF," said Harriet.



### Crossing the Finish Line for CCF

With almost 100 percent humidity and temperatures well into the 80s, **Kavitha Baratakke** ran a half-marathon in San Antonio, Texas, with an impressive time of 2:07:33. She ran in honor of her daughter, Sharanya, who has

hypertrophic cardiomyopathy. Through her efforts, Kavitha raised more than \$2,000. "I'm so glad I was able to do something for CCF because the Foundation has helped me enormously in my journey," said Kavitha.

### Raising Heart Rates, Raising Funds

**Jared Markiewicz** of **Functional Integrated Training** in Verona, N.J. held a "Get Fit" boot camp and raised more than \$1,000 for CCF. The hour-long fitness training was held at **Glacier Edge Elementary School**. "The boot camp went off without a hitch and was awesome," said Jared. It was in honor of a camper whose son has hypertrophic cardiomyopathy.



### Holiday Donation Drive

**Frank and Kristi Shippers** held an online holiday fundraiser in honor of their son Cooper, who was diagnosed with hypertrophic cardiomyopathy and left ventricular non-compaction (LVNC). They sent emails to family and friends asking for online donations on their **crowdwise.com** gift page. "Because LVNC is a rare disease, we created this fundraising page in hopes of raising money for CCF to help with research," said Frank.

### Will CCF Be Mine

For a second year in a row, the **Tyngsborough Elementary School** in Massachusetts held a **February Heart Month** fundraiser in honor of Assistant Principal **Scott Middlemiss'** son Joe who has hypertrophic cardiomyopathy. Led by teachers **Erica Yandow** and **Jen Trischitta**, the school's student council made and sold valentines to students and staff on Valentine's Day.



## CCF Sponsors Documentary, **THE HEART OF THE MATTER**

CCF is working with the **Children's Heart Foundation** to sponsor **The Heart of the Matter**, a one-hour documentary on congenital heart defects (CHD). The program, which focuses on the world's #1 birth defect, premiered Sunday, May 6 on WTTW-Channel 11 in the Chicago area.

Produced by The Children's Heart Foundation and **TMK-Productions**, the documentary is narrated by Golden Globe nominated actor **Chris O'Donnell** and examines all aspects of congenital heart disease from the development of the heart in utero through adulthood. *The Heart of the Matter* includes interviews with the top cardiologists and cardiothoracic surgeons in the field as well as families whose children have been diagnosed with congenital heart defects and other heart diseases. Among the many interviews, **Brian Littrell** of the **The Backstreet Boys** talks about the impact of living with CHD and **Chicago Bears'** cornerback, **Charles Tillman**, shares his story about his daughter's cardiomyopathy and subsequent heart transplant. CCF's involvement will be acknowledged in the documentary credits, website and promotional materials.

The program will be available for broadcast to all PBS station throughout the U.S. after June 1. The trailer and a listing of PBS stations and broadcast times are available on the documentary's website [congenitalheartdocumentary.com](http://congenitalheartdocumentary.com)

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## First-Ever **Cardiomyopathy Legislation** Introduced to the Senate

On February 17 during **National Heart Month**, Senators **Frank R. Lautenberg** (D-NJ) and **Robert Menendez** (D-NJ) introduced the **Cardiomyopathy Health Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act** to the Senate (S.2124).

Since the December introduction of the **HEARTS House Bill** (H.R.3625) by Congressman **Frank Pallone** (D-NJ6), the Children's Cardiomyopathy Foundation (CCF) has been actively working with the New Jersey Senators to introduce this companion bill in the Senate (S.2124). CCF has secured 25 organizations, including the **American Heart Association** and members of the **Sudden Cardiac Arrest Coalition**, to support both the House and Senate HEARTS Bill. The bill also has the bipartisan support of nine co-sponsors in the House of Representatives. CCF continues to make the rounds on Capital Hill to impassion more legislators to co-sponsor this bill, which can help to identify more undiagnosed children with cardiomyopathy at risk of sudden cardiac death.

In August, CCF will introduce its **Advocacy Toolkit** with basic information on the legislative process, a step-by-step guide on being an effective advocate, and sample letter and email templates. These resources are being developed to make it easier for CCF supporters and families to approach their district congressman and state senators to cosponsor the Cardiomyopathy HEARTS Act.

## Research Highlights *continued from page 3*

with DCM, the effect of left ventricular wall thinning in combination with dilation has not been identified.

Led by **Paul Kantor, M.D.**, this study analyzed echocardiogram records from 1,457 DCM patients to determine how progressive changes in the size, thickness and function of the left ventricle are predictive of death, heart transplantation and survival at 12 months.

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*"...these study results could have potentially important ramifications for the treatment of children with dilated cardiomyopathy."*

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They found that when progressive changes in left ventricular size, wall thickness and function were measured, rather than just the degree of abnormality at the time the child was originally diagnosed, the outcome was more clearly predictable. An increasingly enlarged left ventricle or one that continued to show poorer function over time was more associated with a poor outcome (death or transplantation) than one that did not worsen, while a smaller left ventricle with a thicker left ventricle wall was linked to survival. According to Dr. Kantor, "These findings suggest that serial assessments of echocardiographic changes should be considered when determining treatment plans for children with dilated cardiomyopathy." This study emphasizes the importance of ongoing, careful assessment of children with cardiomyopathy to identify whether their risk is increasing or not.

This study was selected for oral presentation at the March 2012 meeting of the **American College of Cardiology**. "This selection indicates the importance of its findings, as pediatric epidemiology studies are not often accepted for presentation during this conference," states **James Wilkinson, M.D., M.P.H.**, PCMR study investigator and director of the PCMR administrative coordinating center.



# LIZZY CRAZE: A Journey with a NEW HEART

## Dressed as Ernie,

her favorite character from Sesame Street, **Lizzy Craze** spent her Halloween trick-or-treating through the white

corridors of Stanford Hospital in Palo Alto, Calif. Just weeks before, on October 8, 1984, Lizzy made medical history as the youngest person to undergo a successful heart transplant in the U.S. Staff beamed at the brave, little girl they taught to ride a tricycle during her one-month stay.

Lizzy, diagnosed at 13 months old with dilated cardiomyopathy (DCM), was only 2 years old when she received a new heart. Her parents lost three children to the disease before Lizzy was born and her brother, Andy, who also has DCM but a milder form, had a heart transplant a year before Lizzy when he was 16 years old. Lizzy's mother calls her two living children "miracles."

Today, 30-year-old Lizzy, an event coordinator for **Facebook**, has been featured in many publications including a 2009 article in *People* magazine. She takes her "celebrity" status in stride. "I don't tell a lot of people," says Lizzy. "I let them find out on their own." When they do learn of her story, Lizzy says, "they're blown away."

Even though Lizzy's transplant was considered a milestone in medical history, Lizzy was too young to understand the significance of the transplant. She lived with the new heart from such an early age she never knew anything different. It was something she always accepted. That is, until at age 15 the anti-rejection medication she was taking for her heart caused her kidney to fail. Needing a kidney transplant made her feel vulnerable for the first time. Until then, she had never realized the seriousness of her condition.

Now Lizzy takes nothing for granted. During a crisp afternoon while brewing beer with her boyfriend — a fun



Lizzie Craze and Sentinel Dome in Yosemite National Park.

hobby they took up together three years ago—they uncovered an old "Life To Do List" she had jotted down on a brew log. She is now busy accomplishing the goals on her list. Last August she completed a 20-mile, 2-day backpacking trip in Yosemite, and recently she received her scuba diving certification after training in Fiji.

"Being active is so important," advises Lizzy to other teen and young adults with cardiomyopathy. "The medicines can increase your appetite and make you feel sluggish. The steroids make your face puffy," says Lizzy who maintains a regular workout regime at the gym and monitors

her heart rate. "Even if you don't feel like it, get out and do something. Go for a brisk walk or bike ride; it's likely you'll feel better when you're done."

About 370 children each year receive a heart transplant with an average wait of six months. Lizzy knows first-hand, from waiting for both a heart and kidney, how lonely being "listed" can be. She now volunteers on a transplant patient advisory panel at Stanford Hospital, which was established to help improve the patient transplant experience. She also works directly with hospital patients providing support and mentoring as they wait for a new heart. Lizzy advises others to "Try to have a positive attitude. It can affect your mind as well as your body!"



Lizzie Craze hiking in Yosemite National Park.

## Ben Breedlove's Message of Hope

continued from page 1



Ben Breedlove

thousands of people who had never met him, including one famous rapper:

CCF recently reached out to Deanne and Shawn Breedlove, Ben's parents, to learn more about Ben and their family's journey with cardiomyopathy. In her quiet, southern drawl, Deanne spoke lovingly about her son, the courageous young man in the video who captivated the world. "It's exciting to know that Ben planted a seed in people's mind to begin thinking about things that really do matter in life," said Deanne.

Ben was diagnosed with HCM at 13 months due to a heart murmur. He was given medication and remained asymptomatic until at age 4 he developed abnormal heart rhythms (arrhythmia). As Ben says in his video, he "cheated death three times." His first sudden cardiac arrest happened at age 4 following a severe seizure. During his near-death experience, he describes a light from above that calmed his fears.

Although the seriousness of his heart condition was now known, Ben grew up happily and, for the most part, unbothered by his cardiomyopathy. He, along with his siblings Ally and Jake, enjoyed an active childhood in Texas filled with swimming and wakeboarding on the lake behind their house. At the same time, he followed his cardiologist's guidelines to take it slow.

"We found smart ways to be active," says Deanne.

Deanne and Shawn tried to keep life as normal as possible for Ben, even though there were concerns related to living with an unpredictable heart condition. They didn't change their parenting style for Ben; they modified it. Ben had chores just like his siblings. "As parents, it's our responsibility to teach our children values and responsibility," says Deanne. One of Ben's chores was taking out the trash, but if he was particularly tired that day or the trash was too heavy, his parents modified the task to accommodate his condition.

The Breedloves have always valued a strong work ethic. When the Breedlove children turn 16, they are expected to find a job. Ben was no different. His first job was working at a local restaurant, but the job was physically challenging. Instead, Shawn suggested that Ben work from home and record a weekly YouTube show for his peers. He was responsible for developing the content, taping and editing.

Ben, from behind a desk like a late night talk show host, covered topics on studying, dating and relationships. It was mature advice from a handsome and charming 18-year-old, who told girls they were beautiful for just being themselves. His two video blogs, *BreedloveTV* and *OurAdvice4You*, developed a devoted following and started to generate ad revenue. Ben was clearly a natural in front of the camera, making it the perfect outlet for Ben's final story.

Even though he appeared confident on screen, the high school years proved to be challenging for Ben. "With peer pressure, team sports and the need to be like his friends, Ben began to test the limits," says Deanne. Seeing his friends develop into more serious athletes, Ben felt sidelined by his condition for the first time. "I was never allowed to play all the sports that my friends did," said Ben in his video. "I really just hoped I could be the same as everyone else."

Deanne was worried when Ben began lifting weights. She did not want to tell him he could not continue so she gently relayed her concerns, "This scares me. Let's talk to your doctor at our next appointment and

develop a plan." Deanne felt this approach worked because, "including Ben in the decision making process with his doctors made him feel more in control of his condition."

Ben was on several different medications throughout his life to treat his arrhythmias. In 2009 Ben was told he needed an implantable device, which was both a cardioverter defibrillator (ICD) and a pacemaker, to treat his abnormal heart rhythms. Ben was opposed to the device until a 6'6", 295-pound football player with an ICD counseled Ben and told him he didn't have a choice. After that, Ben was ready and willing.

After the implant, Ben had more energy — enough strength to do a back flip on the wakeboard. However, by 2011 Ben's heart began to deteriorate. Frequently exhausted and weak, Ben missed weeks of school and suffered two more cardiac arrests — one in the hospital and a second one at school. "My heart stopped and I wasn't breathing for three minutes," said Ben. With these second and third near-death experiences, he once again saw the light that called for him in the same way it had when he was four.

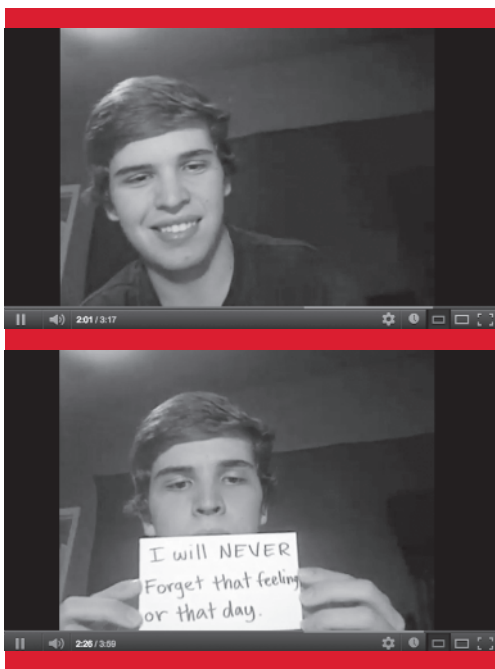
With Ben's heart continuing to fail, the Breedloves began the process of listing him for a new heart. Unfortunately, Ben collapsed unexpectedly on Christmas day while playing outside with his brother. This time he could not be resuscitated.

How could his ICD and pacemaker fail to save him, so many cardiomyopathy families ask? According to Deanne, Ben was not experiencing fast, irregular heart rhythms (ventricular tachycardia, ventricular fibrillation) that normally would trigger the ICD to fire, but his blood pressure was extremely low. Because of his dilated and weakened heart muscle, there simply was not enough pressure to pump blood through his body to sustain life.

"The important message here is that an ICD is not a cure for HCM. It reduces the incidence of sudden death, and overall it prolongs survival for patients," says **Steve Colan, M.D.**, CCF medical advisor and professor of pediatrics at **Boston**

**Children's Hospital.** "ICDs are better than any previously available therapy; however, patients are still at risk for sudden cardiac death and heart failure."

While not much time has passed since Ben's death, Deanne doesn't dwell on painful memories or give consideration to what could have been done differently for Ben. Instead she remembers the beauty Ben brought to life. "We strongly believe we each have a certain amount of time on this earth that we are gifted with, which is beyond any attempts we may make at extending our own life," says Deanne. "We are willing to accept that Ben was given 18 wonderful, fantastic years, which we were blessed to share with him."



Ben Breedlove: *This is my story* video

The funny and light-hearted Ben the family knew was much more serious and contemplative in his final message. Unknown to his family and friends, he created a new channel to broadcast his two three-minute videos. It was Ben's holiday gift for others to find—a hopeful message that even in the midst of fear and uncertainty, faith and courage would carry us through.

Deanne continues to share Ben's message to live life as fully as possible. "Remember to live every day as a gift," says Deanne. "Everyone has challenges, but we all have real hope and he (Ben) saw that."

## CCF Family Assistance Program Awards **FIRST GRANT**



6-year-old Madison and 3-year-old Sydney Rippy

CCF has awarded its first **Family Assistance Program** grant to a worthy family in Minnesota.

The CCF Family Assistance Program was launched in December 2011 at nine medical centers across the U.S. to assist low-income families with cardiomyopathy-related medical and non-medical needs.

The **Rippy family** from Anoka County, Minn. received financial assistance from CCF for their rent, utilities and health insurance. The Rippys have two daughters, Madison and Sydney, both of whom have dilated cardiomyopathy. Madison is doing well after a 2011 transplant, and Sydney recently received a heart transplant at the **Mayo Clinic**.

"When I found out we had been awarded a grant from CCF's Family Assistance Program, I just sat down at the kitchen table and cried," says **Linsey Rippy**, mom to Madison and Sydney. "My husband hasn't gotten paid in six months, and I had to quit my job to stay home with the girls. I just didn't know what we were going to do."

After hearing stories of cardiomyopathy families struggling financially to provide care to their child, CCF established the program with annual appeal donations from CCF families. The assistance program will reimburse qualified families for treatment-related costs; rent, mortgage, utilities and displacement fees during a child's treatment and health insurance premiums, deductibles and co-pays.

"Thank you so much to CCF and to all the wonderful families who have donated to the fund," says Linsey. "It was so frustrating having two very sick kids and getting behind in our bills. Now we have a little bit of peace in our lives, knowing our medical insurance and other bills are paid for a while. We won't need help forever, but just for a few months until we can get back on our feet."

CCF is actively working with other hospital social workers to identify more qualified families. For more information, including program guidelines and an application form, please contact Chris Colón at [ccolon@childrenscardiomyopathy.org](mailto:ccolon@childrenscardiomyopathy.org). To make a contribution to the Family Assistance Program, contact Sheila Gibbons at [sgibbons@childrenscardiomyopathy.org](mailto:sgibbons@childrenscardiomyopathy.org).

# HearttoHeart

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**Children's Cardiomyopathy Foundation**

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## MEMBER SUPPORT SERVICES

**CCF offers a variety of ways for members to share information on pediatric cardiomyopathy and provide support to one another.**

CCF offers a member forum, local support groups and phone sessions. For more information about these services or the scheduled events below, please contact Chris Colón at [ccolon@childrenscardiomyopathy.org](mailto:ccolon@childrenscardiomyopathy.org).

### CCF Forum Guest Q&A Sessions

- **Pediatric Cardiomyopathy and Medications**

Elizabeth Blume, M.D.  
Children's Hospital Boston  
June 4-11

- **Pediatric Heart Transplantation**

Anne Dipchand, M.D., F.R.C.P.C.  
The Hospital for Sick Children  
September 10-17

### Local Support Groups

- **North Carolina**

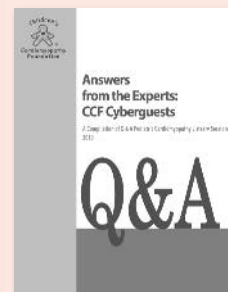
Duke University Medical Center  
Durham, N.C.

May 24 at 6:30 p.m.

Room 4902, McGovern-Davidson  
Children's Health Center



## Now available: CCF 2010-2011 CYBERGUEST COMPILATION



**Answers from the Experts: CCF Cyberguests**, a compilation of Q & A pediatric cardiomyopathy forum sessions is now available. Topics include

"Helping Your Child Cope with Medical Tests or Hospitalization,"  
"The Basics on Health Insurance,"  
"Parenting Teens with Cardio-myopathy or a Heart Transplant"  
and several others. Compilations for Q&A sessions from 2006-2007 and 2008-2009 also are available upon request.