

Heart to Heart

Volume 4, Number 2 • Fall 2007 • Winter 2008

President's Message

From Lisa Yue,
CCF Founder & President

We have been working hard these past few months to complete several projects. In this issue, you'll learn about our partnership with the American Heart Association, a new CCF patient DVD, and our latest outreach efforts. You'll also hear about our various fundraising and local support group activities.

On two recent projects, I had a chance to view the adorable photos of some CCF kids. It was wonderful to put a face to all the names that I've become familiar with in the past year. The photos were a reminder that the story behind each child is what drives us to continue doing what we do. You'll be able to get a glimpse of these special kids in our year-end appeal, which will be mailed soon. We hope that this year's appeal message will be one that touches your heart and motivates you to make a difference.

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CCF and AHA Announce **JOINT RESEARCH GRANT PROGRAM on PEDIATRIC CARDIOMYOPATHY**

The Children's Cardiomyopathy Foundation (CCF) and the American Heart Association (AHA) have established a joint research grant program focused on pediatric cardiomyopathy. The AHA is the leading resource for professionals in cardiovascular science and medicine. CCF will continue to support basic, clinical, population, and translational research through its standard research grant program while the new CCF/AHA joint award will provide an additional funding opportunity for investigators studying the disease.

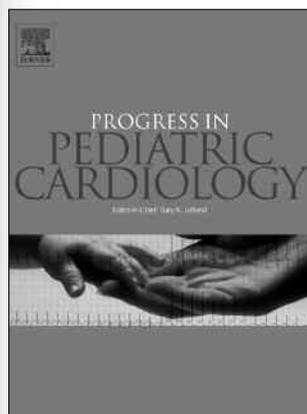
Through this joint research program, CCF will provide \$35,000 per year for two years to fund one AHA Beginning Grant-in Aid or one Grant-in-Aid related to pediatric cardiomyopathy. The AHA will provide the balance of the funds needed to fully fund the selected award. This special research program allows CCF to cast a wider net to the scientific research community and

support cardiomyopathy investigators that might otherwise remain unknown to us. CCF's association with the AHA is an important step in building CCF's credibility in the medical and scientific community.

Interested applicants will apply through AHA's regional affiliates and undergo the AHA peer review process. In June, CCF will then select its designee from a list of meritorious applications that are above the AHA pay line, meaning that they are approved for funding. The deadline for applications this year is January 15, 2008 with the award taking effect July 2008.

The promotion of this award will help build awareness of CCF as a key funder of pediatric cardiomyopathy research by leveraging AHA's reputation as the largest non-government funder of heart research and tapping into its vast membership base. From September to December, AHA will publicize the new funding opportunity to department heads and grants officers of

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CCF Sponsored **SCIENTIFIC WORKSHOP Leads to NEW PUBLICATIONS**

In January 2007, CCF in conjunction with the National Heart, Lung, and Blood Institute and the University of Miami Miller School of Medicine, sponsored the first international scientific workshop on pediatric cardiomyopathy, **Idiopathic and Primary Cardiomyopathy in Children: Research Directions and Strategies.**

Proceedings from the conference are being featured in three dedicated issues of *Progress in Pediatric Cardiology*. Issue 1 was published in September 2007 and presented results from the workshop on topics

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A Cause for Today... A Cure for Tomorrow



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 affected children 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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The Children's Cardiomyopathy Foundation, including all parties to or associated with *Heart to Heart* will not be held responsible for any actions readers take based on their interpretation of articles from this newsletter. As always, readers are encouraged to discuss medical evaluations and treatments with their own physicians.

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CCF GRANT RECIPIENT Presents at the AMERICAN HEART ASSOCIATION SCIENTIFIC SESSION

CCF's 2007 grant recipient, Dr. Anne Dipchand of Toronto Hospital for Sick Children, presented her preliminary research findings at the 2007 American Heart Association Scientific Session in Florida this November. The AHA Scientific Session is the premier global meeting dedicated to cardiovascular health, with over 26,000 attending the sessions.

Her abstract "Outcomes of Children with Cardiomyopathy Listed for Heart Transplant: A Multi-Institutional Study" showed that children with cardiomyopathy awaiting a heart transplant have a low waitlist mortality and good survival post-transplant, with dilated cardiomyopathy patients demonstrating a consistent, modest advantage in survival from listing. The lower survival rate of restrictive and hypertrophic cardiomyopathy patients suggests further study is needed to better understand the causes, timing of death,

timing of listing, and influence of patient characteristics on survival. These findings were based on her analysis of 1,320 children with cardiomyopathy listed for transplant from 1993 to 2006. To date, this is the largest series of such pediatric patients studied in the world. Her research is important in that it will help identify factors that make these patients more likely to need a heart transplant, to survive one, and determine the point at which they should be put on a heart transplant list.

The oral presentation marks a significant accomplishment for Dr. Dipchand, as only 20% of those who submit research abstracts are accepted and invited by the AHA to share findings with their peers. Since 2004, there have been five abstracts related to CCF funded studies that have been presented at various AHA Scientific Sessions.

Scientific Workshop Leads to New Publications *continued from page 1*

ranging from predictive genetic testing, novel medical therapies, heart transplantation, enzyme deficiency metabolic cardiomyopathies, and ethical concerns among others. Issues 2 and 3 will present additional reviews and abstracts from the workshop, including the consensus recommendations on future research directions in the area of genetics, epidemiology, and therapy for cardiomyopathy in children. Issues 2 and 3 are expected to be published in November 2007 and January/February 2008 respectively.

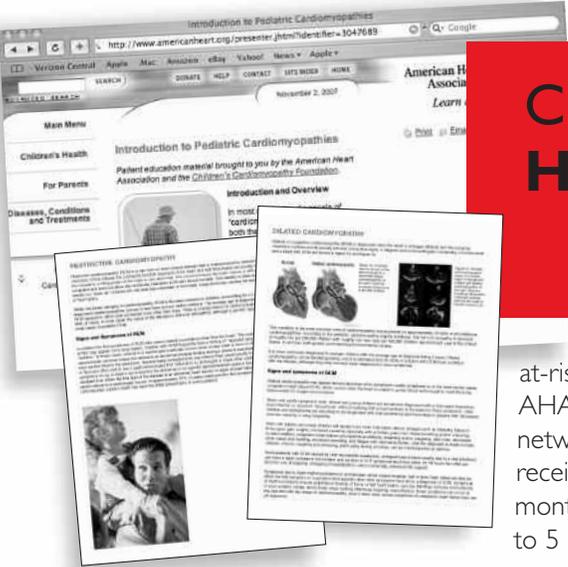
Presentations from the conference are now available on CCF's website.

The Scientific Workshop was held in Bethesda, Maryland, and leading basic and clinical investigators in pediatric

cardiomyopathy from the United States, Canada, and Australia convened to focus on three main areas: molecular and genetic issues; epidemiology, etiology, and outcomes; and clinical issues in pediatric cardiomyopathy.

The aims of the workshop were 1) to review the current understanding of pediatric cardiomyopathy in the above three areas, 2) to identify the most critical and promising areas for basic science and clinical research efforts, and 3) to disseminate the results and recommendations of the workshop. CCF's role has been prominently acknowledged in the published manuscripts and on-line presentations related to the scientific workshop.

Presentations from the conference are now available on CCF's website under Research/Scientific Meetings & Workshop or at this link: www.pediatrics.med.miami.edu/x431.xml.



CCF Partners with the **American Heart Association** to Launch **WEB-BASED MATERIALS**

at-risk and diagnosed families through AHA's well-established presence and network. Currently AHA's call center receives more than 53,000 calls per month and their website attracts close to 5 million unique visitors.

CCF approached the AHA's **Council on Cardiovascular Disease in the Young (CVDY)** to invite the top pediatric cardiologists in the country to write *Introduction to Pediatric Cardiomyopathies*. CVDY Vice Chairman, **Dr. Paul Matherne** (University of Virginia) led the effort with **Dr. Rob Gajarski** (University of Michigan) serving as the medical editor and **Lisa Yue** (CCF) as the lay editor. Contributing writers included **Paul Matherne, MD** and **Rob Gajarski, MD** as well as **Wendy Chung, MD, PhD** (Children's Hospital of New York), **Steve Colan, MD** (Children's Hospital Boston), **Susan Denfield, MD** (Texas Children's Hospital), **Chris Erickson, MD** (University of Nebraska),

Daphne Hsu, MD (Children's Hospital at Montefiore), and **Jeff Towbin, MD** (Texas Children's Hospital).

Covering everything from the definition of cardiomyopathy to the latest treatment options, the information is categorized into four different forms of cardiomyopathy. The downloadable pdfs cover dilated cardiomyopathy, hypertrophic cardiomyopathy, restrictive cardiomyopathy, miscellaneous (rare) cardiomyopathies, and an overview of inheritance for cardiomyopathies.

To read *Introduction to Pediatric Cardiomyopathies*, please go to the AHA site under Children's Health/For Parents/Disease, Conditions, & Treatments (www.americanheart.org/presenter.jhtml?identifier=3047689). The webpage can also be accessed from CCF's site under Support Services/Educational Materials (www.childrenscardiomyopathy.org/site/pamphlets.php).

CCF has partnered with the **American Heart Association (AHA)** to produce web-based materials on pediatric cardiomyopathy specifically for the lay reader. Launched in June 2007, *Introduction to Pediatric Cardiomyopathies* is CCF's latest initiative to provide accessible and easy-to-understand materials for the general public.

In the past, CCF partnered with the **National Organization for Rare Disorders** and the **National Society of Genetic Counselors** to develop better patient resources on pediatric cardiomyopathy. CCF's collaboration with AHA will allow us to reach more

MEDTRONIC Suspends Sale of Sprint Fidelis Defibrillator Leads

In October 2007, **Medtronic Inc.** voluntarily suspended distribution of its **Sprint Fidelis** defibrillation leads and recommended that doctors cease to implant Sprint Fidelis models in new patients.

A defibrillator monitors a patient's heartbeat; if it senses an abnormal heart rhythm, it delivers an electronic shock to reset the heart to a normal beat. A defibrillator system consists of a device implanted near the shoulder with one or more leads connecting the device to the heart.

Medtronic found that there is a "small chance of fractures in particular locations" on Sprint Fidelis models 6930, 6931, 6948, and 6949. Lead fractures may present clinically as audible alerts, inappropriate shocks, and/or loss of output. Medtronic's **Independent Physician Quality Panel**, the **Heart Rhythm Society**, and the **Food and Drug Administration (FDA)**, do not recommend that patients seek prophylactic replacement of Sprint Fidelis leads, as the risks of removal or insertion of another lead exceed

the small risk to patients of a lead fracture. Medtronic has provided patient management recommendations to physicians, which should reduce risks in the affected population. Information is also available for patients and physicians at www.medtronic.com/fidelis and www.fda.gov/bbs/topics/NEWS/2007/NEW01724.html. Medtronic advises patients with questions to consult their physician.

The FDA issued a statement noting that "patients can be assured that the likelihood of fracture is very low and the FDA is committed to ensuring that the risk to patients is minimized... the FDA will continue to monitor information on these devices and will take whatever action may be necessary." Both the FDA and Medtronic have estimated that less than 1% of the 268,000+ leads that have been distributed have fractures. Medtronic continues to communicate with heart patients who have a Sprint Fidelis lead, doctors who manage their care, and various heart organizations such as CCF.



CCF Co-Hosts the PBS Premier of **The Mysterious Human Heart**

On October 10, 2007 **The Medtronic Foundation, PBS, Channel Thirteen/WNET** (New York) and **WETA** (Washington D.C.) hosted a preview screening of the new PBS series, “**The Mysterious Human Heart**”. The Children’s Cardiomyopathy Foundation served as an event co-host along with the **National Heart, Lung and Blood Institute** and eleven other

heart-related patient organizations. Held in Washington D.C. the intent of the reception was to broaden the discussion of heart health and encourage equal patient access to education, support, and advocacy. During the evening, eight distinguished members of Congress were recognized for outstanding patient support and advocacy in an area of heart health.

“The Mysterious Human Heart” aired on October 15th and October 22nd. The three-hour PBS series, produced by nine-time Emmy Award-winning filmmaker **David Grubin**, focused on the intricacies of the

heart’s structure, the way it can break down, and the work that is being done to understand it, repair it, and prevent it from being damaged. Each episode featured compelling stories of patients with various heart disorders and the physicians, scientists, and engineers who push the boundaries of medical and scientific knowledge to save their lives.

For those who missed the series, a 3-pack DVD collection is available through PBS’s online shop for \$49.99. More information about the series, including a tour of the heart, a healthy heart guide, the history of cardiology, an educational discussion guide, and resource listings can be found at www.pbs.org/wnet/heart/index.html.



Bill Hawkins, Medtronic, Lisa Yue, Children’s Cardiomyopathy Foundation, and Lisa Salberg, Hypertrophic Cardiomyopathy Association, recognize Rep. Chip Pickering for his support of cardiovascular issues on the federal and state levels.

NEW Patient Education DVD Available

CCF’s newly developed DVD, *Secrets of the Heart - Living with Pediatric Cardiomyopathy* is now available to cardiomyopathy families, physicians, and healthcare professionals. This new patient resource offers an alternative to printed materials and presents basic information on the disease in a more personal manner. The 38-minute DVD profiles the experience of three families with different forms of cardiomyopathy, all of whom have lived successfully through the challenges associated with the disease. Their personal stories are interspersed with factual information on the disease contributed by some of the top pediatric cardiomyopathy experts. Developed in response to patient and physician needs, the DVD presents information on pediatric cardiomyopathy in an understandable way that families will find useful and those unfamiliar with the disease will find interesting.

Similar to CCF’s other patient education materials, this audiovisual piece is available free-of-charge due to the generosity of the **American Legion Child Welfare Foundation, The Medtronic Foundation**, and the **eBay Foundation** who helped fund the project. A direct mail campaign targeting 300 children’s hospitals

will be launched before year end to promote its availability to pediatric cardiologists, cardiac nurses, geneticists, genetic counselors, social workers, and child life specialists in the U.S. and Canada.

More information about the DVD including a downloadable order form is available on CCF’s website under Support Services/Educational Materials (www.childrenscardiomyopathy.org/site/pamphlets.php)



What Role Does **CoQ10** Play in the Treatment of **PEDIATRIC CARDIOMYOPATHY?**

Coenzyme Q10 (CoQ10),

also known as ubiquinone, is an organic compound present in every cell. It is a vitamin-like substance found naturally in foods and essential in minute amounts for normal body functioning and for the production of cellular energy by the mitochondria (the power house or energy producer of each cell). Although CoQ10 is present in all cells of the human body, the heart has the greatest concentration of it because of the high-energy requirements of the heart muscle cells. Deficiencies in CoQ10 can contribute to mitochondrial disease, and up to 25% of cardiomyopathies are possibly due to mitochondrial disease. For the past 14 years, the majority of clinical work with CoQ10 has focused on heart disease, specifically congestive heart failure. Some studies have shown that there is a correlation between the severity of heart failure and the amount of CoQ10 deficiency.

There have been many studies conducted in the U.S. and abroad on the effectiveness of CoQ10 therapy on adult cardiomyopathy patients. Findings have consistently shown that treatment with CoQ10 can improve heart muscle function with no adverse effects or drug interactions. In 1985, P. Langsjoen published the results of a double-blind, double-crossover trial in *Proceedings of the National Academy of Sciences*. The study involved administering CoQ10 with a matching placebo to two groups of patients with New York Heart Association (NYHA) class III or IV cardiomyopathy. Of the 80 patients who participated in the three-month study, 89% showed significant improvement. However, when treatment was stopped, their heart function deteriorated. In another P. Langsjoen study, conducted in 1990 and published in the *International Journal of Tissue Reactions*, the findings of a six-year open-label trial were presented in which 143 people with NYHA class III and IV cardiomyopathy were given CoQ10 daily in addition to their standard therapy. The results showed a significant improvement in

the cardiac function of 84% of the participants and a lower mortality rate compared to that of individuals who were only on conventional therapy. Smaller studies on patients with dilated cardiomyopathy and hypertrophic cardiomyopathy also showed marked improvement in heart function.

Although research on adults seems promising, there has not been any randomized controlled trial to prove the efficacy and effectiveness of CoQ10 on children with cardiomyopathy. Small scale studies on children with cardiomyopathy have shown mixed results. **H.N. Bhagavan** and **R.K. Chopra**, in their study "Potential Role of Ubiquinone (Coenzyme Q10) in Pediatric Cardiomyopathy" published by *Clinical Nutrition* in June 2005, state that based on the biochemical rationale of CoQ10's importance in mitochondrial function and the large body of data produced from studies conducted on adult cardiomyopathy patients, CoQ10 therapy in pediatric cardiomyopathy should be considered, particularly in children with dilated cardiomyopathy.

"experts in the field continue to debate whether or not it should be part of the standard regime for treating pediatric cardiomyopathy."

In a similar study presented at the **Third World Congress on Pediatric Cardiology and Cardiac Surgery** and subsequently published in the *International Journal of Cardiology* (March 2003), **H. Elshershari** and **S. Ozer** from Turkey reported that CoQ10 proved to be "remarkably beneficial" when used to treat children with dilated cardiomyopathy. The study, "Potential Usefulness of Coenzyme Q10 in the Treatment of Idiopathic Dilated Cardiomyopathy in Children," included children ranging in age from four to twelve months who were diagnosed with NYHA class III cardiomyopathy. The patients were given CoQ10 in addition to their standard therapy and followed for an average of six months. As a result of using CoQ10, the

patients' heart disease classification decreased from NYHA class III to NYHA class I in every patient except for one. As a comparison, the patients had gone through an initial monitoring period of one to eight months during which they received only standard therapy. During this phase of the study, there were no meaningful changes in any of the measured parameters. Only after CoQ10 was introduced did any changes occur. Because of the small size of their study, the doctors acknowledged that additional studies should be done to measure the effectiveness of CoQ10 on pediatric cardiomyopathy patients.

On the other hand, in a study conducted in Thailand by **J. Soongswang** entitled "The Effect of Coenzyme Q10 on Idiopathic Chronic Dilated Cardiomyopathy in Children" and published in *Pediatric Cardiology* (July-August 2005), it was shown that after multiple comparisons were taken into consideration there was no statistically significant improvement in administering CoQ10 to children with chronic heart failure caused by dilated cardiomyopathy (DCM). The study recruited 15 patients ranging in age from six months to 16 years with idiopathic DCM and NYHA class II heart disease.

Since the benefits of CoQ10 are not medically established in the pediatric population, experts in the field continue to debate whether or not it should be part of the standard regime for treating pediatric cardiomyopathy. There are still many physicians that prescribe CoQ10 as an adjunct to traditional therapy. Often, a cocktail consisting of CoQ10, L-Carnitine, and other vitamins and minerals is given to cardiomyopathy patients. However, CoQ10 is considered a supplement, not a drug; so it is usually not covered by insurance. Because it is expensive, it typically is not purchased by families, creating a compliance issue.

An "Introduction to Coenzyme Q10", written by P. Langsjoen, MD in, is available at <http://faculty.washington.edu/~ely/coenz-q10.html>

NEW STUDY: Increased Brain Natriuretic Peptide Secretion is a Marker of Disease Progression in Nonobstructive HCM

In the June 2007 issue of the *Journal of Cardiac Failure*, it was reported that a clinical investigation in Italy showed that increased **Brain Natriuretic Peptide (BNP)** secretion is an indication of disease progression in non-obstructive hypertrophic cardiomyopathy (HCM). There is mounting evidence that BNP may be a reliable clinical marker for advanced heart failure. Studies conducted in the U.S. by **Dr. Barry Maron**, featured in the March 2004 issue of *Circulation*, showed that BNP plasma levels are related to the presence and magnitude of heart failure symptoms in patients with HCM.

Brain Natriuretic Peptide (BNP) is a hormone made by heart muscle and usually is secreted in the lower chamber of the heart. Known for its important role in regulating blood pressure and volume, BNP has several physiological actions including increases in urine production, dilation of the blood vessels, and relaxation of a certain type of muscle called "smooth muscle". All of these actions lead to a decrease in blood pressure.

In **M. Pieroni's** study conducted in Rome, Italy, he recruited forty HCM patients between the ages of 34 and 50 to undergo cardiac catheterization, angiography, and left ventricular endomyocardial biopsy. Each of the

participants had a family history of HCM, as well as marked hypertrophy themselves. It was found that while plasma levels of BNP were higher than normal in the participants, they all had normal arteries and blood pressure. Upon a five to seven year follow up, 75% of the individuals had no changes in diagnosis; however, 25% had deteriorated health with increased blood pressure levels and heart dysfunction. Furthermore, Peironi observed a four-fold increase of BNP in those with heart dysfunction.

Since early identification of patients progressing to end-stage heart failure remains a problem, observation of BNP increases in plasma can provide an index of the disease severity and elicit prompt treatment. As the disease progresses to its end-stage and the heart begins to decompensate, there is increased production and secretion of BNP. In this situation, BNP tries to "save the heart" by decreasing detrimentally high blood pressure. The increase of BNP is thought to counteract filling pressure, wall tension, and remodeling of the ventricle resulting from the progression of

non-obstructive HCM. Constant measurement of BNP levels provides a noninvasive opportunity to identify the extent of damage to the heart. Increased BNP levels are measured either by staining biopsy tissue samples with antibodies specific for BNP or through a blood draw that can assay blood plasma with commercial immunoradiometric kits.

Larger scale studies need to be conducted to investigate whether the relationship applies to other forms of cardiomyopathy, such as obstructive HCM. However, there is great potential in using BNP for hormone-guided treatment with drugs that will slow the progression of HCM as a possible therapeutic effort.

CCF is providing this synopsis as a service to families to keep them current on new research in the field. CCF makes no warranties as to the accuracy or valid methodology of the research study. If you are interested in learning more about a particular study, please contact your child's cardiologist or primary care physician.

SCHIP: FINANCIAL ASSISTANCE FOR HEALTH CARE

The **State Children's Health Insurance Program (SCHIP)** was established in October 1997 to provide low-cost health coverage to children aged 19 and younger from low-income families. Administered by the **Centers for Medicare and Medicaid** under the **U.S. Department of Health and Human Services**, the program is geared towards families whose annual income is too high to qualify for Medicaid but not enough to cover private insurance. An eligible family of four is one that earns less than \$36,200 annually.

Under SCHIP, the federal and state government subsidizes the

cost of health insurance premiums according to the amount a family can afford. For little or no cost, SCHIP pays for doctor visits, immunizations, hospitalizations, and emergency room visits. Although SCHIP expired in September 2007, Congress and President Bush are currently debating how much funding the renewed program requires.

Within broad federal guidelines, each state determines the design of its program, eligibility groups, benefit packages, and payment levels for coverage. To find out what your state provides under SCHIP, please visit www.cms.hhs.gov/home/schip.asp.



CHARITABLE TRAVEL RESOURCES

for Patients and Their Families

For families with sick children who need to travel for specialized medical evaluation, diagnosis, or treatment, there are charitable organizations available to help patients find free or low-cost travel and lodging for family members in cities far from home.

Angel Flight America is a network of seven independent operating entities - six regional Angel Flight organizations and Mercy Medical Airlift. Together they handle 90% of long-distance charitable medical air transportation in the continental U.S., Alaska, and Hawaii. These organizations rely on donated corporate jets with flight crews and the services of volunteer

pilots to provide flight services to families in need.

One of the organizations, **Mercy Medical Airlift**, operates the **National Patient Travel Center (NPTC)** which serves as a clearinghouse of information on all available charitable or deep-discount airline ticket programs for patients and patient

escorts. The NPTC also administers airline patient ticket programs and operates various Special-Lift and Child-Lift programs on behalf of disease organizations and/or clinical research centers in the United States. The NPTC can arrange for the transport of outpatients from several overseas locations to the United States as well.

The NPTC's helpline offers information to families on how to obtain no-charge travel for repeated trips to distant specialized care. To determine eligibility, a family must show proof of financial hardship and medical necessity for the trip.

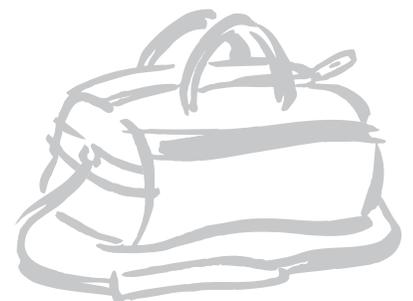
Information specialists determine suitable modes of air travel based on the patient's medical condition, the patient's mobility, and the need for any en route medical monitoring or care. Typically, if the travel distance is less than 1,000 miles (2-3 hour flight) and the patient has sufficient mobility, the services of a volunteer pilot organization will be considered. This will consist of private or corporate aircraft travel on single or small twin-engine aircrafts (4-6 seats) for the patient and accompanying family member(s). If the patient must travel more than 1,000 miles, no-cost or deep discount airline ticket programs will be recommended.

Other organizations providing free airline flights for qualifying patients include:

Aircare Alliance, Children's Flights of Hope, Lifeline Pilots, and Miracle Flights for Kids. As an alternative, some domestic airlines (**Northwest, Delta, TWA, American, Continental, and Midwest Express Airlines**) have special travel programs (free or reduced fee travel) for children facing life-threatening illness. Other airlines offer their lowest available fare for medical emergencies, giving the same discount as a 30-day advance ticket.

Once the destination is reached, the **National Association of Hospital Hospitality Houses, Inc (NAHHH)** can provide affordable home-like accommodations for patients and family members during hospitalizations, before and after surgery, and during repeat visits. The NAHHH offers a "Hospitality Hotline" and online directory of family-centered lodging and support services near various treatment sites.

The National Patient Travel Center can be reached at 800-296-1217 daily from 9am to 5pm EST. The Hospital Hospitality Hotline, 800-542-9730, is available daily from 9am to 5pm EST.



Additional Resources

Links to these resources are available on CCF's website at

www.childrenscardiomyopathy.org/site/additional.php

- **NIH Office of Rare Diseases - Patient Travel & Lodging Links**
http://ord.aspensys.com/asp/resources/pat_travel.asp
- **National Patient Travel Center**
www.patienttravel.org
- **National Association of Hospital Hospitality Houses**
www.nahhh.org
- **Angel Flight America**
www.angelflightamerica.org
- **Pediatric Oncology Resource Center - Airline Flight Information**
www.acor.org/ped-onc/resources/airlineflights.html

A Peek into Cardiac Camp Life

This summer, two kids in the CCF family network – **Joey DiSanto**, 13, and **Rain Test-Balsley**, 7 – attended cardiac camps. Their mothers, **Patti** and **Nichole**, wanted to share their experience so that other families know what awaits them should they decide to attend similar camps.

Joey DiSanto, who was diagnosed with DCM and had a successful heart transplant in July 2006, attended **Hope with Heart Camp** in Warwick, NJ for one week this summer. A typical day for him included pool time, arts & crafts, bowling, campfires, movies, and a talent show at night.



Fishing at Camp Boggy Creek

His counselor, like most of the other counselors, was a heart patient as well.

According to Patti, “[Joey] did not dwell on his heart issues at all while he was there. He did talk to two other bunkmates one night though... I was thrilled that he had a chance to talk to others on his own level about his experiences.” Patti was also very happy with the nurse and support staff at the camp. “I was totally comfortable leaving Joey in the nurse’s care - and I haven’t left his side for over a year.”

Rain Test-Balsley had an equally enjoyable time at **Camp Boggy Creek**, located in Lake County, Florida. Rain had been diagnosed with RCM, and he had a successful heart transplant in May 2007. During the family weekend at the camp, Rain was assigned a “buddy” who participated in whatever activities he chose - from miniature golf and fishing to horse-back riding. For the parents, the camp offered group time in which “you divide



Campers at Boogy Creek clown for the camera

into a men’s circle and a women’s circle to discuss anything from insurance to how to handle what is going on.” In the evening, the families met up for a dinner and dance.

Nichole enthused, “Counselors were incredible... and they have a cabin ‘hospital’ which is run by volunteer doctors. They have everything you could possibly need.”

Both Joey and Rain can’t wait to go back next year.

Both camps are free to attend, with beautiful campgrounds. For more information on Hope with Heart Camp and Camp Boggy Creek, please visit their websites at www.hopewithheart.com and www.boggycreek.org.

Living Courageously with Cardiomyopathy

Many parents have found it challenging to get extended family, friends, and school faculty to understand the special needs and health risks of their affected child because they appear so “healthy”. A few CCF families share what’s worked for them.

“One thing I’ve done that seems to help people get cardiomyopathy is to invite them to a CPR/AED training session. Our local Red Cross will do a course in your home if you get together a group of people. We had a training session in our home recently with a representative of an AED company that was showing us how to use the new AED we had just purchased. I invited some friends to come along. I think learning CPR

and putting their hands on a defibrillator really made an impression on them. It’s as if something clicked, ‘Oh, we’re really talking about the possibility of using this machine on the kids that I know and love.’”

-Mary, mother of 2 children (HCM)

“My son Luke was having a hard time being ‘different’ at school after his recent diagnosis with DCM and subsequent pacemaker implantation. After a particularly difficult time at recess when his friends would not throw the ball at him during dodge ball, he went to see the school nurse. I had sent in CCF’s *Cardio-What?* booklet, and Luke asked her would she please read it to his class. It went over very well and prompted a great discussion. Now his friends all understand better about his DCM and realize he’s not ‘breakable’, he’s just Luke with some limitations.”

-Sharon, mother of Luke (DCM)

“The way that worked best for us was to try to keep family involved and in the loop

from the beginning. We used a Carepage (other options include caring bridges, blog sites etc...) to accomplish this, which allowed family and friends to keep up with our son’s progress and setbacks, learn about the disease, and post their thoughts and prayers for us to read and be encouraged by. In addition, we have tried to have a heart-to-heart discussion with each family member or friend that is involved in Mason’s care. They know the warning signs of heart failure and know what to do in an emergency. Anyone who watches Mason has CPR certification. We explained to them that although Mason looks healthy he does have a heart disease and needs to be watched as such.”

-Stormy, mother of Mason (DCM/LVNC)

What has helped you and your child the most in dealing with the challenges of living with a chronic heart disease?

We welcome your thoughts.

CCF LOCAL SUPPORT GROUP Update

CCF's newly established support groups have been well received by both families and hospitals. It is a wonderful way to have face-to-face interactions with others experiencing similar challenges in raising a child or children with cardiomyopathy. Also, families that have lost children to the disease have found the groups to be a comforting way to connect with others that understand. Besides the below established groups, there has been interest in setting up groups in Florida, Arkansas, Colorado, Illinois, and California. If you are interested in being a support group leader or becoming more involved in any of the below groups, please contact **Stormy Hill**, CCF Patient Outreach Coordinator, at 866-808-CURE, ext 905 or thill@childrenscardiomyopathy.org for more information.

Georgia -

The GA group has been partnering with **Sibley Heart** of Atlanta and more specifically its **Kids at Heart** group to attract more members. At their last meeting in May 2007, the **Boslets** were invited to speak about their son **Ryan** who passed away suddenly from undetected HCM in 2003. The next support group meeting is November 11th, 1-3 p.m. at **Ledo's Pizza, Pasta and Pub**. CCF Georgia families were invited to attend **Kids at Heart "Boo at the Zoo" Event** on October 27th and the **2007 Atlanta Heart Walk** on November 3rd at Piedmont Park. The Georgia support group leader, **Audrey Callahan**, continues to meet with parents of diagnosed children staying at the hospital. Contact: **Audrey Callahan** at dacallahan_99@yahoo.com.

Michigan -

The MI support group is affiliated with both **Mott Children's Hospital** and **Detroit Children's Hospital**. The group held their First Annual **CCF Michigan/Midwest/Canada Summer Picnic** on August 18th at the Rolling Hills Park in Ypsilanti, Michigan. Six CCF families attended, and everyone had a great time socializing, sharing, and getting to know one another. The next meeting will be sometime in the winter/spring. **Brian Hill**, the MI support group leader, also has been visiting families whose children are in the hospital. Contact: **Brian Hill** at hillb2@wowway.com.



Michigan summer picnic gathering

Tennessee-

The TN group is still in the process of establishing an affiliation with a university hospital in the area. In the meantime, they are planning an informal get-together with CCF families in the area. Contact: **Patricia Simpson** at flynboy1@comcast.net.

North Carolina -

The NC group held their first meeting on October 25th at **Duke University Medical Center** with six families attending.



North Carolina group meeting

Sheila Rittgers, Clinical Social Worker and **Bronwyn Bartle**, Cardiology Physician Extender, helped to facilitate the meeting. **Dr. Michael Carboni** will serve as the medical advisor to the group. The group plans to meet monthly and the next meeting is scheduled for January 24, 2008. Contact: **Angela Henderson** at ahenderson919@aol.com.

Massachusetts -

The MA support group will be partnering with **Children's Hospital of Boston**, and **Dr. Steve Colan**, Chief of Noninvasive Cardiology, will act as medical advisor for the meetings. **Jane Messere**, the Pediatric Cardiomyopathy Registry Nurse Coordinator, has been very helpful in getting the group going. The first meeting will likely be in the winter. Contact: **Stephanie Thorsen** at msthorsen@verizon.net.

Start a LETTER or E-MAIL CAMPAIGN



Not quite ready to plan a family fun day or golf tournament? Then consider doing a letter-writing campaign. This can be accomplished in the least amount of time with little expense.

With a short personal letter, your message comes from the heart in honor of your loved one. CCF will supply sample letters, pamphlets, and donation envelopes. All you need to do is to write your story... "My daughter/son" or "My friend... has been diagnosed with pediatric cardiomyopathy" and send it with a CCF brochure and donation envelope to family, friends, and business associates. Ask that they "Please make the mission of the Children's Cardiomyopathy Foundation their cause to support." After CCF receives the donations, you will receive a gift notification, and the donor receives a tax deductible acknowledgement letter. It is so simple and you will be surprised at people's enthusiasm and willingness to help.



Fifth Annual GOLF CLASSIC Raises More than \$401,500

Men's and Women's U.S. Amateurs, and is a frequent host to the New Jersey Open.

Due to heavy rain on the scheduled date of July 23rd, the event was postponed until September 10th. Despite this, and an early downpour on the 10th, 160 golfers still came out to play and support CCF. The game was followed by cocktails, dinner, and a silent auction of fine wine, popular golf packages, coveted restaurant and spa certificates, and eclectic gift items. Thirty additional people attended the evening activities.



left to right: Sean Finnerty (Deutsche Bank), Robert Burke (Tullett), Rich Willard (Deutsche Bank)

This year's event raised a remarkable \$401,507 – none of which would have been possible without the generosity of CCF's sponsors and donors. The net proceeds from the event once again will go towards CCF's research grant program, which provides seed funding to investigators studying pediatric cardiomyopathy.

The winning foursomes were: **Brian Nold, Eric Needleman, John Heffers, and Chris Basta** (First prize); **Robert Frahm, Clint Kollar, Dan Ornstein, Brian Hewitt** (Second prize); **Kevin Kavanagh, Jon Jachman, Mike Belloli, Dave Pucciarello** (Third prize); and **Jay Kim, Seon Jung Kim, Do Seok Kim, Sung Sool Kim** (Fourth prize).

The prize for Closest to the Pin went to **Norm Kopack** and **Jason Gefaell**. The prize for Longest Drive went to **Michael McBride** and **Dave Pucciarello**. Finally, the Raffle prizewinner was **James Fitzpatrick**.



left to right: James Fitzpatrick (Seix), Jason Safriet (Credit Suisse), Tim Brennan (Credit Suisse)

This year's **Golf Classic** took place at the historic **Montclair Golf Club** in West Orange, New Jersey. Founded in 1893, "Montclair" is reputed to be the 13th oldest club in the country and famous for having three Metropolitan Golf Association presidents and two U.S. Golf Association presidents come from its ranks. A much larger course with 36 holes (four nine-hole courses), it is one of the few clubs to have hosted both the

Thank You 2007 Event Sponsors!

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Internet Searching for a Cure

Now you can make a difference in the lives of many people, simply by changing the way you search the Internet!

GoodSearch, an innovative new search engine powered by Yahoo, will donate a penny to CCF every time a user specifies CCF when searching the Internet. Just log on to **www.goodsearch.com** and type in "Children's Cardiomyopathy Foundation" into the "I support" box. If 500 CCF supporters searched four times a day, CCF would raise \$7,300 in a year without anyone spending a dime!

GoodSearch works by directing advertising revenue to a supporter's designated charity. To make searching easier, bookmark the page with CCF selected as your charity of choice using the link **www.goodsearch.com/?charityid=845342** or add the GoodSearch toolbar to your browser. Don't forget to spread the word so that more people can participate in this easy way to raise money for CCF.

OTHER EVENTS Benefiting CCF



Sylih Volmar

Sylih Volmar Foundation Launched

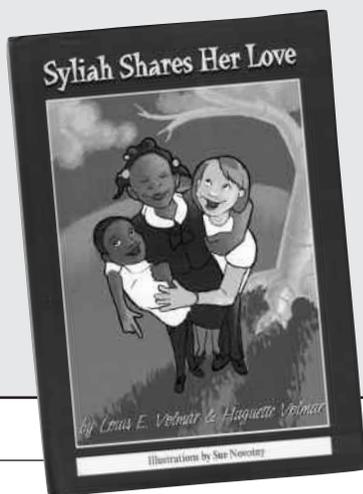
The Sylih Volmar Foundation (SVF), founded by CCF family members **Louis** and **Huguette Volmar**, held its **First Annual Community and Family Event** on

April 21st for over 200 people. The festivities included raffles, giveaway prizes, guest speakers, and live performances from singers and dancers. The Foundation also distributed CCF pamphlets and sold CCF curebands at the event. SVF was created by the Volmar family in memory of their daughter, Sylih Volmar, who died of dilated cardiomyopathy while awaiting a heart transplant in November 2003.

SVF's mission is to make a positive difference in the lives of children, primarily through educational and creative activities. The Foundation is currently working to restore the kindergarten playground at the school Sylih attended, developing a children's memorial park, and building a family center in Cambria Heights, New York.

Three years earlier, Louis and Huguette wrote a children's book, **Sylih Shares Her Love**, to introduce their daughter's story to others.

For more information on SVF or to purchase **Sylih Shares Her Love**, please visit www.sylihvolmarfoundation.org



Pauline Pierrot (CCF) and Al Chanese (AI)

Appraisal Institute Golf Tournament

For the second consecutive year, the Metro New Jersey chapter of the **Appraisal Institute** hosted its **Fourth Annual Golf Classic** to benefit CCF. The tournament was held on June 20th at the **New Jersey National Golf Club** in Basking Ridge.

Last year, CCF was nominated by **Victor DiSanto**, a board member at the Institute, in honor of his 13-year-old son, **Joey**. Joey had been diagnosed with dilated cardiomyopathy and was undergoing a heart transplant at the time of last year's event. This year, President **Al Chanese** chose CCF as the event beneficiary to celebrate the first anniversary of Joey's successful heart transplant. The event raised \$5,300 for CCF.

The Appraisal Institute is an international organization that supports education for real-estate appraisers.

Brat and Hamburger Fry Fundraiser in WI

Tara Krueger held an informal **Brat and Hamburger Fry** fundraiser on June 30th in Wrightstown, Wisconsin. The event was planned to commemorate the birthday of her niece, **Peyton Huss**. Peyton would have turned 1 year old in June. She had passed away unexpectedly at 3 weeks old on July 24, 2006 from cardiomyopathy. Friends and family wanted to donate to CCF's research fund to help prevent any family from having to experience the same heartbreak.



The Altieri fundraiser

Dinner Gathering at the American Legion in MA

On June 22nd, **Jamie Carragher** organized a fundraiser, "**Big Night for Small Hearts**" at the American Legion Hall in Manchester, MA to honor **Jackson Altieri**. Jackson is the 16-month-old son of Jamie's former colleague **Nicole**. Jackson was diagnosed with dilated cardiomyopathy at one month old and is currently awaiting a heart transplant at **Children's Hospital Boston**.

"I was appalled at how little research there is but how many families are affected by [cardiomyopathy]. I wanted to do something. I approached Nicole about putting together a fundraiser, and she was all for it as long as the money was donated to CCF," says Jamie. With the help of Nicole's parents, she organized an entertaining night that included dinner, a DJ, raffles, and a silent auction. Nearly 130 people attended and Jamie raised over \$5,000 for CCF. Jamie added, "I am honored to have done this for a wonderful family. Nicole and [her husband] Mark are an inspiration to all parents... and Jackson is a happy, playful little boy who doesn't let his sickness knock him down."

CCF's **AUSTRALIAN FAMILIES** Get Together



Left to right: Leigh King, Suzanne Gallpen, Lisa Logie
Matilda King, Gemma Gallpen, Nicholas Logie

Three CCF families from Australia – **Wayne and Suzanne Gallpen** of Portland, Victoria, **Peter and Lisa Logie** of Brisbane,

Queensland, and **Rob and Leigh King** of the Sunshine Coast, Queensland and their children – met for the first time at Brisbane Bay in Queensland on August 5, 2007. The three heart children – **Gemma Gallpen** (DCM), **Nicholas Logie** (DCM), and **Matilda King** (LVNC) – and their siblings had a wonderful time getting to know each other. The three mothers established a strong friendship on

CCF's forum and met in person when the Gallpens traveled 1,200 miles north to where the Logies and the Kings live.

Donate to CCF through **American Express'** **GIVING EXPRESS** Program

Another way to make a credit card donation to CCF is through the **American Express** giving website - www.americanexpress.com (search "Giving Express Program"). By making contributions online at the **Giving Express** page, American Express cardmembers who are enrolled in the Membership Rewards program can earn double reward points for every dollar donated through December 31, 2007.

Joint Research *continued from page 1*

medical institutions, members of AHA's peer review committees, past AHA applicants and awardees, AHA council members, medical societies and organizations, and well known funding databases. The program will also be promoted in AHA journals, website, newsletters, meetings, and conferences. On average, AHA receives roughly 500 Beginning Grant-in-Aid applications and 1,000 Grant-in-Aid applications per year in all areas of heart research.

For more information on this award, please visit AHA's "Special Research Program" webpage located under Science & Professional/Research/Funding Opportunities (www.americanheart.org/presenter.jhtml?identifier=3041239).

CCF MATERIAL DISTRIBUTION

CCF distributed materials at the following medical meetings from April to November 2007:

- April 10-12: **Society for Pediatric Nursing** in Milwaukee, WI
- June 24-26: **Fifth World Congress of Pediatric Critical Care** in Geneva, Switzerland
- June 12: **United Mitochondrial Disease Foundation** in San Diego, CA
- June 28: **National Association of School Nurses** in Nashville, TN
- July 13: **Pediatric Nursing** in Philadelphia, PA
- October 23: **American Society of Human Genetics** in San Diego, CA
- October 27: **American Academy of Pediatrics** in San Francisco, CA
- November 3: **American Public Health Association** in Washington DC
- November 6: **American Heart Association Scientific Session** in Orlando, FL

Heartto**Heart**

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