From the PRESIDENT

I still remember the day when our second son was diagnosed with cardiomyopathy, the same disease that unexpectedly claimed the life of our first son. Depression turned to anger and then to worry. My husband and I wished that there were a support group we could turn to for information and emotional support. At the time there wasn’t. Thankfully, this resource exists today.

The Children’s Cardiomyopathy Foundation (CCF) started out with humble beginnings, but in less than two years we have raised over $400,000. We established CCF with the belief that we can make a difference in the future of this disease. While we have made good progress in two years, there is still much that needs to be done. To our families, I ask you to become more involved and lend your voice to this disease. To our scientists and clinicians, I ask you to collaborate and assist us in identifying ways we can improve outcomes for affected children.

I am pleased to present our first newsletter, Heart to Heart. In this issue you will read about CCF’s achievements, receive information about cardiomyopathy and be acquainted with families living with the disease. We hope that by reading this newsletter you will begin to feelpart of our community, comprised of families, healthcare professionals and CCF supporters who are working together to battle this rare heart disease.

Sincerely,

Lisa Yue
President & Founder

The Children’s Cardiomyopathy Foundation (CCF) has awarded $100,000 to the Children’s Hospital of New York (CHONY) to establish a formal Comprehensive Pediatric Cardiomyopathy Program. The specialized program will make available in one distinct setting a clinical care center, genetic diagnostic unit and research facility all focused on pediatric cardiomyopathy. This unique program will ensure a complete, coordinated and concentrated approach to the disease, which will serve as a treatment model for other medical centers caring for children with cardiomyopathy.

The clinic will provide consultative services to families with children suspected of or diagnosed with cardiomyopathy in the Northeast region, but the services of the research and genetic diagnostic lab will be made available nationwide. This multi-disciplinary program will address the current challenges faced by physicians managing an extremely variable disease.

Establishing this repository will be a major step towards accelerating research into the prevention and treatment of cardiomyopathy in children. Currently, identifying and enrolling a sufficient number of children remains a key obstacle to conducting research on this rare disease. A repository of this caliber will enable scientists to focus valuable resources on studying the disease instead of spending time recruiting patients. For the first time, investigators will have access to well-characterized and categorized genetic samples and corresponding clinical information on children with cardiomyopathy. Previously, this was not available on a national scale.

CCF Helps to Establish Comprehensive Care and Research Program in New York

The Children’s Cardiomyopathy Foundation (CCF) was awarded $125,000 from the Andor Capital Management Foundation to establish a critically needed national biologic specimen repository. This seed money will be combined with additional funding from CCF to develop the infrastructure to collect blood and tissues samples for basic molecular studies on pediatric cardiomyopathy.

Establishing this repository will be a major step towards accelerating research into the prevention and treatment of cardiomyopathy in children. Currently, identifying and enrolling a sufficient number of children remains a key obstacle to conducting research on this rare disease. A repository of this caliber will enable scientists to focus valuable resources on studying the disease instead of spending time recruiting patients. For the first time, investigators will have access to well-characterized and categorized genetic samples and corresponding clinical information on children with cardiomyopathy. Previously, this was not available on a national scale.
The Heart to Heart newsletter is published semi-annually by the Children's Cardiomyopathy Foundation (CCF), a national voluntary health organization dedicated to saving lives and improving the quality of life for those affected by pediatric cardiomyopathy. Pediatric cardiomyopathy is a chronic and life-threatening heart disease that affects roughly 10,000 children in the U.S. CCF's mission is to accelerate the search for a cure by stimulating research, educating physicians, 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 SPREADS THE WORD to Healthcare Professionals and Families

With a generous grant from the Guidant Foundation, CCF has initiated a physician outreach program that has distributed pamphlets and letters to 2,000 pediatric cardiologists and allied health professionals (cardiac nurses, geneticists, researchers) across the U.S. and Canada. To expand the reach of this program, CCF has partnered with Pediatric Cardiology Today to advertise in their monthly newsletter that is distributed to 1,500 pediatric cardiologists. In addition, CCF regularly distributes information to genetics and cardiology conferences around the U.S. CCF recently exhibited at the Children's Hospital of Philadelphia “Pediatric Cardiology 2004” meeting in Orlando, Florida, which was attended by 600 pediatric cardiology physicians and nurses. The combined outreach efforts have resulted in more than 3,000 additional pieces of CCF information being sent to major children's cardiac centers.

In an effort to reach more families, CCF is working with several top pediatric cardiomyopathy clinics to distribute information to diagnosed families. To date, close to 700 patient letters have been sent to families through five leading U.S. medical centers. Plans are underway to expand this patient outreach program.

### CCF Invited to Attend NIH Meeting

CCF was recently invited by Dr. Claude Lenfant, former Director of the National Heart Lung and Blood Institute (NHLBI), to the Fifth Annual Public Interest Organization (PIO) Meeting in Bethesda, Maryland. Held February 11, the meeting was attended by almost 70 public interest groups. The aim of the meeting was to enhance PIO participation in National Institute of Health activities, introduce NHLBI staff and advisory council members, and facilitate discussion of best practice ideas.

**Comprehensive Care**, continued from page 1

disease without standardized evaluation and treatment protocols. Serving as a referral center, CHONY will enlist a team of experts comprised of pediatric cardiologists, pediatric surgeons, neurologists and geneticists to perform a comprehensive diagnostic and therapeutic evaluation in a single visit. This will eliminate the need to schedule and coordinate multiple appointments with different sub-specialists. In addition, there will be cardiac nurses, a pediatric social worker and a child psychiatrist available to help families cope with the psycho-social aspects of the disease. The genetics diagnostic unit will offer specialized testing to identify any metabolic condition and/or other genetic syndrome associated with cardiomyopathy. Although rare, there are certain types of cardiomyopathy that result from the body’s inability to break down or metabolize certain substances.

Families will also have the option to enroll in the latest pilot studies and multi-center clinical trials. Current studies being supported by CCF include Gene Expression and Protein Profiling of Pediatric Cardiomyopathy and Determining the Genetic Cause of Cardiomyopathy in Children.

For more information on the Comprehensive Pediatric Cardiomyopathy Program, please call CHONY at 212-305-6575.
CCF COLLABORATES with the PEDIATRIC CARDIOMYOPATHY REGISTRY in Two Studies

The Children’s Cardiomyopathy Foundation awarded $30,000 to the North American Pediatric Cardiomyopathy Registry (PCMR) to initiate two studies focused on the clinical aspects of the disease. These studies will analyze the accumulated data of 3,000 patients from 252 participating centers in the U.S., Canada and Puerto Rico. This project will define the most useful factors in determining the course of the disease. Analysis of factors such as age of diagnosis, gender, ethnicity, and type and stage of cardiomyopathy may offer healthcare providers the ability to predict when children will remain stable, improve or have resolution of their cardiomyopathy over time.

CCF’s partnership with the PCMR is the first attempt at developing outcome predictors and treatment protocols using national patient data. The variability and rareness of the disease makes it difficult for any one pediatric cardiology center to see a sufficient number of patients to fully understand the disease. Determining the medical management of this disease has always been a challenge for physicians because of the lack of reliable population based studies for guidance. Studies in the past have been largely skewed because they were regionalized, restricted to one medical center or without sufficient follow up time.

Participants from the first “think tank” session are currently finalizing a manuscript entitled Baseline Predictors of Outcome in Children with Cardiomyopathy to be published the end of 2004 in a major medical journal. The published findings from CCF’s funded study will give guidance as to what groups of children will most likely need a transplant and the timeframe for listing them. The second study will focus on the impact of familial cardiomyopathy on outcomes in children presenting with the disease. This “think tank” session will be scheduled in Fall 2004 with publication of a manuscript in 2005.

What is the Pediatric Cardiomyopathy Registry?

The North American Pediatric Cardiomyopathy Registry (PCMR) was established in 1995 to track and record the epidemiologic features and clinical outcomes of selected cardiomyopathies in children up to 18 years old and to promote the development of etiology targeted treatments. The PCMR is the only National Institute of Health funded, nationwide patient registry for this disease. Patient enrollment in the registry is through participating PCMR medical centers. More information on the registry is available at www.pcmregistry.org

See back cover for complete information on the Second Annual GOLF CLASSIC!

FIRST ANNUAL GOLF CLASSIC A SUCCESS!

The Children’s Cardiomyopathy First Annual Golf Classic was held on Sept 16, 2003 at the New York Country Club in New Hempstead, New York. More than 140 participants from the tri-state area came together on a sunny weekday to play golf and raise funds for medical research. Ed Kranepool, retired New York Mets player, joined in the day’s activities and served as the evening’s emcee. Sponsored by Morgan Stanley and heavily supported by the financial services industry, the event exceeded all expectations by raising more than $160,000. The event helped generate awareness about the disease and broadened CCF’s donor base to more than 360 contributors.

Plans are now underway for the Second Annual Golf Classic. The Foundation is currently seeking sponsorships and in-kind donations (auction items and product donations). If you are interested in being on the fundraising committee or contributing to the event, please contact Lisa Yue at lyue@childrenscardiomyopathy.org

Host Ed Kranepool with Bill Seibold, Mike Donoghue and Ted Burdick on the green.
**CCF HELPS Build Disease Awareness**

CCF has collaborated with the National Organization for Rare Disorders (NORD) to draft a disease report on pediatric cardiomyopathy. This report is important for educating the public, medical professionals and families with a diagnosed child. The new report can be found in the NORD rare disease database accessed through their office and website at www.rarediseases.org by searching “pediatric cardiomyopathy”.

The report will also be included in future editions of NORD’s printed book, NORD Guide to Rare Disorders, which is sold to physicians and other healthcare professionals. NORD receives approximately 100,000 visits per month to their web site and approximately 6,000 telephone calls per month.

**Tissue Repository, continued from page 1**

multi-institutional level. This systematic process of collecting and distributing high quality samples and data to world-class researchers will also help to facilitate more collaborative research in the field. The benefit of the repository to families is that they will finally have a way to participate in several research studies with a single tissue and/or blood donation.

Protocol documents are being developed and a steering committee is being formed to have the repository operational by fourth quarter 2004. Initially, CCF will work with selected institutions from the Pediatric Heart Transplant Study Group to collect blood and tissue samples from children with cardiomyopathy. The collected specimens will then be matched with clinical patient data from the Pediatric Cardiomyopathy Registry and be made available to a committee approved pilot study. In the second phase of the project, CCF hopes to receive Federal funding to expand the number of participating medical centers and initiate additional national studies on the disease.

**RUNNERS Support CCF Fundraising Efforts**

Earlier this year, Sharon Eason and Raymond Yue were able to combine two things they feel passionate about - running and raising money for the Children’s Cardiomyopathy Foundation (CCF). Sharon, a CCF volunteer, ran in the Houston Tenneco Marathon and Raymond Yue, a CCF board member, participated in the San Francisco Half Marathon. Raymond is now preparing to run in the San Francisco Chronicle 5 K Marathon on August 1 and will represent the Children’s Cardiomyopathy Foundation. CCF will receive a portion of any runner’s registration fee and online pledges if they select CCF as their cause. For more information, please visit www.causetorun.com and click on team 17 under the “Cause to Run” page.

**CCF and Neiman Marcus Host Charity Fashion Show & Luncheon**

The Children’s Cardiomyopathy Foundation is partnering with Neiman Marcus in two locations to host a charity fashion show and women’s luncheon. Organized by CCF board member; Tami Horan, the Summer Blast Off benefit was held on May 5 at the Garden State Plaza store in Paramus New Jersey. The event was attended by 86 guests and raised more than $10,000 for CCF’s research fund.

CCF family member, Jennifer Ghandour is coordinating the Fall into Fashion and Holiday Style event, which will take place September 12 and November 18 respectively at Neiman Marcus in Troy, Michigan. More information about these events can be found on CCF’s website under “News & Events”. Interested attendees, please contact Event Chair; Jennifer Ghandour, (imadghanour@yahoo.com) for the Michigan benefits.
Alone we can do so little, **TOGETHER WE CAN DO SO MUCH**

**Funding research** remains the core focus of CCF, but medical and scientific research remains extremely costly. We continue to need your help in obtaining monetary and/or in-kind donations. There are many ways that you can help to support our goal of finding a cure.

- **Engage in a letter writing campaign** to friends, families and business contacts to generate money for CCF’s research endowment fund. CCF can provide letter templates and help you draft a personal note.

- **Shop online at Igive.com.** When you make online purchases from your favorite retailers (i.e. Neiman Marcus, Gap, Disney Store, Barnes and Noble, Baby Style,Sharper Image to name a few) at www.igive.com and specify the Children’s Cardiomyopathy Foundation, a percentage of your purchase price will be donated to our organization.

- **Hold an event at school, work, home or your community.** CCF will send you a volunteer fundraising packet that includes guidelines, templates and idea sheets. The funds you raise can be set aside for a specific project of importance to you.

- **Volunteer your time or services.** We are always in need of dedicated people, especially those with experience in writing, fundraising and development, law, accounting, graphic design, web administration, or marketing and public relations.

- **Make an online donation in memory of a loved one or in honor of someone special.** Celebrate any occasion (mother’s day, anniversaries, birthdays, Christmas/Hanukah, thank you) with a gift that can help save the lives of others. For any donation of $10 or more, we will send a card in your name to the person or family that you wish to honor or memorialize.

*Helen Keller*

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**Cardiomyopathy: a Mother’s Perspective**

By Jennifer Ghandour
Mother to Anthony (Age 5 - HCM) and Eli (Age 3 - HCM)

Back in December 2000 we joyfully gave birth to our second son, Eli, after having a healthy son in 1999 (or so we thought). Within 24 hours we were told that Eli had a severe case of hypertrophic cardiomyopathy (HCM) and that we should immediately have Anthony, our first son, evaluated. One of the happiest days of our lives became the worst. One month later we found out that our first son, then 2 years old, also had a mild form of the disease. Both immediately began taking beta-blockers. We were devastated and began our journey to learn more about the disease. We were fortunate to hear about the Children’s Cardiomyopathy Foundation.

Everyday is a challenge for us especially with 2 active boys. We do not allow them to participate in gym class, and at recess the teachers keep a close eye on how much running they do. Outdoor activities and warm temperatures make them uncomfortable. We are also careful about them getting sick because a cold hits them much harder than a normal, healthy child. We’ve tried to explain their condition to them but they don’t like the fact that they are “different”. We remind them that they don’t have to play sports to have fun and succeed in life. This is a lifestyle we will have to deal with for the rest of our lives. A day doesn’t go by that we hope and pray that there will soon be a cure for this chronic disease.
Cardiomyopathy is a condition that clearly affects your child, but could it have implications for other family members or future children as well? Why did the condition occur in your child? What can you expect in the future?

To answer these questions, often a genetic evaluation with a medical geneticist and genetic counselor can be helpful. There are many different causes of cardiomyopathies. In the majority of cases of pediatric cardiomyopathy the cause is not identified; however, with comprehensive evaluation it is becoming clear that many cases can be attributed to a genetic etiology. Making a genetic diagnosis helps to explain what caused the cardiomyopathy, how best to treat it, what the prognosis will be and if other family members are at risk.

**Q. When should a family with cardiomyopathy work with a geneticist or genetic counselor?**

**A.** A genetics team should evaluate almost all children diagnosed with a cardiomyopathy of unknown cause. This is especially true if there are multiple members of the family with the disease, or if your child has other medical, developmental or growth problems.

**Q. What should you expect from a genetic evaluation?**

**A.** An appointment generally lasts between 60 to 90 minutes. During this time you should expect to discuss your child’s medical background, including pregnancy, birth and developmental history. Another component of the session is a review of your family’s medical history, including information about siblings, aunts, uncles, cousins and grandparents. Try to come prepared with knowledge of any medical conditions your family members have and if any of them have had echocardiograms. After collecting the relevant background, a physical exam is performed. Not only will the doctor listen to your child’s heart, but he/she will also look for any special characteristics that might suggest an underlying genetic condition.

**Q. What type of genetic testing is available?**

**A.** Depending upon the family’s medical history and findings on the physical exam, various tests may be offered. The majority of the tests offered involve simple blood or urine tests. Genetic conditions associated with cardiomyopathy generally fit into one of four categories: metabolic conditions, genetic syndromes, neuromuscular diseases or familial isolated cardiomyopathies. Results of genetic testing generally take from 2-8 weeks for results and may require pre-certification by your insurance company.

There is a battery of tests to screen for metabolic conditions - conditions in which your child’s body may have difficulty breaking down certain naturally occurring proteins, fats or sugars. In some of these conditions, an unusual build-up of these materials is what causes the cardiomyopathy as well as other problems. In rare circumstances a skin or muscle biopsy may be helpful in making the diagnosis of a metabolic condition.

Cardiomyopathy can also be seen in people with genetic syndromes such as Noonan syndrome, Alstrom syndrome, Naxos disease, and Beckwith-Wiedemann syndrome as well as chromosome abnormalities. These conditions tend to have other associated medical problems and specific physical characteristics that are evident on examination. These syndromes can be tested with specific genetic tests designed to test for a mutation in the gene associated with the condition. These conditions can occur sporadically in a family and affect only one person or they may be inherited from one or both parents with a tendency to recur in families. Once the specific condition is diagnosed, the mode of inheritance can usually be determined.

Neuromuscular diseases associated with cardiomyopathy are often associated with hypotonia (a floppy infant) or muscle weakness or myotonia. Some neuromuscular conditions associated with cardiomyopathy include Becker or Duchenne muscular dystrophy, myotonic dystrophy and Friedrich ataxia. Diagnosing neuromuscular disease may involve specialized blood tests, nerve conduction studies and/or muscle biopsies.

In some types of cardiomyopathy, the only problem is the heart disease. Sometimes there is more than one person in the immediate or extended family with similar symptoms. In these cases there may be an underlying genetic basis for the familial isolated cardiomyopathy. There are specific

“Making a genetic diagnosis helps to explain what caused the cardiomyopathy, how best to treat it, what the prognosis will be and if other family members are at risk.”
genetic blood tests that may be offered to your child and other family members to search for your family's genetic alteration causing cardiomyopathy.

Q. What do I do with genetic results?

A. Some metabolic conditions can be treated with a special diet. Other metabolic conditions can be treated with bone marrow or liver transplant or enzyme replacement. Other genetic conditions do not currently have a cure, but can be monitored to anticipate and treat whatever symptoms do occur. When a genetic diagnosis is made, it is often important information for other family members who are at risk themselves or at risk of having affected children. Many genetic conditions, once identified in a family, can be tested in future pregnancies via methods such as chorionic villus sampling or amniocentesis.

Q. What are some general recommendations for my family?

A. In some families, individuals are diagnosed with cardiomyopathy only after another family member is diagnosed. It is strongly recommended that all first-degree relatives (mother, father, and siblings) of the affected child have an echocardiogram and EKG annually. One normal exam does not automatically exclude the possibility of a cardiomyopathy developing at a later time.

Q. How do I find a pediatric genetics department?

Pediatric genetics departments are most readily found in large medical centers and children's hospitals. In searching for the name of a geneticist, you may try a hospital website or the membership directory of the American Society of Human Genetics and American Board of Medical Genetics. Genetic counselors are often members of the National Society of Genetic Counseling. These societies have websites with up-to-date member contact information. You might also ask your cardiologist if there is a genetics department to whom they could refer you.

Dr. Wendy Chung is the Herbert Irving Assistant Professor of Pediatrics and Medicine, Director of Clinical Genetics and the medical geneticist for the Comprehensive Pediatric Cardiomyopathy Program at Columbia University. She also conducts research on the genetic basis of cardiomyopathy in children and is working on developing better clinical methods for genetically diagnosing these disorders.

Elana Cox is a certified genetic counselor at New York Presbyterian Hospital who coordinates all the genetic services for the Comprehensive Pediatric Cardiomyopathy Program.

New Listserve Brings Families and Healthcare Professionals Together

Since the launch of CCF’s website in September 2002, more families are participating in CCF’s public discussion forum and connecting with one another. CCF now has close to 100 registered families throughout the U.S. and from countries as geographically diverse as Estonia, Israel, the United Kingdom, Belgium and South Africa. Earlier this year, CCF launched a listserve for registered families and physicians to increase communication among all CCF members. The listserve is a private email discussion group open only to registered members.

Occasionally, healthcare professionals are invited as cyber-guests for a week to cover an assigned topic and answer questions from CCF members. Past cyber-guests have included Dr. Steve Colan (Boston Children’s Hospital), Dr. Bill Mahle (Children’s Healthcare of Atlanta), Drs. Seema Mital and Beth Kaufman (Children’s Hospital of New York), and Dr. Elfriede Pahl (Children’s Memorial of Chicago). To subscribe to the listserve, families and physicians should fill out CCF’s online registration form (click “Contact Us - Join the Support Network”) and request to be added to the listserve. Physicians or nurses who would like to be a featured guest for a week, please contact Lisa Yue at lyue@childrenscardiomyopathy.org for more information.
As a parent of a child with cardiomyopathy you might question how to best meet your child’s educational needs. Depending on the stability and current state of your child’s health, his or her educational needs may vary and change often within a school year. When our daughter returned to school after being diagnosed with cardiomyopathy she was very ill. We determined that she needed an IEP (individualized education plan) in place at school to address her needs. When researching accommodations and modifications to include in her IEP we realized that there were no specific recommendations for cardiomyopathy or heart related conditions published or available through pediatric cardiologist offices.

Due to the severity of the cardiomyopathy in a particular child, the accommodations and modifications are broad and need to be adjusted to your child’s specific needs. We found the following definitions and modifications or accommodations helpful when we were considering an IEP for our child.

**Individuals with Disabilities Education Act (IDEA)**

The IDEA ACT, U.S. Public Law 94-142 Part B requires a free appropriate public education in the least restrictive environment for all handicapped children from pre-school through high school.

If it is determined that a student is “handicapped” and in need of special education, an IEP must be developed. Children with cardiomyopathy generally qualify under “other health impaired”. This category refers to students whose chronic or acute health problems cause limited strength, vitality or alertness that could adversely affect their educational performance.

**Evaluation and Placement**

The evaluation report used for initial eligibility should be current within one year with reevaluations occurring more frequently if warranted by the prognosis. Typically an evaluation would include:

1. Diagnosis and prognosis of the students health impairment
2. Information about medications, special health care procedures, special diet or activity restrictions
3. An educational assessment that details the adverse effects of cardiomyopathy on the student’s educational progress

Special educational services can be provided on a short-term, long-term or intermittent basis in the classroom, hospital or homebound setting depending on your child’s needs as documented in the IEP.

It is important to ensure that an educational environment is created that challenges your child’s intellectual abilities and builds self-esteem while accommodating special needs and identifying potential problems before they occur. By creating an IEP and remaining flexible, secondary consequences related to the disease can be avoided such as anger, depression, anxiety, frustration, low self-esteem, oversensitivity, social embarrassment and social withdrawal.

**Suggested Modifications or Accommodations for Children with Cardiomyopathy**

**CLASSROOM AND ACADEMIC MODIFICATIONS**

1. A shortened school day or week
2. Modified class schedule so a child is learning key academic subjects at their best time of the day
3. Grant time extensions on taking tests as needed
4. Keep an extra set of books at home for absences and to reduce fatigue
5. Provide a quiet place in school for the child to rest if needed
6. Assign lockers conveniently to reduce fatigue
7. Allow student to use elevator as needed in place of stairs
8. Modify curriculum and homework assignment to still teach concepts but minimize fatigue
9. Provide adaptive physical education
10. Inquire about special testing arrangements for ACT, SAT and other scholastic aptitude tests that take into account the effects of medication or symptoms on test performance

**SCHOOL INTERVENTIONS OR PREPAREDNESS**

1. Assess school medical emergency action plan
2. Ensure staff members are CPR certified
3. Determine availability of automatic external defibrillator at school
4. Educate staff about the side effects of cardiomyopathy medication such as fatigue, foggy thinking etc.
5. Set up an effective communication system such as e-mail, notebook log, voice mail etc. to allow teachers to be flexible and responsive to your child’s changing needs
6. Educate classmates about cardiomyopathy so they understand the reason behind any special needs, accommodations, absences etc.
7. Determine who is responsible for medication administration
CHRISTOPHE’S STORY

“Over the years my parents and I have become quite familiar with all the necessary strategies needed to keep me healthy and safe in school. During the early years, my mother would arrange a meeting with the school nurse to explain the complexities of my unique disease and the steps to take in an emergency situation. She would provide the school nurse with a doctor’s letter explaining my illness and request that the school be equipped with an extra set of my medication as well as an automatic external defibrillator with pediatric pads. For school trips, I would keep my medication in a temperature controlled snack pack. I also carried with me a special identification card that listed my essential medical information and important contact numbers. In the event that I was not feeling well or suddenly became unconscious, anyone in the area would understand the severity of the situation and react quickly and appropriately.”

Christophe Lafontant
Age 20 - HCM
First diagnosed at age 6

Children’s Heart Camps
PROVIDE SUMMER FUN

Children with cardiomyopathy deserve the same opportunities for summer fun as other children. There are now “heart camps” for children ages 4-18 with cardiomyopathy and other heart conditions. The camps promote self-esteem and personal development, and provide a wonderful opportunity to connect with other children with similar health issues. These camps provide a safe and supportive environment and range from one to two weeks in duration. Many camps are run by hospitals and are either free to qualifying children or are heavily subsidized. Descriptions of the listed heart camps can be obtained through the Congenital Heart Defect Resource Page at www.babyheartspress.com/chd/resources.html#camps

CA
Camp Del Corazon
11615 Hesby Street
N. Hollywood, CA 91601
Tel: (818) 754-0312
www.campdelcorazon.org

Camp Taylor
PO. Box 1722
Modesto, CA 95353
Tel: (209) 545-4715
www.kidssheartcamp.org

FL
The Boggy Creek Gang
30500 Brantley Branch Road
Eustis, FL 32736
Tel: (352) 483-4200
www.boggycreek.org

GA
Camp Braveheart
3495 Brittany Way
Kennesaw, GA 30152
Tel: (770) 919-2775

LA
Camp Bon Cœur
PO. Box 53765
Lafayette, LA 70505
Tel: (337) 233-8437
www.heartcamp.com

MA
Edward J. Madden Memorial Open Hearts Camp
250 Monument Valley Road
Great Barrington, MA 01230
Tel: (413) 528-2229
www.openheartscamp.com

MN
Camp Odayin
PO. Box 39
Afton, MN 55001
Tel: (651) 998-1333
www.campodayin.org

MO
Camp Systole
Children’s Mercy Hospital
2401 Gillham Road
Kansas City, MO 64108
Tel: (816) 234-3000

NC
Camp Kaliedoscope
Duke Medical Center
Henderson, NC
Tel: (888) 275-3853

NJ/NY
Hope with Heart
PO. Box 618
Hewitt, NJ 07421
Tel: (973) 728-3854
www.hopewithheart.com

OH
Children’s Hospital Heart Camp
700 Children’s Drive
Columbus, OH 43205
Contact: Mary Rummell
Tel: (614) 722-2530

OK
CHAMP Camp
Shepherd’s Fold Ranch
Avant, OK
Contact: Debi Lammert
Tel: (918) 494-5470

TN
Cardiac Kids Camp
LeBonheur Children’s Medical Center
50 North Dunlap Street
Memphis, TN 38103
Tel: (901) 572-4562.

TX
Camp John Marc
2824 Swiss Avenue
Dallas, TX 75204
Tel: (214) 360-0056
www.campjohnmarc.org

PA
Camp Victory
PO. Box 810
Millville, PA, 17846
Tel: (570) 458-6530
www.campvictory.org

Heart Camp
Children’s Hospital of Philadelphia
Children’s Heart Center
3705 Fifth Avenue
Pittsburgh, PA, 15213-2583
Tel: (412) 692-5540

Two children with special needs were standing in the yard of their house. One child had a heart condition and the other had a genetic disorder. They were both very happy to be able to attend a special summer camp that was designed for children with heart conditions. The camp provided a safe and supportive environment and allowed them to connect with other children who had similar health issues.

The child with heart condition was very excited to attend the camp. He had been diagnosed with a genetic disorder that had caused his heart to become enlarged. He had been taking medication and receiving treatment for his condition, but he was still very nervous about attending the camp. He was afraid that he might not fit in with the other children and that they might not understand his condition. However, the camp staff made him feel very welcome and he was able to make many new friends. He enjoyed all of the activities at the camp and he felt much more confident after attending.

The child with the genetic disorder was also very happy to attend the camp. She had been taking medication and receiving treatment for her condition, but she was still very nervous about attending the camp. She was afraid that she might not fit in with the other children and that they might not understand her condition. However, the camp staff made her feel very welcome and she was able to make many new friends. She enjoyed all of the activities at the camp and she felt much more confident after attending.

The camp was a great success and the children were both very happy with their experience. They were able to make many new friends and they felt much more confident after attending. They both plan to attend the camp again next year.”
ENSURING Correct Emergency Care

Most parents are concerned about emergency care when their child begins attending school. They may wonder, “What happens if my child has a cardiac arrest? or “Will someone know what to do if my child becomes unconscious”\(1\). With a complex heart condition, a young child may not be able to communicate what medication they are on, the details of their heart condition or explain that they have an implantable defibrillator. As a result, children with cardiomyopathy may be at a greater risk for less than optimal care in an emergency situation. Possible problems might include misdiagnosis, slow reaction to cardiac warning signs and unfamiliarity with cardiomyopathy related syndromes. If a heart condition is not mentioned, a child that complains about dizziness, extreme fatigue, abdominal or chest pain or excessive sweating may be thought to have the flu, an upset stomach or heat stroke. However, if school officials or other health personnel are aware of a child’s cardiomyopathy, they may react differently. Parents can discuss the below options with their child’s cardiologist and school to ensure that their child receives quick and appropriate treatment in an emergency situation.

Automatic External Defibrillators in Schools

Although a diagnosed child with cardiomyopathy is at a relatively low risk for having a cardiac arrest, every parent should still request a school to have CPR trained instructors with easy access to an automatic external defibrillator (AED) with pediatric pads. Currently there are 13 states that have legislation to help support AED’s in schools. If a school does not have one, there are various ways that parents can petition a school to fund one. This includes getting a portion of the school budget to cover it, holding school fundraisers, getting government or state grants, or applying for funds from civic organizations, private foundations and local industries. Some parents have also elected to purchase one for personal use. Insurance companies are now more willing to reimburse for AEDs if a physician writes a note stating necessity.

There are several portable AED products with pediatric pads (for ages 1-8) that reduce the shock voltage for children. Currently, Philips Medical Systems, Medtronic, Cardiac Science, Defibtech and Access Cardio offer models that range from $1,500 to $3,700 for 4-7 year use. All brands are lightweight, portable and user friendly with visual and voice prompts. Comprehensive information on AED implementation, policies, usage and product comparisons can be found at www.momsteam.com by clicking the “Articles” tab under the “Cardiac Awareness Center” page.

Emergency Protocol Letter

An emergency information form (EIF) or emergency protocol letter is a 1-2 page document signed by your child’s physician stating the medical problem, current management, contact numbers and proper procedures for a medical emergency. This thorough but easy to understand document can be given to your child’s teacher or school nurse and carried by you at all times. The objective is to give any doctor, nurse or emergency room resident a concise summary of your child’s medical condition and the precautions needed for evaluation and treatment. This is a necessity for a child with a life-threatening condition (i.e. metabolic based cardiomyopathies), restrictions to certain drugs or other urgent medical needs. A sample emergency information form, Emergency Preparedness for Children With Special Healthcare Needs is available from Pediatrics, Oct. 1999, vol 104, pg. e53 at http://pediatrics.aappublications.org

Medical Identification Jewelry

Medical identification jewelry can also help to eliminate management errors in a crisis situation. Medical ID necklaces, bracelets and sports bands are designed to alert emergency personnel to your child’s heart condition if they become unconscious. This may be important for children at high risk for sudden death (a relatively small proportion of cardiomyopathy patients), where care will be quicker if the diagnosis is immediate.

An identification bracelet can be used with an electronic transmission system such as MedicAlert\(®\), which provides up-to-date medical information to emergency health care providers. MedicAlert\(®\)’s belief is that the engraving space on the ID tag is limited and cannot fully communicate all the vital facts regarding a person’s medical condition and treatment requirements. Many parents find peace of mind in subscribing to such a system, especially if their child is not old enough to understand the seriousness of their condition, become unconscious or are too ill to speak.

How the MedicAlert® System Works

1. MedicAlert® emblem alerts emergency responders to the primary medical condition and prompts their call to the 24 hour emergency response center.

2. Upon contact, MedicAlert® relays key medical facts and treatment protocol to emergency responders, so that the member receives faster and safer treatment. Contents of the member’s computerized medical file, which includes medications, allergies, implanted device details, emergency contacts and insurance information are transmitted.

3. Then, MedicAlert® calls the member’s family in the event the member is unaccompanied.

MedicAlert® is offering a special rate to CCF families. The initial first year enrollment fee is discounted to $30 (includes basic stainless steel emblem). Annual renewal fees are $20 thereafter. For more information about MedicAlert®, visit www.MedicAlert.org or call 888-633-4298.
Contrary to claims in medical textbooks, children who develop cardiomyopathy are more likely to do so in the first year of life than later in childhood, according to a study published in the April 24, 2003 issue of the New England Journal of Medicine. This study of nearly 500 children at 38 sites nationwide utilizes data from the North American Pediatric Cardiomyopathy Registry funded by the National Heart, Lung and Blood Institute.

Pediatric cardiology textbooks say it is highly unusual for children to develop cardiomyopathy before they are teenagers. That couldn’t be further from the truth says Steve Lipshultz, MD, the primary investigator of the study. The study shows that children are about 10 times more likely to develop cardiomyopathy during their first year of life than ages 2-18 combined. Knowing that most cases of cardiomyopathy in children develop within the first year of life is crucial for the proper diagnosis and management of the disease. Symptoms of cardiomyopathy are often vague, so a pediatrician who sees an infant who is unhappy, not feeding well, and is breathing hard may elect to prescribe antibiotics and recheck the child in a few weeks. “Clinical impressions can be misleading, and a child like this could die of cardiomyopathy,” Lipshultz says. “If pediatricians don’t know to look for cardiomyopathy, they won’t find out the child has it.”

If cardiomyopathy is detected early enough, there are effective treatments. During the past year, Lipshultz published a study in the Journal of Clinical Oncology that showed when doctors gave a medication known as enalapril to certain children with asymptomatic cardiomyopathy, they experienced up to eight additional years of improved heart function. The full text article can be found at Pub Med (www.pubmed.gov) by searching the original article, “The Incidence of Pediatric Cardiomyopathy in Two Regions of the United States”, N Engl J Med 2003; 348: 1647-55.

Findings about Pediatric Cardiomyopathy*

- Annual incident rate of 1 per 100,000 children
- Leading cause of heart transplant in children over one year of age
- Most common form is dilated cardiomyopathy followed by hypertrophic cardiomyopathy
- 68% of cases were idiopathic (of unknown causes)
- Most common causes of dilated cardiomyopathy were neuromuscular disorders and myocarditus
- Most common causes of hypertrophic cardiomyopathy were familial isolated cardiomyopathy and inborn errors of metabolism
- Boys were more likely to receive a diagnosis of cardiomyopathy than girls
- Higher rates of cardiomyopathy found in black and Hispanic children than in white children

Welcome to Heart to Heart
The Newsletter of the Children’s Cardiomyopathy Foundation
Volume 1, Number 1 • Spring • Summer 2004

INSIDE THIS ISSUE:

- Foundation News
  Cover News: CCF’s grant awards are making a difference in advancing research and improving treatment.

- Fundraising Update
  Page 3 & 4: First Annual Golf Classic and Neiman Marcus fashion benefit are a great success!

- Family Information
  Page 5, 8, & 10: Families and children learn to cope with the daily challenges of living with cardiomyopathy.

- Medical News
  Page 6 & 7: Geneticists play an important role in the overall evaluation and treatment plan.
  Page 11: Misconceptions about the disease in children shown in new nationwide study.

2ND ANNUAL
Children’s Cardiomyopathy Foundation

Golf Classic

Save the Date!
Join us for a fun-filled day on the course while raising money for medical research!

Tuesday, September 14, 2004
New York Country Club, New Hempstead, NY

10:30 AM - Registration
11:00 AM - BBQ Lunch & Driving Range Opens
12:00 PM - Shotgun Start - 4 player scramble
5:00 PM - Cocktails & Silent Auction
6:00 PM - Awards Dinner

Player Fee: $300/person  Dinner Guest: $90/person

Please call us at 201-227-8852 or visit our website (www.childrenscardiomyopathy.org) for information on attending the event, being an event sponsor or making a gift donation for our silent auction.