One of the Children's Cardiomyopathy Foundation's (CCF) top priorities is to promote and support research on pediatric cardiomyopathy. As awareness of CCF’s research grant program has grown over the years, the number of grant applications has increased as well. This year we are pleased to support the promising work of four grant recipients:

Bruce Gelb, MD of Mount Sinai School of Medicine, Enkhsaikhan Purevjav, MD, PhD of Baylor College of Medicine, Monte Willis, MD, PhD of the University of North Carolina Hospitals, and Stephanie Ware, MD, PhD of Cincinnati Children’s Hospital Medical Center.

Dr. Bruce Gelb is a Professor of Pediatrics and Genetics & Genomic Sciences at the Mount Sinai School of Medicine in New York City. He has had an interest in pediatric cardiomyopathy since his fellowship training at Baylor College of Medicine. He has had an interest in pediatric cardiomyopathy since his fellowship training at Baylor College of Medicine. Now the Director of Heart Transplantation and Co-Director of the Cardiovascular Genetics Program at Mount Sinai, his research laboratory focuses on identifying genes responsible for heart abnormalities or dysfunction. Thus far, his research group has discovered four genes responsible for Noonan syndrome, a systemic disease that is a common cause of hypertrophic cardiomyopathy (HCM) in children. The most recently discovered gene is called RAF1 and is highly specific to HCM.

His proposed CCF study, “Hypertrophic Cardiomyopathy and RAS-MAP Kinase Signaling” ($49,587), will first study the effects of introducing a mutation in the RAF1 gene into the heart muscles of a mouse with Noonan syndrome. This mouse model is intended to replicate the human disease and permit studies of the heart as it hypertrophies.

The second part of the study will introduce mutant RAF1 genes into mouse heart muscle cells in cell culture, allowing the cardiac hypertrophy to be studied biochemically. The goal of this study is to understand how changes in the heart caused by the mutant gene result in HCM and to determine the direction for developing therapies to prevent or improve the hypertrophy related to Noonan syndrome.
Dr. Gelb hopes that the study findings will enable the search for drugs that would block the disease effect caused by this mutant gene and other HCM causing genes unrelated to Noonan syndrome.

Dr. Enkhsaikhan Purevjav also has ties to Baylor College of Medicine in Texas. An Instructor of Pediatrics in the Department of Pediatric Cardiology at Baylor, she also holds a doctorate in medical genetics and is part of the research team at the Phoebe Willingham Muzzy Pediatric Molecular Cardiology Laboratory studying cardiovascular disease.

Early in her career, Dr. Purevjav worked as a pediatric cardiologist in Mongolia where she managed several patients with cardiomyopathy. She lost many of them to the disease, which has motivated her to “keep doing research in order to find clues” to better understand the disease. As part of her research, she has generated mouse models that have been implanted with a human mutation in the nebullet gene that leads to the inherited form of dilated cardiomyopathy (DCM).

In Dr. Purevjav’s proposed CCF study, “Effects of ACE Inhibitors and Beta-Blockers on Cardiac Function in Murine Models of Inherited Dilated Cardiomyopathy” ($45,000), she will aim to “cure these transgenic mice using the drugs captopril (an ACE inhibitor) and carvedilol (a beta-blocker) which are broadly used for treatment of cardiomyopathy and heart failure in humans.” She plans to administer the captopril and carvedilol before and after the mice exhibit symptoms, in order to investigate the individual and combined effects of administering these two therapeutic agents. Cardiac function will be monitored during drug treatment, and then the mice hearts will undergo histological, immunohistochemical, ultrastructural, and protein analyses after treatment. This study will provide insight into the molecular mechanisms of the drugs’ preventative and therapeutic effects on inherited DCM. It will also highlight the importance of starting drug treatments earlier, at asymptomatic stages before heart failure occurs.

CCF’s third grant recipient is Dr. Monte Willis, an Assistant Professor in Pathology and Laboratory Medicine as well as the Assistant Director of the Clinical Core Lab at the University of North Carolina. Dr. Willis’ current research focuses on how the heart regulates energy metabolism in cardiac diseases such as HCM. According to Dr. Willis, “Changes in how the heart generates energy occurs in patients with cardiomyopathies, but the underlying cause for this is unknown. Because these changes in energy metabolism leave the heart vulnerable to injury, it may underlie some of the morbidity and mortality in cardiomyopathies.” Dr. Willis has discovered that the cardiac specific protein, MuRF1 (Muscle Ring Finger-1), regulates the turnover of cardiac myosin binding protein-c (cMyBP-c), a common mutated protein found in familial HCM.

Dr. Willis’ proposed CCF study, “Role of MuRF1 in MyBP-C Turnover and Its Effects on Cardiac Energy Metabolism in Familial Hypertrophic Cardiomyopathies” ($50,000) will investigate whether the MuRF1 regulation of metabolism alters hearts in which the cMyBP-c mutation exists. He believes that in this situation, MuRF1 is spending all its time clearing the defective cMyBP-c proteins instead of regulating energy metabolism, making the heart more vulnerable to stress. Additionally, this shift to clearing mutant cMyBP-c makes MuRF1 unable to fulfill its role of regulating the heart size, leading to an enlarged heart. These findings might explain the cardiac hypertrophy and the energy deficits associated with familial HCM patients. By identifying the specific role of this protein in this energy deficit, Dr. Willis’ research could potentially identify ways to improve cardiac energy reserves and, thus, cardiac function in patients with cardiomyopathy.

Dr. Stephanie Ware, CCF’s fourth grant recipient, is an Assistant Professor of Pediatrics in the Divisions of Human Genetics and Molecular Cardiovascular
Garners focus on structural cardiomyocyte-specific of pediatric cardiomyopathy, with particular and validate a gene chip for the diagnosis cause this heart disease in children.

The goal of her proposed CCF study, “Development of a Novel Resequencing Chip to Diagnose Pediatric Cardiomyopathy” ($49,750), is to develop a methodology that allows for more comprehensive screening of genes that cause this heart disease in children. More specifically, Dr. Ware will develop and validate a gene chip for the diagnosis of pediatric cardiomyopathy, with particular focus on structural cardiomyocyte-specific and metabolic etiologies. A customized gene chip (array) encompassing 30 genes coding for structural/metabolic proteins will be used in combination with a commercially available mitochondrial gene chip to provide the most comprehensive investigation of genetic causation to date. DNA from 20 patients with known causes of cardiomyopathy will be used for validation of the customized array. The development of this gene chip is an important step in “improving diagnostic options for pediatric cardiomyopathy patients.” Dr. Ware adds, “The identification of the precise cause of cardiomyopathy is important for development of individualized management strategies.”

In the second part of the study, Dr. Ware will focus on determining the incidence and prevalence of these mutations in a defined group of children. DNA from 40 pediatric cardiomyopathy patients with a diagnosed mitochondrial disorder and 40 pediatric patients with an unknown genetic basis for cardiomyopathy will be analyzed. “We will use information from this screening to prioritize the most frequent causes of cardiomyopathy in the pediatric population. This information will be useful for the future development of clinical genetic testing,” she concludes.

For more information about each investigator’s funded study, please visit our website at:

www.childrenscardiomyopathy.org/site/grantsawarded.php

Jeff Towbin, MD, a CCF medical advisor and the Director of the Pediatric Cardiomyopathy Repository, recently received a five-year, multi-million dollar grant from the National Heart, Lung, and Blood Institute (NHLBI) to maintain and expand the Pediatric Cardiomyopathy Repository.

The model for this repository was first developed with input and seed funding from CCF. The NHLBI grant will allow for blood and myocardial tissue specimens to be obtained from children enrolled in the Pediatric Cardiomyopathy Registry, a National Institutes of Health funded patient database. It will also support the correlation of clinical and scientific data, enable the identification of etiologies (genetic, viral etc.) responsible for clinical phenotypes, and encourage multi-center collaborations among scientists and clinicians in order to better understand the mechanisms involved in the development of cardiomyopathy in children.

In 2005, CCF took the lead in establishing the Pediatric Cardiomyopathy Repository. The goal was to collect DNA and tissue samples from children with cardiomyopathy and to link the samples to a child’s clinical information. Before the repository, few resources had been designated for the study of children with cardiomyopathy and understanding of the causes of the disease in children was worse than that in adult disease. Less than 25% of the patients enrolled in the Pediatric Cardiomyopathy Registry had a defined etiology despite rigorous, standardized evaluation.

The repository provides a much-needed resource for researchers that could potentially accelerate studies on pediatric cardiomyopathy. Researchers could use the samples and data to better understand the genotype - phenotype relationship, which is how a person’s genetic makeup influences how they clinically present with symptoms of the disease.

To date, 225 blood and 37 tissues samples have been collected and stored at Baylor College of Medicine in Houston, TX. To ensure that researchers have equal access to the samples, the repository is monitored by an eight-person steering committee comprised of clinicians and researchers from various medical institutions.

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Seema Mital, MD

Seema Mital, MD, a 2004 CCF grant recipient, published her latest research findings in the December 2007 issue of Human Genetics. Her molecular study, “RAAS Gene Polymorphisms Influence Cardiac Remodeling in Children with Hypertrophic Cardiomyopathy,” looked at different genetic variations, called polymorphisms, that control the production of hormones (renin-angiotensin-aldosterone) that help to regulate blood pressure. The study investigated how these specific genetic variations impact the progression of hypertrophic cardiomyopathy (HCM) in children. Sixty-five children with HCM participated in the study, which revealed that children with the RAAS genotype were more likely to develop left ventricular outflow tract obstruction. The study also showed that the heart gets thicker much faster in children with more than two polymorphisms or genetic variations, as compared to those with less than two polymorphisms.

The significance of these findings is that physicians will be able to identify which children with HCM are at a higher risk of developing a severe form of the disease that requires closer monitoring. It may also help to segment which family members with the same disease are likely to do better or worse depending on the number of these polymorphisms. In many cases, it may be possible to adjust treatment according to these polymorphisms, thus enabling physicians to better manage the disease in children in the long term. Dr. Mital’s study was the first to evaluate the effect of these particular genotypes on the progression of HCM in children and to identify a potential genetic determinant of the obstructive phenotype.

Ju Chen, MD, PhD

In 2005, CCF awarded a research grant to Ju Chen, MD, PhD of the University of California at San Diego. Dr. Chen’s study, “Role of Cypher in Cardiac Muscle,” was designed to understand the role of the disease-causing Cypher gene by generating mouse lines to replicate these human mutations and then to perform preliminary characterization of the mouse models.

After one year of funding, Dr. Chen successfully generated two mouse lines in which long and short Cypher isoforms were deleted, and then observations were made on which mouse models developed cardiomyopathy, at what age and life stage, the severity of it, and final outcomes. Based on those findings, Dr. Chen received a five-year $1.5 million grant from the National Heart, Lung, and Blood Institute in 2006.

“In the coming months, Dr. Dipchand will finalize four manuscripts for publication in major medical journals.”

Anne Dipchand, MD

CCF’s 2007 grant recipient Anne Dipchand, MD of Toronto Hospital for Sick Children was invited to present her research findings at the International Society for Heart and Lung Transplantation’s (ISHLT) 28th Annual Meeting in Boston on April 9-12, 2008. The ISHLT has over 2,200 members from more than 45 countries, representing over ten different disciplines, including anesthesiologists, cardiologists, cardiac surgeons, nurses, scientists, immunologists, ethicists, perfusionists, and transplant coordinators.

Three abstracts were presented at the scientific sessions: “Outcomes of Children Listed for Transplantation for Dilated Cardiomyopathy: A Multi-Institutional Study” (poster, April 11), “Outcomes of Children Listed for Transplantation for Restrictive Cardiomyopathy: A Multi-Institutional Study” (mini-oral, April 11), and “Outcomes of Children Listed for Transplantation for Hypertrophic Cardiomyopathy: A Multi-Institutional Study” (oral, April 12). The study analyzed the different variables that may contribute to favorable or unfavorable outcomes for children with various forms of cardiomyopathy in need of a heart transplant. Dr. Dipchand presented similar research findings at the American Heart Association Scientific Session in November 2007. In the coming months, Dr. Dipchand will finalize four manuscripts for publication in major medical journals.
In a CCF supported study, Tracie Miller, MD and others at the Miller School of Medicine in Miami, FL reviewed studies that examined the relationship between nutrition and the health of patients with cardiomyopathy. Their findings, published in *Progress in Pediatric Cardiology* (2007 November; 24(1): 59-71), show that ancillary therapy involving optimal intake of micronutrients (nutrients needed in small amounts) can be beneficial to cardiomyopathy patients. While nutritional intervention may not cure cardiomyopathy, Dr. Miller and others believe it has the potential to improve cardiac function and quality of life for children with all types of cardiomyopathy.

Growth failure is one of the most significant problems of children with cardiomyopathy with nearly one-third of affected children experiencing growth failure during the course of their illness. For these children, the body spends substantial energy compensating for a dysfunctional heart and devotes less energy to normal metabolic processes. This reduces a child’s ability to properly absorb and recycle important nutrients, thus affecting his/her growth. In general, children with cardiomyopathy need to receive additional calories and nutrients to compensate for their degree of heart failure and to provide for normal growth.

Children with cardiomyopathy may also require greater than standard intakes of certain micronutrients to optimize their cardiac function. In particular, antioxidants can help prevent free radical cell damage associated with heart failure. Eating more fruits, vegetables, and whole grains can help ensure patients take in enough antioxidants, including vitamins A, C, and E. Avoiding an excess of carbohydrates and saturated fat is generally recommended. Omega-3 fatty acids, found in such fish as tuna, salmon, and trout have been shown to improve left ventricular function and counteract harmful inflammation. Other nutritional supplements to consider include taurine, an amino acid that regulates abnormal calcium levels in myocardial energy production, and co-enzyme Q10, a natural vitamin-like substance that can improve mitochondria energy production. The mitochondria produces energy for all cells in the body. The above-mentioned supplements may help heart tissue produce enough energy to maintain good health.

Apart from antioxidants, nutrients known to augment myocardial energy production in adults may help to improve cardiac function in affected children. Thiamine (vitamin B1) is important in carbohydrate metabolism. Up to 93% of patients with heart failure show a deficiency. Thiamine supplementation seems to reverse some of the symptoms of congestive heart failure. L-carnitine, an amino acid derivative that helps the body move fatty acids into the mitochondria, has also proved beneficial. Patients given L-carnitine supplements for a year following a heart attack had improved 3-year survival rates. Other important nutrients for heart function include vitamin D, calcium, folate (vitamin B12), magnesium, zinc, and selenium. Patients with heart failure often show deficiencies in one or more of the vitamins and minerals mentioned.

The researchers point out that little is understood regarding the role of growth and nutrition in predicting the outcome of children with cardiomyopathy. Many scientific studies in adults with heart failure are contradictory, and there are few studies among children. Miller and others advocate that understanding the relationship among nutrition, growth, and patient outcomes would help physicians identify who would benefit most from transplant or other types of medical treatment. Physicians may also be able to recommend early and aggressive nutritional interventions that would prevent or delay declines in heart function, keeping children healthier as they await a transplant or receive other means of treatment.


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**PROGRESS IN PEDIATRIC CARDIOLOGY:**

**New Cardiomyopathy Issues Released**

*Progress in Pediatric Cardiology* has published two additional issues focused on pediatric cardiomyopathy. These two issues were part of a three-part series dedicated to the disease. The second issue, published in November 2007 (volume 24, issue 1), included reviews and abstracts presented at the 2007 scientific workshop sponsored by the Children’s Cardiomyopathy Foundation and the National Heart, Lung, and Blood Institute. Issue three, published In March 2008 (volume 25, issue 1), included additional review articles and consensus recommendations on future directions in pediatric cardiomyopathy research. Volume 23, issue 1-2, the first in the series, was published in September 2007. It was the first time the publisher, *Elsevier*, dedicated three issues to genetics, epidemiology, and therapy for cardiomyopathy in children.
Approximately 20% of cardiomyopathy in children is familial, either as isolated cardiomyopathy or associated with neuromuscular disorders, inborn errors of metabolism, or malformation syndromes. These cases of cardiomyopathy are due to genetic variations (mutations) in specific single genes, many of which have been identified. Below are commonly asked questions about using genetic testing to diagnose these forms of cardiomyopathy.

• What is genetic testing?
Genetic testing looks for variations (mutations) in the sequence of genes associated with a specific inherited disease. Detection of a disease-causing mutation indicates the presence of the disease or a high risk of developing the disease.

• What are the benefits of genetic testing for cardiomyopathy?
Genetic testing can allow a definitive diagnosis of cardiomyopathy in cases where the clinical diagnosis is uncertain. It often is used to identify the specific cause of cardiomyopathy, helping to clarify the prognosis and, in some cases, alert physicians and patients to the possibility of other non-cardiac disease symptoms (e.g. bleeding disorders related to Noonan syndrome). Genetic testing can also be used to determine which family members of a patient are at a high risk for cardiomyopathy.

• Should all children with cardiomyopathy receive genetic testing?
Use of genetic testing should be guided by the patient’s symptoms and the family history. It may be best to consult a pediatric geneticist as well as a pediatric cardiologist.

• If I don’t have the gene, does that mean I do not have the disease?
Unless the familial mutation is known, failure to find a disease-causing mutation does not “rule out” a diagnosis of cardiomyopathy. Instead, failure to detect a disease-causing mutation can mean one of three things: (1) the patient is affected by the disease but the disease-causing mutation was not detected because it is located in a gene that was not included in the test, (2) the patient is affected by the disease but the disease-causing mutation is of a type that cannot be detected by current testing methods, or (3) the patient is not affected by the disease.

• What is a familial mutation and how is it identified?
All cases of cardiomyopathy in one extended family are likely to be associated with the exact same mutation or the “familial mutation.” If a parent harbors a disease-causing mutation, his or her children each have a 50% chance of inheriting this mutation. In contrast, the risk of harboring a different mutation associated with the same form of cardiomyopathy is at most 0.5%.

To identify the familial mutation, many different genes have to be evaluated in a family member that has cardiomyopathy (known as the “index patient”). If that is not possible, both parents of an affected family member should be screened, since the affected family member, in all likelihood, inherited the mutation from one of his or her parents. The parent who is found to harbor a disease-associated mutation would then become the “index patient” for the family.

• What are the benefits of knowing the familial mutation?
Once the familial mutation for a family is known, genetic testing can both confirm and exclude an increased risk of cardiomyopathy in family members. If the familial mutation is present, the family member and his or her parents, siblings, and children are at an increased risk of cardiomyopathy. They should undergo regular screening and seek treatment as soon as symptoms appear. If the familial mutation is not present, the family member and his or her descendants are at no greater risk of cardiomyopathy than the general population.
Another consideration is that screening through standard diagnostic means, such as an echocardiogram, cannot rule out an increased risk of cardiomyopathy. For example, a family member without any symptoms may still harbor the familial mutation and (1) be presymptomatic – that is symptoms of the disease may not show yet or (2) may never develop symptoms of the disease (known as “low penetrance” of the disease). However, this individual can still pass on the mutation to his or her children, who may then develop symptoms of the disease.

• Does every mutation found in a disease-associated gene cause disease?

No. While some mutations in a disease-associated gene cause disease, other mutations in the same gene may not cause disease.

When it is not known or not certain whether a particular mutation is associated with disease or not, the mutation is called a “variant of unknown significance (VUS)” or a “possible disease variant” respectively. One way to clarify the meaning of a VUS or a possible disease variant is to determine if all affected members of a patient’s extended family harbor the VUS. If all affected family members harbor the variant in question, it is likely to be associated with the familial disease. If some affected family members do not harbor the variant in question, it is less likely to be associated with the familial disease.

• Can genetic testing predict severity of a cardiomyopathy?

Genetic testing typically cannot predict severity of a particular form of cardiomyopathy. Instead, the results of genetic testing only indicate the probability or risk of disease.

• Which genetic tests for cardiomyopathy are available and where?

Gene Tests at www.genetests.org offers a list of genetic tests to detect different forms of cardiomyopathy and the laboratories offering testing. At this time, Correlagen (www.correlagen.com) and Harvard Partners Lab (www.hpcgg.org) are the only two CLIA (Clinical Laboratory Improvement Amendments) approved labs in the U.S. to offer clinical genetic testing for cardiomyopathy. Information on CLIA can be found at www.fda.gov/cdrh/clia/.

• Can patients directly order genetic testing?

For most conditions, genetic testing can only be ordered through a physician, to guarantee that this diagnostic tool is used only when appropriate and that the test results are considered in the context of all other medical information for a patient, such as the results of other diagnostic tests and the personal and family medical history.

• Is genetic testing expensive and is it covered by insurance?

The price for genetic testing is determined by the number of genes tested and the size of the genes. Family testing is less expensive than testing of the index patient, since only a small part of one gene, where the familial variant is located, has to be screened. Insurance coverage varies with each insurance provider. The policy of diagnostic testing laboratories with regard to insurance also varies.

• Can genetic testing lead to discrimination by health insurance and life insurance providers?

If genetic testing is ordered by a physician, the results of any physician-ordered tests are recorded in the patient’s medical records and will be available for the insurer to view at any time.

For health insurance, the individual cannot be discriminated against if insured under an employer or state-sponsored insurance plan. HIPAA, the Health Insurance Portability and Accountability Act, prohibits discrimination in enrollment and in premiums charged to employees and their dependents based on health status-related factors. For more information about employee protection from HIPAA, go to www.dol.gov/ebsa/newsroom/fshipaa.html. For life insurance, discrimination may occur. Parents may choose to enroll their children in a life insurance plan before obtaining genetic testing.

• Can genetic testing lead to discrimination by an employer?

While there is no federal law in place, many states have passed legislation to prevent discrimination based on genetic information. For more information on individual state laws, please visit the website of the National Conference of State Legislatures at www.ncsl.org/programs/health/genetics/charts.htm. An article that explains the risks and laws related to genetic discrimination is “Genetic Discrimination” written by Mark A. Hall, JD, of Wake Forest University School of Medicine (www.ncbiotech.org/services_and_programs/genomics_consortium/consortium_projects_and_events/geneticdiscrimination.pdf).

Ute Geigenmuller is the Chief Scientific Officer at Correlagen Diagnostics, a CLIA-certified genetic testing laboratory. Dr. Geigenmuller can be contacted at 866-647-0735 or ugeigenmuller@correlagen.com.
CCF to Sponsor

HEART FAILURE RESEARCH CONFERENCE

CCF will be one of three sponsors for an upcoming research conference entitled “The Scientific Basis of Heart Failure in the Young” which will be held May 14-16, 2008 at the Stanley Hotel in Estes Park, CO. The conference is organized by Mark Payne, MD, Professor of Pediatric Cardiology at Indiana University School of Medicine, and co-sponsored by the American Heart Association Councils on Cardiovascular Disease in the Young and Basic Cardiovascular Sciences, and the National Heart, Lung, and Blood Institute.

The conference will fulfill an unmet need to bring together scientists and clinicians to define the problems related to the understanding and treatment of heart failure in the young. Cardiomyopathy is a leading cause of acquired heart failure. Heart failure in children has been less well studied when compared with the rich literature and basic understanding of heart failure in adults. As a result, therapy has advanced more slowly for the pediatric population.

The goal of the three-day conference is to present state-of-the-art clinical and basic research on the basis of heart failure in children and to map out future directions in heart failure research. In particular, new research directions and collaborations will be encouraged and discussed. Five topics of research will be covered: basic mechanisms in pediatric heart failure, novel tools for quantifying heart failure, clinical science of pediatric heart failure, and tools for building a pediatric heart failure research program.

Registration is ongoing for this meeting. For more information about this cardiac medical conference, please visit www.heart.org/presenter.jhtml?identifier=3051868#Audience.

Heart Caths for Kids
A book for parents of children needing heart catheterization

This step-by-step guide covers every aspect of a child’s cardiac catheterization (heart cath) procedure. It explains the types and purpose of catheterization, how they are done, who will care for your child during his/her heart cath, what to expect before, during, and after the procedure, and how to help your child through this procedure. The booklet provides areas for personalization, checklists, and an appendix of terms.

Your Child Has a Pacemaker
A book for parents of children with a pacemaker or defibrillator

This booklet is for the family of a child who needs a pacemaker or an implantable cardioverter defibrillator (ICD). It covers topics such as why a pacemaker is needed, how it works, the different types, how it is put in, your child’s health care team, what to expect before, during, and after surgery, how it will affect your child’s activities, and how to care for the device. It also includes a checklist, resource page, and glossary.

Family Resource Center

A Review of Pritchett & Hull’s CARDIAC PUBLICATIONS

Based in Atlanta, GA, Pritchett & Hull Associates (P&H) develops patient education materials covering cardiology and pulmonology, among numerous other health topics. They offer a series of cardiomyopathy-related educational booklets that are 30-64 pages long and are written in a conversational tone (4th-8th grade reading level) that makes the information easy to understand. P&H booklets use eye-catching art, anatomical drawings, and cartoons to communicate basic facts in an amusing way. Booklets range from $2.95 to $4.45, and they are available online at www.p-h.com, or by calling Pritchett & Hull at 1-800-241-4925.

Heart Caths for Kids
A book for parents of children needing heart catheterization

To Mend a Broken Heart - Pediatric Heart Surgery
Available in English or Spanish

Written for parents, this resource helps parents take a more active role in their child’s healing and recovery following heart surgery. Illustrated with easy-to-understand diagrams, it covers anatomy and physiology as well as the child’s health care team, types of surgery and testing, what to expect before, during and after surgery, terminology, and follow-up care. It also includes interactive fill-in pages and a resource page.

The Beat Goes On!
A book for young adults living with a pacemaker or ICD

Written for young adults, this booklet explains what a pacemaker and implantable cardioverter defibrillator (ICD) are, how they work, what precautions to take, and how the device is monitored. Diagrams, illustrations, and wording are user-friendly. Interactive writing exercises educate young adults on symptoms, follow-up, daily activities, and device care.
New MEDICAL ID OPTIONS for Children

As spring and summer approach, many families return to a more active, outdoor lifestyle. The use of medical identification jewelry can provide peace of mind during these warm weather months when your child may be more involved in activities such as swimming, baseball, or day camp.

In the past, medical ID jewelry was negatively viewed as boring and ugly but now there is a broad selection of formats and styles to please everyone. Formats vary from bracelets, pendants, necklaces and sports bands to watches, charms and traditional “dog tags.” The main purpose of medical ID jewelry is to make others aware of your child’s medical and health conditions as well as any medications he/she may be taking. This is particularly important if your child needs emergency medical attention when you are not with him/her. All medical IDs feature the Caduceus or the Staff of Asclepius, which are internationally recognized medical emergency symbols. Typically, the child’s name, medical condition, allergies, medications, doctor’s name and contact number and/or parent’s name and contact number are engraved on the front or back of the plaque. The information engraved on the medical ID ensures appropriate and timely medical care from first responders and medical personnel, preventing possible misdiagnosis and medical errors.

Although the safety benefits are apparent, convincing a child with a medical condition to wear medical ID jewelry can sometimes be challenging. A child may feel self-conscious about wearing something that calls attention to their heart condition. But with the wide variety of style choices now available, kids can proudly wear a medical ID bracelet or necklace their friends will envy without compromising on safety. Medical ID retailers offer different jewelry styles and metal finishes to suit the lifestyle of young children, teens, and young adults. Aside from the traditional stainless steel necklace or bracelet, retailers now offer fashionable beads such as pearls, gemstones, and Swarovski crystal as well as higher-end materials such as 14K gold, sterling silver, and titanium. Bracelets come in the traditional metal chains and also with interchangeable rubber, beaded, leather, or polyester “sports” bands.

Traditional IDs

There are several retailers offering traditional medical ID jewelry and finishes, including classic bracelets, pendants, watches, charms, and tags in silver, gold, and surgical stainless steel. These include American Medical ID (www.american-medical-ID.com) and Sticky Jewelry (www.stickyj.com). Non-corrosive 316L stainless steel is recommended for outdoor physical activities over sterling silver or gold, which may be more prone to scratching.

Fashion-Forward Medical IDs

Medical ID jewelry can be fun, and a child can select one that reflects his/her personality from cool and funky to pretty and sophisticated. Popular choices for active boys are the rubber/jelly and stainless bracelets or colorful sports bands. Girls like the do-it-yourself sets, which allow them to select the beads, colors, charms, clasps and ID tag of their choice. Engraving your child’s name on the front can make it more personal, and changing the straps to coordinate with different outfits can make them seem more fashionable. Companies offering more “designer” options include Beaded Daisy (www.beadeddaisy.com), Lauren’s Hope (www.laurenshope.com), N-Style ID (www.n-styleID.com), and Petite Baubles Boutique (www.petitebaublesboutique.com).

High-Tech IDs

MedicAlert offers medical ID jewelry in conjunction with a 24-hour emergency response service. Upon phone contact, it relays critical medical information to emergency personnel and also contacts the child’s family.

A new type of medical ID alert is the E-HealthKey or MedicTag, a small USB-enabled storage device that can be worn on a necklace, lanyard or keychain. Due to the memory capacity on the flash drive, these USB medical alert tags are capable of carrying much more information than conventional medical ID bracelets. In addition to recording basic emergency information, it can store medical images and a child’s complete medical history as well. Emergency personnel can instantly access the information with any computer. It is available through MedicAlert (www.medicalert.org) and MedicTag (www.medictag.com).

With so many medical ID options available, children with cardiomyopathy can now be stylish and safe at the same time.
New Guide for Media Outreach Available

Do you have a compelling story to tell about your child’s experience with cardiomyopathy? Are you willing to share your story to raise awareness of the disease? If so, you may be interested in CCF’s newly-developed “Media Outreach Handbook.” This new resource was created to help families reach out to their local media and increase awareness of cardiomyopathy and CCF. The handbook provides step-by-step instructions on how to target and approach the media, as well as tips and letter templates to pitch your story. To receive a pdf version of the handbook, please contact Pauline at ppiernot@childrenscardiomyopathy.org or 866-808-2873, ext. 902.

Curebands Are Here!

A new batch of CCF curebands have arrived. The red rubber wristbands are embossed with “A Cause for Today... A Cure for Tomorrow” and CCF’s website address, and packaged in a clear polybag with a CCF sticker. Popular as fundraising and awareness building pieces, they also make great party giveaways. Curebands are $5 each, with the net proceeds going toward CCF’s patient support fund. To download an order form, please visit our website: www.childrenscardiomyopathy.org/site/merchandise.php

Shopping for a Cause

The best thing about online shopping is that you can buy from the comfort of your home while avoiding the mall crowds and limited parking. When you shop through Igive.com and Goodsearch.com, and select the Children’s Cardiomyopathy Foundation, CCF will receive a donation averaging 3% on all your purchases. Both sites feature an online shopping mall with hundreds of well-known retailers, including Best Buy, Macy’s, Apple, Nike, eBay, Gap, and Target among others. You receive the same prices and services as if you went directly to the store’s website, and you have the added satisfaction of contributing to CCF in a hassle-free way.

Tribute Gifts for Every Type of Gathering

Having a birthday party, wedding, shower, bar mitzvah, or other celebration coming up? In lieu of gifts, why not ask friends and family to make a tribute donation to CCF in honor of yourself, the party host, or someone special. Your guests will be pleased to know that their gift has special meaning to you and others. CCF can provide cards to include with your invites to inform guests of this gift option. All tribute gifts are tax deductible and will be acknowledged by CCF. The recipient will also receive a notification letter or tribute card informing them that a donation has been made in their name, along with the sender’s contact information. This is truly a unique way to make a difference while making your event extra special.

Scrapping with Heart Fundraiser

CCF parent Jenni Hughes hosted a scrapbooking event, Scrapping with Heart, on October 26, 2007 in Idaho Falls, ID in honor of her one year old daughter; Emersyn, who has hypertrophic cardiomyopathy.

Scrapbooking is a popular and creative hobby that combines photos, memorabilia, and stories into a keepsake scrapbook. Twenty-five friends and family members worked with various materials and techniques to create scrapbooking pages to raise funds for CCF. Attendees enjoyed dinner, and local merchants donated items that were given away as door prizes.

Hope for Little Hearts Event Raises Over $8,000

On February 28, 2008, CCF family members Melissa and Jake Sabin hosted a fundraiser for CCF in honor of their son, Brody. Last summer, Brody was diagnosed with left ventricular non-compaction cardiomyopathy. “As his parents, we felt so helpless like there was nothing we could do... focusing my energy on a fundraiser was better then researching the negative outcomes of this disease on a daily basis,” explained Melissa.

The Sabins planned the inaugural Hope for Little Hearts Benefit held at the Swiss Sportsman Club Park in Bonney Lake, WA. The event included dinner; live entertainment, raffles,
and various auctions. CCF cureband bracelets were also sold. The event attracted 200 people and raised over $8,200 for CCF. “It was so great to feel like I was helping other families besides mine,” said Melissa. The Sabins plan to make the Hope for Little Hearts Benefit an annual event. “We hope that we can raise more money each year; we are delighted that the funds will be used towards research for a cure,” added Melissa.

Locks of Love for CCF

CCF family members Greg and Cindy Ryan organized a Cut-A-Thon with Salon Easy Street in honor of their son, Jack Ryan, who has dilated cardiomyopathy. The Ryans planned the event to increase public awareness of cardiomyopathy and to raise money for research. The community event took place on Sunday, April 6, 2008 in Clark, NJ. Haircuts were $20, and the beauticians volunteered their time. The event was well-attended and raised over $4,000 for CCF.

“The money raised will go towards a great cause. Jack celebrated his second birthday on April 10th, and has been progressing well since his diagnosis,” said Cindy. Loyal supporters of CCF, the Ryans previously raised nearly $1,500 selling CCF curebands and secured more than $9,000 worth of donated printing services for CCF.
On June 14, 2008, thousands of spectators will cheer for CCF supporter Michael Hausler as he competes in the 26th Annual Wyckoff/Franklin Lakes, NJ Triathlon organized by the YMCA and Rotary Club of NJ. Michael will swim 1/2 mile, bike 17 miles and run 5 miles to raise funds for CCF. Michael, himself, overcame minor heart conditions in his youth. When CCF was brought to his attention, he decided to compete in the triathlon in honor of all children with cardiomyopathy.

Sponsorships are still needed to help Michael meet his fund-raising goal. Sponsors will receive recognition at the race and within the tri-state community. If you, your employer, or business is interested in sponsoring Michael, please contact him at mikehaus@gmail.com and request a sponsorship form.

The Medtronic Foundation recently donated $1,000 to the Children’s Cardiomyopathy Foundation on behalf of Kirk Pfrangle, a Medtronic 2007 Global Hero. Medtronic Global Heroes is a unique program that brings runners together to compete in the Medtronic Twin Cities Marathon, celebrating the accomplishments of those who run with medical devices. Kirk successfully completed the TC 10 Mile in 1:32:15. An avid runner from Alpharetta, GA, Kirk has an implanted cardiac defibrillator, a medical device that many cardiomyopathy patients have. “Prior to a virus-caused episode of ventricular tachycardia two and one-half years ago, I had been a seriously competitive runner and coach for over 40 years,” stated Kirk. “As I lay in the hospital for two weeks in 2004, I feared that my running days were over.”

Global Heroes is a unique program that brings runners together to compete in the Medtronic Twin Cities Marathon, celebrating the accomplishments of those who run with medical devices.

“The little piece of extraordinarily sophisticated technology that is implanted in my chest, however, has allayed my fears and concerns. I live my life with a high degree of energy and enthusiasm because of the defibrillator, and for that I am extremely thankful.”

This year’s Medtronic Twin Cities Marathon will be held October 5, 2008 and is open to all runners with approved medical devices (any manufacturer). For more information, visit www.medtronic.com/globalheroes.