

Heart to Heart

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CCF Announces 2010 Research Grant Recipients

INNOVATIVE RESEARCH Into Heart Cells and Mutant Proteins

CCF is pleased to support the innovative work of two physician-scientists for 2010: **Bernhard Kuhn, M.D.**, assistant professor of pediatrics at **Harvard Medical School** and cardiologist at **Children's Hospital Boston**; and **J. Carter Ralphe, M.D.**, assistant professor of pediatrics at **University of Wisconsin-Madison** and division chief of cardiology at the **American Family Children's Hospital**.



Bernhard Kuhn, M.D.



J. Carter Ralphe, M.D.

Out of 12 submitted grant proposals, Drs. Kuhn and Ralphe's studies were chosen for their innovative research concepts, significance to the pediatric cardiomyopathy community and potential for future

therapeutic application. "We selected research that was directly related to children with cardiomyopathies and from investigators who would use this 'start up' funding to secure additional grants to continue their work in studying cardiomyopathies," says CCF Medical Advisor **Dr. Wendy Chung**.

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CCF Extends Funding on

GENETIC TESTING Study

CCF has awarded **Stephanie Ware, M.D., Ph.D.**, of **Cincinnati Children's Hospital** a two-year extension on her 2008 CCF-funded study. The goal of her pilot study was to develop a comprehensive method for DNA genetic testing of children with cardiomyopathy.

Using a new genetic analysis technology called next generation sequencing, Dr. Ware and her team set out to understand what role cardiomyopathy-causing gene mutations in adults play within the pediatric population. The extension of this study will continue this analysis with the intent

of developing a more accurate, rapid and cost-effective sequencing method that will identify cardiomyopathy-causing genes specific to children affected by the disease. Dr. Ware is especially interested in understanding how genetic variations and the interplay of multiple mutations can lead to early onset cardiomyopathy and a more severe form of the disease.

"The problem is that there is a lot of variation in gene expression among individuals, and not all of those variations

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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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From Lisa Yue, CCF Founder & President

The Dr. Oz Show recently aired a segment on sudden cardiac arrest in children, which was a topic I could relate to having lost my first son to sudden cardiac arrest at 11 months. Even though my husband has a mild form of the disease, there was never any concern from doctors that the disease might affect our young son at such an early age. He died unexpectedly because his cardiomyopathy was undiagnosed. As I watched the Dr. Oz program, I was reminded of the complex genetic nature of cardiomyopathy and how variable the disease can be, from mild to severe, within the same family.

In this issue, we touch upon some of these same topics. We announce a new CCF-funded study that looks at how different mutations in a common hypertrophic cardiomyopathy gene can result in wide ranging disease severity. We also hear from a CCF parent about how genetic testing revealed how cardiomyopathy runs in her family – who inherited it and how each member is affected differently.

As in my own situation, as well as many other cardiomyopathy families, there is still much to learn about the disease. Fortunately, there are many supporters, as highlighted in this issue, who continue to help CCF fund research that can potentially improve screenings and treatments. It is my hope that with continued media attention, like the Dr. Oz show, cardiomyopathy will garner more advocates who will champion our mission of saving lives and finding cures.



Nathan and Tucker Davis

SPRING APPEAL Campaign Underway A Big Brother's HOPE

CCF's spring campaign this year focuses on the touching story of **Tucker Davis** and his special relationship with his youngest brother, **Nathan**, who has cardiomyopathy. Tucker's determination to make life better for his younger brother mirrors CCF's mission to create a better future for children with cardiomyopathy. We hope you will be as inspired by Tucker's words as we are, and in turn will support our ongoing work.

Watch your mail for CCF's appeal mailing or make an online donation today: childrenscardiomyopathy.org

(click on "Make a donation/Online donation").

 Find us on
Facebook

Become a CCF fan, group member
and/or cause supporter.

Then invite your friends and family
to help spread awareness of
pediatric cardiomyopathy!

Update on the PEDIATRIC CARDIOMYOPATHY REPOSITORY

The **Pediatric Cardiomyopathy Repository** was established in April 2006 with initial funding from the Children's Cardiomyopathy Foundation (CCF). Working in conjunction with **Baylor College of Medicine** (repository core laboratory), **New England Research Institute** (data coordinating center) and the **Pediatric Cardiomyopathy Registry (PCMR)**,

CCF took the lead in setting up protocols and forming a steering committee to oversee the repository. Two years later, the National Heart Lung and Blood Institute provided a multi-year grant to maintain and expand the repository. To date, the repository has collected 681 blood samples from 361 patients and 315 tissue samples from 86 patients, exceeding its original projections.

Eleven clinical sites are currently participating: **Hospital for Sick Children**, Toronto; **Children's Memorial Hospital**, Chicago; **Children's Hospital at Montefiore**, New York; **Washington University School of Medicine**, St. Louis; **Texas Children's Hospital**, Houston; **Children's Hospital Boston**; **Cincinnati Children's Hospital Medical Center**; **Primary Children's Medical Center**,

Salt Lake City; **Children's Hospital of Pittsburgh**; **Children's Hospital of Philadelphia**; **Children's Hospital of New York**.

Repository samples have been utilized for viral testing and G4.5 mutational screening (genotyping). The intents of these pilot studies were to better define the etiologic basis of cardiomyopathy in children and to examine the correlation between test results and the clinical status of patients enrolled in both the pediatric cardiomyopathy registry and repository. Study results were recently presented at the **American College of Cardiology Annual Meeting** in March, and an oral presentation is scheduled at the **Pediatric Academic Society Meeting** in May.

Repository samples are available to any qualified investigator interested in

CLINICIANS & SCIENTISTS

Request for Research Applications on Pediatric Cardiomyopathy

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

Funding Opportunity:

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

Eligibility Requirements:

The principal investigator must hold an M.D., Ph.D. or equivalent degree and reside in the United States or Canada. The investigator must have a faculty appointment at an accredited U.S. or Canadian institution and have the proven ability to pursue independent research as evidenced by original research in peer-reviewed journals.

Application Deadline:

Grant guidelines and application form are available online at www.childrencardiomyopathy.org/site/grants.php. The 2010 deadline for application submission is Friday, September 3, 2010 with final award decisions to be made by January 2011.

For more information, contact
Lisa Yue, CCF president at
866-808-2873, ext 901 or
lyue@childrencardiomyopathy.org

studying cardiomyopathy in children age 18 and under. Research proposals requesting use of the samples are reviewed by an eight-person repository steering committee comprised of clinicians and researchers from various medical institutions.

CCF Extends Funding on Genetic Testing Study *continued from page 1*

are harmful or disease causing," she elaborates. "We need to understand more about these variations in order to predict when a change or variation in DNA is a problem, and potentially disease causing, and when it is benign."

Dr. Ware will use her CCF-funded extension of \$86,735 to custom design a genetic screening panel that will consist of the most common genes known to cause cardiomyopathy in

children, while permitting multiple genes to be investigated and reducing the labor needed for such genetic analysis. The study will improve the sophistication and ability to interpret genetic variations between adults and children so that mutations that increase the risk of cardiomyopathy developing in children can be identified.

"The second study involves a completely different step in genetic analysis and

pioneers unique technology, but the long-term goals remain the same – to identify the genetic basis of pediatric cardiomyopathy." Identifying the disease-causing genes and disease-associated risk factors can impact diagnosis, surveillance and early management of pediatric cardiomyopathy. In order to do that, Dr. Ware states, "We are working on making this genomic technology accurate enough for wide-spread clinical testing."

CCF Announces 2010 Research Grant Recipients

continued from page 1

Dr. Kuhn's research seeks to understand the signals heart cells use to regenerate and thereby manipulate the heart to repair itself. Dr. Ralphe will examine the role of particular mutant human proteins on heart function and the development of hypertrophy.

"We selected research that was directly related to children with cardiomyopathies and from investigators who would use this funding to secure additional grants to continue their work..."

CCF Medical Advisor, **Dr. Wendy Chung**

"A leading hypothesis as to the cause of cardiomyopathy," says Dr. Kuhn, "is that cardiomyocyte, or heart muscle cell, loss contributes to cardiomyopathy and thus poor heart function. Current heart failure therapies are based on the notion that once these heart muscles are lost, they are gone for good, with a transplant being the only biological replacement therapy."

Recently, Dr. Kuhn and his team showed

that cardiomyocytes, which normally stop dividing early in life, can be induced to proliferate by injections of the growth factor Neuregulin 1 (NRG1) – a diverse family of more than 15 proteins generated from a single gene – and periostin peptide, a component that makes up the structure of the heart. These two factors have been shown to regenerate heart muscle, improve heart function and reduce hypertrophy.

For his scientific model, Dr. Kuhn will use microarray technology, a genetic tool that measures all genes expressed in a biological sample, to examine changes in heart muscle cell gene expression throughout the cell cycle. He will also examine which genes "light up" during each phase of the cell cycle generating a list of novel candidate genes that play a role in the regeneration of cardiomyocytes. This process will help clarify the cellular and molecular mechanisms that underlie cardiomyocyte proliferation after birth.

The significance of this study is that with transplantation being the only clinical treatment for children with heart failure, the findings could lead to new innovative treatment options for

these high-risk patients. "Regenerative therapies could offer the potential for children with heart failure to repair damage to their hearts," adds Dr. Chung, "by stimulating their own heart cells to replace and repair themselves."

Dr. Ralphe's CCF-funded study will focus on one of the most common genetic causes of hypertrophic cardiomyopathy: a protein called cardiac myosin binding protein C (cMyBP-C). Different mutations in the gene for cMyBP-C result in widely ranging disease severity and age of onset. This is one of the mysteries of cardiomyopathy – how it varies from case to case even within a family with a common genetic link. One family member may be symptom free and diagnosed as a teen or young adult while another family member may have severe symptoms and be diagnosed at birth.

To better understand how certain mutations result in childhood onset disease, the study will adapt a 3-D model of cardiac tissue made from mouse heart cells deficient in mouse cMyBP-C but possessing human MYBPC3. The human protein will then be used to introduce specific HCM-causing mutations. A novel element to Dr. Ralphe's study is he plans to isolate and grow the heart cells at a much younger age than typically studied, affording the opportunity to examine disease development and pinpoint how mutations in the same protein lead to a range in disease severity.

"We can look at the impact of the mutation on heart function," Dr. Ralphe says, "and hopefully tease out some of the mechanisms that lead to functional impairment."

One of the long-term goals of defining these genetic mutations mechanisms is the development of treatment options that are targeted to counteract them. "Eventually the mouse models that Dr. Ralphe develops," says CCF Medical Advisor Dr. Steve Colan, "can be used to evaluate the response to various pharmaceutical interventions."

Medtronic GLOBAL HEROES Chooses CCF As Beneficiary for Third Consecutive Year

The Children's Cardiomyopathy Foundation (CCF) received a \$2,000 donation from the **Medtronic Foundation** on behalf of two of its 2009 **Global Heroes**, **JJ O'Malley** and **Leslie Minnix-Wolfe**. The Global Heroes program selects runners from around the world, whose lives have been improved by medical devices, to participate in the **Medtronic Twin Cities Marathon** event in Minnesota. As part of the program, Medtronic covers travel, lodging and meals for participating runners and donates \$1,000 to each runner's selected nonprofit patient organization. This is the third consecutive year CCF has been named a beneficiary.

Eight years ago, Leslie Minnix-Wolfe was having syncope attacks (fainting spells) due to her arrhythmia. Eventually she had a pacemaker implanted. JJ O'Malley was diagnosed with congenital heart failure and has an implantable cardioverter-defibrillator to treat his arrhythmia. Both runners credit their medical devices with allowing them to continue their training and passion for running.

CCF Second Annual POKER EVENT A ROYAL FLUSH

CCF's second annual poker fundraiser, **All-In For A Cure: No Limit Texas Hold 'Em Tournament**, was held at **Crimson** in New York City on February 3. Attended by more than 200 guests with 26 sponsors, the event raised more than \$203,700, surpassing last year's proceeds by more than 60 percent.



Brian Golden (2010 winner) and Jason Alpin (2009 winner)

"We're very excited about the continued success of the poker tournament as evidenced by the dramatic increase in attendance and revenues generated by the event," says CCF Board Member **Carney Hawks**. "We appreciate the positive feedback we received from so many attendees and look forward to their continued participation next year."

The night's grand prize winner, **Brian Golden** of **MetroNorth Railroad**, won a \$10,000 entry to the **2010 World Series of Poker (WSOP) Main Event** in Las Vegas. Second prize, an all-inclusive trip for two to Las Vegas, went to **Mark Frank** of **InTrade**. **Michael Balzano** of **Barrone Carting** won third prize, an Atlantic City get-away at **Caesar's Resort**. Fourth

prize, golf and lunch at **Hudson National Golf Club**, went to **Kyle Lanphear** from **Credit Suisse**. **Benji Chung** won fifth prize, season tickets to a **NY Giants** game. Sixth through tenth prize winners of \$100 **Modell's Sporting Goods** gift certificates were **Marc Warm**, **John Maher**, **Spencer Wells**, **Adam Celentano** and **Paul Lee**.

Last year's grand prize winner, **Jason Alpin** from **Imperial Capital** and a three-time contender at the **WSOP Main Event**, went to Las Vegas in July with hopes that he would be able to clinch the main event title. Although he was knocked out the second day of the tournament, he thoroughly enjoyed the experience. "Although I was not so lucky as to win this year, I look forward to trying my luck at the CCF event again and at the **WSOP** next year!" says Jason.



(L-R): Lisa Yue (CCF president), Ian Sandler (CCF board member) and David Fisch



Top photo: Playing poker at Crimson
Bottom, (L-R): Steve Rosen, Won Choi and Carney Hawks (CCF board member)

8th Annual
Golf Classic
2010



Children's
Cardiomyopathy
Foundation

SAVE THE DATE!

Montclair Golf Club
West Orange, New Jersey

Monday, July 19, 2010

To reserve your playing spot or inquire about sponsorship opportunities, please contact Sheila Gibbons at 866-808-CURE (ext. 902).

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

2010 Event Sponsors:

Brigade Capital Management, Capstone Advisory Group, Eric Cole, Covenant Review, Credit Suisse/Bob Franz, John Florio/Andy Stock, Rob Gallivan, GFI Group, GLC Advisors & Co, Bill Goebelbecker, ICAP High Yield, Imperial Capital, Intrade, Katten Muchin Rosenman, Knight Libertas, Kramer Levin Naftalis & Frankel, Stephen Lehner, Norm Louie, Drew McKnight, Michael McLaughlin, Eric Needleman, Michael Neumann, RBS Greenwich Capital, The Sandler Family, Taconic Capital Advisors, The Yu Family

Event photos are now online under "News & Events."

FAMILY FUNDRAISERS

Family fundraisers are increasing awareness of cardiomyopathy everywhere!

If you would like to join in the cause, please contact Sheila Gibbons, 866-808-CURE ext. 902 for more information on how to plan a community fundraising event.

Holiday Shopping FOR A CAUSE

Heather Cinca, with the help of friend **Brenda Grochowski**, held a holiday shopping extravaganza with more than 30 holiday vendors at the **Doubletree Hotel** in Cocoa Beach, Fla. The event was held in honor of Heather's daughter **Cristina** who

was celebrating her 9th birthday. The event raised more than \$3,890 and a good time was had by all. The hotel donated the room and each vendor donated a raffle item. Heather was able to give an item away every five minutes throughout the event. The raffle included items such as tennis lessons, retail gift certificates and dinner reservations.



photo: Jenny Denson

Clockwise: Brenda Grochowski (Event Coordinator), Heather and Jorge Cinca, Parker Cinca and Cristina Cinca

More Family Fundraisers...



Tara Wasserman

- **Tara Wasserman**, a high school junior from Quakertown, Penn. who has hypertrophic cardiomyopathy, held a cardiomyopathy awareness campaign at her school. She gave a persuasive speech about the disease to her student body while holding a fundraiser for CCF.
- **Christopher Piccininni** and his mom visited CCF staff to present a check for his fundraising efforts. Christopher celebrated "heart day," the 8th

anniversary of his heart transplant, by asking friends and families to donate to CCF in lieu of receiving gifts.

Christopher Piccininni with the CCF staff members



"Lots of family and friends sent donations if they were unable to attend," said Heather. "It was such a great success and a win-win for both the vendors and CCF that we hope to make it an annual event."



photo: Jenny Denson

Cristina Cinca



DiMonda Photography

- **Amanda DiMonda** of **DiMonda Photography** was diagnosed with peripartum cardiomyopathy after her second child. The diagnosis inspired her to give back, and she recently donated 10 percent of her holiday print sales to CCF.



Reily Green

- **Kelly Green** hosted a **Thirty-One Gifts** party at her Orlando, Fla. home with friend, **Ashley Haley**, a Thirty-One Gifts consultant. The party was in honor of her son, **Reily**, who has hypertrophic cardiomyopathy. Friends purchased everything from throw blankets to baby bibs, donating all sales to CCF.
- For five years running, CCF has been chosen as the beneficiary of the **Salem Road Race**, a 5K-community run held in Salem, Conn. **Rick Konon**, an avid runner and long-time CCF supporter, organized the April 10th event in tribute to his nephew, **Aidan**, who has hypertrophic cardiomyopathy.

CCF DONOR SPOTLIGHT

Lucille Protas

When **Lucille Protas** received CCF's sports inspired **Holiday Appeal** in the mail, she was reminded of the day her 15-year-old son, an all-star athlete, was told he had hypertrophic cardiomyopathy. "That appeal, which said 'We can't let cardiomyopathy sideline one more child,' was so powerful it made me cry and resurfaced all of the feelings we had as my very athletic son was sidelined because of cardiomyopathy. With that diagnosis his world was turned upside down," says Lucille.

Lucille's life dramatically changed as well. As the chief operating officer for an asset management firm, her days are filled with multiple challenges and the ability to provide solutions, but her son's diagnosis left her stunned and feeling powerless. This was the challenge of a lifetime, which she could not resolve. "I was a mess and my son was suffering. I was spinning in circles, but when I called CCF and spoke with Lisa Yue (CCF founder) she was so comforting and reassuring," says Lucille. Because of CCF's invaluable support, Lucille did not have a second thought about making a donation. "I am a very lucky person because I have the means to give. I know my donation is being used correctly without a lot of administrative red tape and with the objective of finding a cure," continues Lucille.

Now a pre-med student in college, her son wants to go on a medical mission over summer break, if approved by his doctor. She is proud that he has developed non-sports related interests, and he feels satisfied giving back to those less fortunate. "Someday when I retire from Wall Street I am going to commit my time to helping CCF," says Lucille. "Why wouldn't I—CCF helps my son every day."



NEW FUNDRAISING & MEDIA OUTREACH RESOURCE Guides

To provide more guidance and resources to those interested in planning a community fundraiser, two new guidebooks have

been developed. **Partnership in a Cause: A Guide to Raising**

Funds and Awareness covers fundraising event ideas, planning tips, and includes letter templates and forms. **Reaching Out to the Media: A Guide for Increasing Public Awareness of Pediatric Cardiomyopathy** outlines steps needed to get optimal media coverage and includes planning tips, letter templates and a national media list. A fundraising packet is also under development, which will include an event banner; poster; handout, balloons and give away items. These items, available to volunteers planning an event, will build CCF awareness and present a consistent foundation image.

For a copy of these two new guidebooks and to learn more about planning a fundraiser or working with the media, contact Sheila Gibbons at sgibbons@childrenscardiomyopathy.org.

The FDA Expands Commitment to Patients with Rare Diseases

Expanding on its commitment to facilitate the development and approval of safe and effective drugs for Americans with rare diseases, the **U.S. Food and Drug Administration (FDA)** has created a new position in the Agency's **Center for Drug Evaluation and Research's (CDER's) Office of New Drugs (OND)**. The new associate director for rare diseases will assist stakeholders and developers of rare disease drug and biologic products navigate the regulatory requirements for bringing safe and effective treatments to patients.

The position also will develop CDER policies and procedures for the review and approval of treatments for rare diseases and ensure appropriate training of CDER staff. An important focus of this new initiative will be to encourage collaboration among scientists and clinicians throughout CDER and to promote new scientific and regulatory innovations that will help facilitate timely development and approval of new treatments for patients with rare diseases.

CCF Joins the Sudden Cardiac Arrest Coalition

The Children's Cardiomyopathy Foundation (CCF) is now part of the steering committee of the **Sudden Cardiac Arrest Coalition (SCAC)**. The SCAC is comprised of advocacy organizations that have an interest in promoting awareness of sudden cardiac arrest and in preventing sudden cardiac deaths through legislative initiatives, increased public awareness, research, and access to life-saving therapies. Through a collaborative focus on national issues, the SCAC hopes to influence the media, policy makers and health care providers.

CCF and other coalition members – **Hypertrophic Cardiomyopathy Association, Sudden Arrhythmia Death Syndromes Foundation, Sudden Cardiac Arrest Association, Parent Heart Watch, WomenHeart, Mended Hearts, American Heart Association and Sudden Cardiac Arrest Foundation** – are working on scheduling an awareness event at the **National Press Club** in Washington D.C. for October 5. Open to the media and government officials, the meeting will commemorate **Sudden Cardiac Arrest Awareness Month** and feature a high profile speaker and surviving patients who have experienced sudden cardiac arrest. A "Briefing on the Hill" also will be organized to educate Capitol Hill staff and congressional representatives. More information about SCAC can be found at www.stopcardiacarrest.org.

The Latest on HEALTH CARE REFORM

On March 23, **President Obama** signed legislation designed to change the nation's health care system, leaving many Americans asking, "What does this mean for my family?" While some of the law's implications are clear, others are not yet fully understood. The full scope of the law will be brought into focus in the coming weeks with regulations issued by the **Department of Health and Human Services**. The following is a summary of the changes that will affect the American family.

Health care coverage for children is addressed in several ways. Under the new law, children who are dependant and cannot get health insurance through work will be able to remain on their parent's policies until the age of 26. Regulations will soon create the definition of a dependent. Also, the law protects children with pre-existing conditions, but it is unclear whether insurers must accept all children with a pre-existing condition to a health plan (a guarantee granted to adults in 2014) or whether it only protects insured children from being denied coverage of particular

treatments due to pre-existing conditions. Finally, the law indicates the states children's health insurance programs (**CHIP** or **SCHIP**) must be maintained until at least 2019.

Health insurance for families is also addressed in the law. Beginning in 2014 everyone (with the exception of American Indians, those who are incarcerated, illegal immigrants, or those with religious objections) must have a health insurance plan providing "minimal essential coverage" for themselves and their dependants or they will be fined. Exchanges, which will be set up by 2014 as new places to buy health insurance, will allow individuals who purchase their own health insurance and small businesses (firms with 100 or fewer employees) to come together for better prices on health care coverage. Additionally, financial assistance will be available for families and individuals making less than four times the poverty level, and an expanded Medicaid program will extend coverage to more Americans who are below, at or slightly above the poverty level.

HEALTH INSURANCE RESOURCES

- **Summary of Consumer Protections by State**
www.healthinsuranceinfo.net
- **Listing of Federally Qualified Health Centers**
www.findahealthcenter.hrsa.gov
- **Assistance with Prescription Drug Costs**
www.needymeds.org
- **Supplemental Security Income for Disabled Children**
www.ssa.gov/pgm/links_ssi.htm
- **State Government Programs Offering Health Insurance for Kids**
www.insurekidsnow.gov



Q with Jennifer C. Jaff, Esq.

The Basics on Health Insurance

Jennifer C. Jaff, an attorney with 30 years experience, is an expert on the law as it affects patients with chronic health problems. She is the founder of **Advocacy for Patients with Chronic Illness**, an organization that provides free information and advocacy services to patients with chronic illnesses. Visit her website at www.advocacyforpatients.org or email her at patient_advocate@sbcglobal.net.

1. What is the difference between a fully funded health insurance plan and a self-funded health insurance plan?

A fully funded health insurance plan is what you typically think of as insurance – you or your employer pays a premium and the insurance company pays for your health care. Under a self-funded plan, the employer pays a third party – usually an insurance company – to administer the plan and the employer actually pays for the health care. Self-funded plans are only governed by a federal law called the **Employee Retirement Income Security Act**, so state laws that mandate certain coverage or provide for independent reviews of coverage denials do not apply to self-funded plans. That can make a big difference when it comes to what the insurance covers. There is no way to tell if an insurance provided by your employer is fully funded or self-funded.

2. What are the differences between PPO, POS, HMO and catastrophic coverage plans?

A PPO and POS typically have some out of network coverage, whereas with an HMO you must stay within the provider network. In addition, with POS or HMOs you need a referral to a specialist, which you do not need for a PPO. Catastrophic coverage plans will only pay if you are hospitalized and have an emergent, significant medical problem but will not pay for preventive care or prescription drugs.

3. A change in jobs often means switching to a different health insurance. What questions should the parent of a child with special health care needs ask a potential employer when evaluating the health care benefits offered with a new job? Is there a benefit waiting period?

Even if you change from one employer-based group plan to another, there may be a waiting period before you are eligible for any benefits, in which case you should use **COBRA** (pay for your old plan) until your new plan kicks in.

4. Where can people looking to buy their own health insurance turn to for advice on which provider or policy to choose from?

This depends on where you live and what resources are available. Many state insurance departments will help you explore your options as well. Sometimes a knowledgeable insurance broker can help.

5. What is a medical loss ratio and why is it important to know when choosing a health insurance provider?

A medical loss ratio (MLR) is the amount of every premium dollar an insurance company spends on health care. If your insurer has a MLR of 70 percent, they are spending 30 percent of your premium dollars on administration and profit. If

they have a MLR of 90 percent, they are only spending 10 percent of your premium dollars on administration and profit. The lower the MLR, the lower your cost is likely to be and the less money your insurer is earning as profit.

6. What is a pre-existing condition?

This depends on how the policy defines the term. In general, a pre-existing condition is one that you had before you signed up for the insurance. Typically, insurers can look back six months to see if you had the condition, symptoms of the condition, or a reason to go to the doctor about this condition. However, I recently worked with a policy that included conditions that were reasonably anticipated complications of an existing illness when the insurance was brought. Even though the condition didn't exist at the time, it was a known complication of the existing illness so it was excluded as pre-existing. Therefore, get a copy of your policy and start with the policy language when deciding whether you have a pre-existing condition. If you go directly from one plan to another, a pre-existing condition is not a problem, but if you have a break in coverage you may have to wait as long as 12 months before your new plan begins. The new legislation will make some changes to this – immediately for children and in 2014 for adults.

7. How will the new health care bill impact families?

Children who already have insurance will not be denied coverage of particular treatments due to pre-existing conditions. There is some disagreement about whether insurers will have to cover them from the start, but the President has stated that this will soon be clarified in regulations to be issued by the **Department of Health and Human Services**.

A PARENT'S PERSPECTIVE Revealing Family Secrets

By Faith Settles

Mother to Ryan (11, HCM) and Chance (6, Unaffected)

Do you have a family secret? We did until we exposed it through genetic testing. Our secret was hypertrophic cardiomyopathy (HCM). It runs in our family with varying degrees of severity. Cardiomyopathy is a complex disease with hidden causes and on occasion acute symptoms, like in the case of my 11-year-old son **Ryan**. He had a very prominent heart murmur at birth and shortly thereafter was diagnosed with Asymmetrical Septal Hypertrophy also known as HCM. He needed to have a myectomy at the age of six and is currently taking Atenolol, 50mm daily. When he was diagnosed, we were left wondering if the heart problems that plagued our family could all be attributed to cardiomyopathy.

I also have HCM that was diagnosed

through genetic testing. I currently have no symptoms nor do I take medications. We have a younger son, **Chance**, who is free of the genetic mutation

that runs in our family. At age 48, my brother was diagnosed with HCM but fortunately has no symptoms nor does he take any medications.

We learned that my uncle died at the age of 26 from an undiagnosed heart condition that we now have been told was HCM. My 85-year-old father also has an implantable cardioverter-defibrillator and a pacemaker due to heart problems that are more likely related to our family's HCM.

I feel extremely fortunate to know our family's genetic history. We have always been aware that heart problems existed in our family, and as physical educators and athletes, we adjusted our lifestyle to accommodate the problems. It was only once Ryan was diagnosed with a severe heart problem that we realized what the

cause was and how variable the disease can be. This is why cardiomyopathy remained a secret within our family for so many years. When one family member has no symptoms, why suspect the disease?

Of course none of us like this diagnosis. However, we have chosen to attack this disease head on rather than let it creep up on us and then strike unexpectedly. For that reason, we are trying to learn as much as we can about this disease rather than let it control our lives. We want to be able to make informed decisions on treating this disease in our family. We believe that knowledge is power!

The result of not knowing or doing anything about it would have caused us a lifetime of worry and regret. Although we are still concerned, it is with knowledge and understanding that we move forward to a better tomorrow without fear in dealing with this disease. We feel relieved that cardiomyopathy has been confirmed in all our family members, and we can now prepare our family for generations to come.

Home is Where the Heart Is

CCF Family Receives a New Home on
Extreme Makeover: Home Edition



Jhett, Merit, Audra and Brian Skaggs with
Extreme Makeover host, Ty Pennington

The Skaggs, CCF family members from Oklahoma, were featured on ABC Network's **Extreme Makeover: Home Edition** in March. The Skaggs were chosen based on the moving story of their three-year-old son, **Jhett** who nearly lost his life to hypertrophic cardiomyopathy but received

a heart transplant at 11 months old. The poor condition of the family's home was posing serious health risks to Jhett's weakened immune system, and because of mounting medical bills, the family could not afford the costly home repairs. The Home Edition team, along with many corporate sponsors and local volunteers, were able to provide the Skaggs with a safe and healthy new home.

Mom, **Audra Skaggs**, feels so fortunate to get a beautiful home and to have the opportunity to reach so many viewers with their story. "Our life has changed now because we have a mold-free home for Jhett," says Audra. "The house is great, but being able to share Jhett's story with others was even better!"



A Call To Action: REACH MILLIONS WITH YOUR HEART STORY!

The Dr. Oz Show recently filmed a segment on sudden cardiac arrest in children, and has covered dilated cardiomyopathy in the Q&A section on its website, www.doctoroz.com. Show producers are now searching for parents who have lost a child to a heart condition to share their personal story. If you have faced such a loss and are comfortable sharing your story, including how CCF has made a difference in your life, please submit your story to Dr. Oz at www.doctoroz.com/plugger?tid=2977.

It would be a powerful way to reach millions on national television and to raise awareness of pediatric cardiomyopathy and CCF's important work.



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Update on CCF Local Support Groups

CCF support groups offer a chance for parents of affected children to share information in an informal setting and connect with others who are facing similar experiences.

To RSVP for a meeting or to learn more about starting a group in your area, contact Kella Boyer at kboyer@childrenscardiomyopathy.org.

CALIFORNIA

- Children's Hospital Oakland
Oakland, Calif.
Outpatient Center, Room C
May 22: 10:00 a.m. - Noon

FLORIDA

- Holtz Children's Hospital
Miami, Fla.
PICU Conference Room, 5th Floor
June 26: 1:00 - 3:00 p.m.

MICHIGAN

- C.S. Mott Children's Hospital
Ann Arbor, Mich.
Pediatric Cardiology Library
May 22: 1:00 - 3:00 p.m.

NORTH CAROLINA

- Duke University Medical Center
Durham, N.C.
McGovern-Davidson Health Center,
Room 4902
May 27: 6:30 - 8:00 p.m.

OHIO

- Nationwide Children's Hospital
Columbus, Ohio
Room ED 025A
June 15: 6:00 - 7:30 p.m.

- Cincinnati Children's Hospital
Cincinnati, Ohio
Room ED A1.603
May 15: 11:00 a.m. - 1:00 p.m.

UPDATE on CCF's MEMBER FORUM

The CCF Member Forum, one of CCF's most popular resources, allows members the opportunity to share information and provide support through group e-mail exchange. Several times each year professional guests volunteer to answer member-submitted questions. Listed below are scheduled guests for the next few months.

HEALTH INSURANCE

Lynda Honberg, MHSA, MCHB/HRSA
Program Director;
Children with Special Needs
Maternal and Child Health Bureau
May 17 - May 24, 2010

VENTRICULAR ASSIST DEVICES

David Rosenthal, MD
Director, Pediatric Heart Failure Program
Lucile Packard Children's Hospital
September 20 - September 27, 2010

Parents and health care professionals who would like to subscribe to CCF's Forum or volunteer to be a forum cyber-guest should contact Kella Boyer at kboyer@childrenscardiomyopathy.org.