CCF is pleased to announce the 2009 joint Children’s Cardiomyopathy Foundation and American Heart Association grant recipient, Jay Reddy, Ph.D., and his funded study, “Delineating Autoimmunity in Postinfectious Myocarditis.”

Dr. Reddy, associate professor of veterinary and biomedical sciences at the University of Nebraska-Lincoln, will use the $308,000 award towards research into the relationship between the autoimmune response to cardiac proteins and the development of chronic inflammation in postinfectious dilated cardiomyopathy.

In some individuals, exposure to and infection by coxsackievirus B3 (CVB3) can lead to myocarditis, which is an inflammation of the heart muscle. In certain cases, this inflammation becomes chronic and develops into dilated cardiomyopathy. Currently, it is not known why or how a CVB3 infection can lead to dilated cardiomyopathy. Dr. Reddy proposes that an underlying reason might be an autoimmune response triggered by CVB3. An autoimmune response is one in which the body recognizes its own tissues as foreign and attacks them, causing inflammation.

Jeffrey A. Towbin, M.D., a CCF-funded investigator, received much news coverage for his team’s discovery of a novel gene responsible for heart muscle disease and chronic heart failure in some children and adults with dilated cardiomyopathy (DCM). Among the publications to cover the groundbreaking finding were U.S. News & World Report, Discovery.com and Science Daily along with several local news stations and online medical news sites.

Towbin and his team screened 208 patients, mostly children and young adults with DCM, and identified three disease-associated variants of the ANKRD1 gene. According to their study, which was published in the July 21 issue of Journal of the American College of Cardiology (JACC), the ANKRD1 gene encodes a protein that plays a role in the structure and function of the heart. This research was partially supported by CCF in association with his 2006 funded study, “Identification of Mutations in Genes Associated with Hypertrophic Cardiomyopathy and Dilated Cardiomyopathy.”

“Our study indicates that variants in ANKRD1 result in dysfunction..."
From Lisa Yue,
CCF Founder & President

Each and every one of us within the CCF community has been touched by cardiomyopathy in some way: the families with a diagnosed child, the physicians caring for the child, the researchers searching for better treatments, and the donors wanting to improve the lives of those affected. Together, we are a team, and it takes the collective effort of each person to defeat this disease.

In this issue, we focus on the contribution of each team member. We present a new donor spotlight introducing the people behind CCF’s support. We highlight the work of new researchers and cover the topic of integrative medicine and the additional considerations involved in managing a child with cardiomyopathy. This includes an interview with a nutritionist and a parent’s perspective on the team approach to treatment focusing not only on the physical illness but on the emotional and psychological aspects as well.

Team effort is also the thought behind this year’s annual appeal. During this time of giving, I ask that we come together and rally as a team to help fund the research and provide the support services families need to beat the odds. Help us to reach our winning goal of finding a cure for cardiomyopathy.

Spread Holiday Cheer While Supporting CCF

This holiday season, there are many ways to increase awareness of cardiomyopathy and raise funds for research on the disease. Here is a list of gift ideas you’ll feel good about giving:

- Purchase our cheerful “Hope” tribute cards to use as holiday greetings.
- When shopping online for family gifts, use goodsearch.com or igive.com and select the Children’s Cardiomyopathy Foundation (CCF) as the charity to support. A portion of your purchase will go directly to CCF at no extra charge.
- CCF’s red silicone curebands are fun and trendy and make excellent stocking stuffers. Other CCF stocking stuffer ideas are available for purchase through CCF’s online merchandise store (www.cafepress.com/cardiomyopathy).
- New York family members, get your holiday family photos taken while supporting CCF. DiMonda Photography is donating 10 percent of print sales to CCF through December 15. For more information, visit www.dimondaphotography.com.

We can’t let cardiomyopathy sideline ONE MORE CHILD.

Be part of the team working to defeat this disease.
Watch your mail for CCF’s annual appeal or make an online donation today.
www.childrenscardiomyopathy.org
Click on “make a donation/online donation.”
George Porter, M.D., Ph.D. of the University of Rochester was the first recipient of the joint CCF-AHA grant awarded in July 2008. Dr. Porter has been progressing with his study “Calcium Channel Disruption, A New Model of Non-Compaction Cardiomyopathy” and sees important clinical implications from the study findings.

In testing his research hypothesis Dr. Porter discovered that altered calcium signaling affects mitochondrial structure and function in the hearts of his mouse models. Because the mitochondria are involved in calcium signaling, and mutations in mitochondrial genes can cause non-compaction in humans, Dr. Porter is investigating whether deletion of CaV1.2, a major calcium channel, impacts the mitochondrial function in the developing heart and how this interaction eventually leads to non-compaction cardiomyopathy. Further studies will reveal more details on the mechanisms of this process.

“There are many clinical implications for these results, including treatments for patients with non-compaction to improve their symptoms and preventative measures for patients at risk for developing non-compaction,” said Dr. Porter.

Dr. Porter’s preliminary experiments have been presented at the Gordon Research Conference on Cardiac Regulatory Mechanism (July 2008), the NIH Mitochondrial Biology in Cardiovascular Health and Disease Conference (October 2008) and the Upstate New York Cardiovascular Research Symposium (December 2008).

Circulating antibodies, or infection-fighting proteins, have been seen in patients with dilated cardiomyopathy. These antibodies attach themselves to various foreign objects. In these particular patients, the body reacts to cardiac myosin, a protein found naturally in the heart muscle, as a foreign substance. This suggests that there is some similarity between the foreign CVB3 and the naturally occurring cardiac myosin proteins, resulting in antibodies mistakenly attacking the latter.

In order to understand this further, Dr. Reddy will use a mouse model, which has been infected with the CVB3 virus and has subsequently developed myocarditis. He expects to see the mice develop T-cells, a type of immune cell, to battle CVB3 and to mistakenly recognize their cardiac myosin as foreign. He hopes to discover why this occurs and how it contributes to chronic inflammation of the heart muscle.

“Study findings should provide new insights into how postinfectious dilated cardiomyopathy develops. These insights will lay the foundation for new, effective therapy to be targeted at a known cause of dilated cardiomyopathy,” said Dr. Reddy.

CCF family member Sharon Tramm, who lost her infant daughter to myocarditis-induced DCM, is hopeful this study will provide answers for others diagnosed with myocarditis-induced DCM. “For years we suspected that the cause of our child’s DCM was viral but we didn’t know why she was more susceptible to developing DCM,” said Susan. “Dr. Reddy’s study will help us to understand some of the possible reasons and hopefully lead to some innovative therapies for this type of acquired DCM.”

Jeffrey A. Towbin, M.D., a CCF-funded investigator, received much news coverage for his team’s discovery of a novel gene responsible for heart muscle disease and chronic heart failure in some children and adults with DCM. Among the publications to cover the groundbreaking finding were U.S. News & World Report, Discovery.com and Science Daily.

Dr. Towbin is co-author of another study in the same issue of JACC showing that the ANKRD1 gene also contributes to hypertrophic cardiomyopathy.

Publications:
ANKRD1, the Gene Encoding Cardiac Ankyrin Repeat Protein, Is a Novel Dilated Cardiomyopathy Gene
J Am Coll Cardiol. 2009 Jul 21;54(4): 325-33

Cardiac Ankyrin Repeat Protein Gene (ANKRD1) Mutations in Hypertrophic Cardiomyopathy
The research that CCF has funded has resulted in over 77 published manuscripts and meeting presentations since the grant program was implemented in 2002. Eleven publications and eight meeting presentations resulted from CCF funded studies in 2009:

**Anne Dipchand, M.D.**


“Outcomes of Pediatric Patients with Hypertrophic Cardiomyopathy Listed for Transplant,” *Journal of Heart & Lung Transplantation* 2009

**Bruce Gelb, M.D.**
“Pathogenesis of Cardiac Hypertrophy from Noonan Syndrome-Associated Mutant RAF1,”
Abstract at the Annual Meeting of the Eastern Society for Pediatric Research, Philadelphia, PA, March 2009

**T.Y. Hsia, M.D.**
“Pathogenesis of Cardiac Hypertrophy from Noonan Syndrome-Associated Mutant RAF1,”
Abstract at the Annual Meeting of the Eastern Society for Pediatric Research, Philadelphia, PA, March 2009

**Tracie Miller, M.D.**
“Nutritional Status is Associated with Cardiac Outcomes and Mortality in Children with Idiopathic Dilated Cardiomyopathy,”
Platform presentation at the American Heart Association Scientific Session, Orlando, FL, November 2009

**Seema Mital, M.D.**
“VEGF Genotype Is Associated with Adverse Outcomes in Children with Hypertrophic Cardiomyopathy,”
Oral presentation at the American Heart Association Scientific Session, Orlando, FL, November 2009

**Enkhsaikhan Purevjav, M.D., Ph.D.**
“Effects of ACE Inhibitors and Beta-Blockers on Cardiac Function in Murine Models of Inherited Dilated Cardiomyopathy Due to Mutations in the Nebulette Gene,”

**Jeff Towbin, M.D.**
“ANKRD1, the Gene Encoding Cardiac Ankyrin Repeat Protein, Is a Novel Dilated Cardiomyopathy Gene,” *Journal of the American College of Cardiology*, 2009 July; 54(4): 325-33

**Stephanie Ware, M.D., Ph.D.**
“Massively Parallel Sequencing in Pediatric Cardiomyopathy Patients,”
Abstract at the American Society of Human Genetics 59th Annual Meeting, Honolulu, Hawaii, October 2009

**Monte Willis, M.D., Ph.D.**
“Long-Term Improvement in mdx Cardiomyopathy after Therapy with Peptide-Conjugated Morpholino Oligomers,” *Cardiovascular Research*, 2009 October 8


“Familial Hypertrophic Cardiomyopathy: Basic Concepts and Future Molecular Diagnostics,” *Clinical Biochemistry*, 2009 June; 42(9): 755-65

For the third year, CCF’s Golf Classic was held at the historic and beautiful Montclair Golf Club in West Orange, N.J. on July 20. A sold-out crowd of 165 attendees from top name law firms, hedge funds, asset management firms, and other financial service companies enjoyed a day of lovely weather, challenging golf and delicious food. Despite the economic strains felt by all, this year’s event raised $325,600. The net proceeds from the event will be earmarked for CCF’s research grant program and 2010 scientific conference. In the evening, prizes were given to the winning foursomes: Josh Sock, Brad Roberts, Paul Arquet, Andy Arthur (First prize); Brian Charters, Gene Pagnozzi, Mike McBride, James Fitzpatrick (Second prize); David Shaw, David Shapiro, David MacDonald, Marc Lucas (Third prize); and Robert Frahm, Brian Hewitt, Chris Majak, Dan Ryan (Fourth prize).

The prize for closest-to-the-pin went to Nick Weber and Mike Kirkpatrick. The prize for longest drive went to Dave Pucciarello and Rob Fitzpatrick. Raffle prizewinners were Tom Janover, Pete Coviello and Hunt Roeder.

For Paul Haskel giving back runs in the family. With several of his family members in the field of social work, Paul Haskel has seen first-hand the significance of supporting those in need. Now a partner at the law firm Richards Kibbe & Orbe (RK&O) in New York City, Paul has continued this philanthropic drive. He and his firm have donated more than $50,000 and many hours of pro bono legal counsel to CCF.

“Our firm has been privileged to become directly involved in supporting the CCF mission,” said Paul. “Forming a relationship with an organization dedicated to improving the lives of children with cardiomyopathy has been an honor for us.” RK&O has been a major supporter of CCF’s work since 2005, and a key sponsor of CCF’s Annual Golf Classic. This year RK&O was a silver sponsor at the $12,000 level.


For more information, please contact Sheila Gibbons at 866-808-CURE (2873) ext. 902.

Mark your calendars!

**All-In For A Cure No-Limit Texas Hold ‘Em Tournament**

**Wednesday, February 3, 2010**

6 – 11 p.m.

**Strata Nightclub, New York City**

Join us for a lively evening of charity poker, cocktails and hors d’oeuvres.

2009 Event Sponsors:

**SEVENTH ANNUAL GOLF CLASSIC: A HOLE-IN-ONE RAISING MORE THAN $325,000 FOR RESEARCH**

(L-R): Carney Hawaks, Pete Joseph, Brad Roberts, Jun Li

(L-R): Peter Gingold, Eddie Yu, Brad Patelli, Tod Arden
CCF is working on several new projects to address the needs of both families and medical professionals. These projects are aimed at advancing knowledge of the disease and providing additional resources to meet the evolving needs of parents managing their affected child's care.

CCF Projects

ON THE HORIZON

• Second Annual Scientific Workshop

CCF is planning the Second International Conference on Pediatric Cardiomyopathy to be held May 12-14, 2010 at the Marriott Bethesda, Md. The workshop will bring together the best and brightest from many different disciplines, including pediatric cardiologists, geneticists, molecular biologists and epidemiologists, to identify critical research areas, share best practices and research findings, and analyze new data on pediatric cardiomyopathy. Approximately 45 clinicians and scientists from the U.S., Canada and Australia are expected to participate.

“An important outcome of this meeting will be the ability to share this vital information with the rest of the pediatric cardiology community and to draw attention to the state of the disease,” said Steve Lipshultz, M.D., CCF medical advisor.

The first scientific workshop was held January 25-26, 2007 in Bethesda, Md. The conference proceedings were featured in three dedicated issues of Progress in Pediatric Cardiology, a leading journal in the field.

• Pediatric Cardiomyopathy Guide for School Personnel and Parents

CCF is developing a comprehensive school education packet, Ensuring A Good Learning Environment: A Pediatric Cardiomyopathy Guide For School Personnel & Parents, to address the needs of children with cardiomyopathy in the school setting. The packet serves two purposes: 1) to educate school personnel on the effects of the disease and the school requirements related to treatment and 2) to offer guidelines and resources for parents to effectively work with the school system to address their child’s special needs.

The school education packet will include several components: a guide for school personnel, a guide for parents, and useful templates such as a letter to the school, individualized healthcare plan, 504 education plan and emergency care plan. These materials will address the important need for a comprehensive, coordinated and systematic approach to implementing school accommodations and modifications for a child with cardiomyopathy.

To help in the creation of the packet, CCF formed a review committee consisting of parents who work in the education field or have had experience dealing with schools on child accommodations and modifications. CCF family members involved in the project include: The packet is currently being developed and will be completed by year-end.

• On-Line Community Web Pages

Since the Internet is the preferred mode of access for information and interaction with other cardiomyopathy families, CCF will be restructuring its website to be more dynamic and developing new community networking pages for registered members. The password-protected community pages will allow CCF members to come together and more easily exchange information, share ideas, and meet other affected families and physicians experienced with the disease.

The goal is to make this community site a center of social activity on pediatric cardiomyopathy, linking families with other families, families with physicians, and physicians with other physicians to strengthen the cardiomyopathy community. These site enhancements will enable members to post their story and photos, search for other families and specialty centers, join the email discussion forum and blog on a particular topic, as well as download additional patient resources and post messages to other members on the community bulletin board.

CCF will be working with Evolution Point, an interactive marketing agency, and Atlas Software Technologies to complete this project by Spring 2010.

• New CCF Physician Information Packet

CCF has developed a new resource for families to share with their child’s healthcare team. The Physician Information Packet was developed to increase awareness of CCF’s programs and resources and promote CCF as a reliable source of patient information and support. The packet includes a letter from the chairman of CCF’s medical advisory board, information about CCF’s patient services and research grant program, and sample patient educational materials.

CCF families are assisting in distributing these packets to their child’s physician. By reaching out to more healthcare professionals, CCF will be able to extend its services to more newly diagnosed families. To request a Physician Information Packet, please email kboyen@childrenscardiomyopathy.org with your mailing address and the name of the physician to whom you will give the packet.
FAMILY FUNDRAISERS

$31,000 and Counting... Family Fundraisers Are Going Strong!

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 details on how to plan a community fundraising event.

Art for the Heart

Bride-to-be, Jacqueline Greto, lost her fiancé, Bradley Tully, unexpectedly to hypertrophic cardiomyopathy a year ago. On October 10, their scheduled wedding day, Jacqueline with the support of family and friends honored her fiancé with “Art for the Heart.” The event, which raised more than $9000 for CCF, was an outdoor arts and crafts fair with live music and food donated by the community.

“Our efforts stand with the importance to not only honor a life cut short by cardiac disease, but also to build awareness of cardiomyopathy so that, ultimately, others can be saved,” said Jacqueline.

The event brought with it more laughter than tears, and Bradley’s life was celebrated for all the joy and passion he brought to it, and all the lives he touched.

Racing For A Cure

For the fourth year in a row, CCF has been chosen as the beneficiary of the Salem Road Race. This year’s race raised close to $3,000 for our cause. Rick Konon, an avid runner and organizer of the race, plans the event every year as a tribute to his nephew, Aidan, who has hypertrophic cardiomyopathy. More than 200 runners participated in the 5K-community run that took place in Salem, Conn. on April 10.

Cardio-A-Thon Increases Heart Rates and Awareness

Jodie Sancetta and Dan Hornby of the Straight from the Heart Foundation, held a “Cardio-A-Thon” May 16 in Verona, N.J. that got the hearts of more than 200 attendees pumping to the tunes of DJ Arob. The event, which was held in memory of two young men who lost their lives to cardiomyopathy, raised more than $7,000 for CCF. Event sponsors included Fleet Feet Sports, Adrenaline Training Studio, Mary Kay Cosmetics and Villani Chiropractic Center.

Karl Weber, an emergency medical technician and special education teacher, was teaching at Cedar Grove high school in December 2004 when he collapsed from hypertrophic cardiomyopathy (HCM). In September 2007, 23-year-old, Rob Diess, died after a routine morning jog due to undiagnosed HCM. The lives of these young men inspired Jodie, a personal trainer, to use her incredible energy and talent for physical training to make a difference.

“This event was such a great success and an honor for me to do this in memory of two great men and their families,” said Jodie Sancetta. “Next year’s event will be bigger and better!”

More Family Fundraisers...

- Patti Gerber of Hamilton, N.Y. embarked on a letter-writing campaign in honor of her son, Stephen, raising more than $1,000 through the generous donations of family and friends.
- Linsey Rippy of Blaine, Minn. raised more than $500 selling CCF cure bands to friends, family and coworkers, hoping to raise awareness and funds for cardiomyopathy research. Her daughter, Madison, was diagnosed with dilated cardiomyopathy and received a heart transplant in July.
- In honor of her husband who died suddenly of hypertrophic cardiomyopathy while playing hockey, Caroline Parisi held the “Lenny Skates with Me” memorial hockey game at the Centennial Ice Rink in Wilmette, Ill. A free skate was held before the game and then attendees continued the festivities at a local restaurant after the game.
- Rachael Fulreader, Lauren Acone and Macie Bridge of Groton, Mass., former students of CCF family member Scott Middlemiss, decided to fundraise for CCF in honor of Scott’s son who has left ventricular non-compaction cardiomyopathy. Rachael and Lauren donated their proceeds from a summer camp they organized for neighborhood children. Macie Bridge, a 5th grader, raised more than $400 asking family and friends to donate to CCF in lieu of birthday presents.
A PARENT’S PERSPECTIVE
Whole Pediatric Cardiomyopathy Medical Care: TREATING THE BODY, MIND AND SPIRIT

By Mary Wood  Mother to two children with HCM

Cardiomyopathy, like other chronic illnesses, creates the need to rebuild a new sense of identity for the child and family. A young child or toddler may have to deal with a new sense of him or herself as a child who goes to the doctor frequently, who needs special tests or whose mom often looks worried. The diagnosed teen may find struggles with identity intensified, especially if he or she has had to give up athletics or other activities. Both child and family need to grieve the loss of the former self as well as the loss of an imagined future. Parents might need to mourn the star basketball player or the avid tree climber. As parents, we might experience a shift in our own identities as we learn how to negotiate with schools on individualized education plans, how to get enough calories into an underweight child, or how to distinguish flu symptoms from signs of heart failure.

Traditionally, the doctor takes care of the biomedical needs of a diagnosed child, while the emotional and psychological effects of the disease are left for the parents to deal with. However, parents are often struggling with their own grief and shock while trying to remain strong for their children. Harvard psychiatrist and anthropologist Arthur Kleinman, who specializes in treating chronically ill patients, summarizes the situation, “Chronic illness places the family under substantial, ongoing pressure that exacerbates existing conflicts while it creates new ones. The practitioner may come to see the entire family as the focus of care” (1988, The Illness Narratives).

Increasingly, hospitals are addressing the whole child and family with an integrated, team approach to medical management. An example is the David J. Perini Quality of Life Clinic at the Dana-Farber Cancer Institute in Boston. There, a team of professionals work together to address the long-term physical and emotional needs of pediatric cancer survivors and their families. Clinicians are beginning to see the need for the same kind of treatment in pediatric cardiomyopathy. A recent article in Progress in Pediatric Cardiology urges hospitals to create comprehensive care centers for cardiomyopathy patients, making the case that “educating families at the beginning of their child’s care, when they are the most overwhelmed, should be part of the overall management of the disease” (Bublik, Alvarez, Lipshultz et al., Progress in Pediatric Cardiology 208; 25: 103-111). The article suggests that this model of care may be cost-effective in the long run and certainly merits further study.

In a scenario of comprehensive care for a child with cardiomyopathy, a social worker might accompany the cardiologist to speak with the family at the time of diagnosis. The care team would assess the needs of the family, asking questions about how this diagnosis might affect their lives. The family would learn what to expect in both the short-term (grief, depression, withdrawal, fear; anger) and the long-term (restructuring of identity, dealing with the schools, handling reactions of family and friends). The ongoing care team might include a school counselor to help review 504 plans or IEPs, a nutritionist to assist with infant feeding issues or an occupational therapist to encourage a cardiomyopathy child to find new interests outside of sports. A psychologist with expertise in living with chronic illnesses might also remain an ongoing presence in the child’s care.

As the parent of two affected children, I believe families can benefit tremendously from this approach in which pediatric cardiomyopathy is viewed not only as a medical condition but as an emotional, psychological and spiritual restructuring of both the child’s self and the whole family.
FO R FAMILIES

Dr. Patel is the executive director of Clinic 4 Kidz, which specializes in caring for children with pediatric feeding disorders, autism and other special needs. Dr. Patel’s research focuses on developing appropriate treatments to increase oral intake and decrease tube dependency. She can be reached at 415-332-6066 or www.clinic4kidz.com.

Encouraging Good Eating Behaviors and Maintaining a Balanced Diet

Dr. Patel is the executive director of Clinic 4 Kidz, which specializes in caring for children with pediatric feeding disorders, autism and other special needs. Dr. Patel’s research focuses on developing appropriate treatments to increase oral intake and decrease tube dependency. She can be reached at 415-332-6066 or www.clinic4kidz.com.

Expertise, the treatment of choice is to use an interdisciplinary team in which several types of professionals come together to develop a comprehensive treatment plan.

3. What advice do you have for parents of a child who is not having difficulty gaining weight but is a picky eater? How can a parent help the child increase the quality and diversity in their diet?

Picky eating has become more common and in my opinion it seems to occur as a result of the environment. This may include presenting a variety of food options, allowing the child to control food options, and not requiring the child to eat a variety of foods. The key is to set healthy eating habits at an early age and to not allow the child to control the food options. Preferences develop over time with exposure and a food may have to be consumed at least 12-15 times before a preference develops. A child may initially refuse the food, but that does not mean that the child does not like it. They may refuse it simply because it is new. Children should be provided with choices from all four food groups. Initially the parent may want to set up requirements, such as eating one to two bites of a new food before allowing the child to eat the preferred food. The parent may want to focus on one to two new foods per week and progressively increase the requirement from two bites to four bites. If the child still does not prefer the food after consuming the food multiple times then introduce another food in the same food group. Start with small requirements so the child feels successful and praise the child for trying the new food. Once a requirement is set, the parent should follow through with what is asked of the child. Reinforcement may be necessary initially but if you follow through every single time the child will learn the requirement and will consume new foods without external reinforcement.

4. What are some ways to encourage a child with a feeding tube to take in more calories by mouth so that the tube may eventually be removed?

Start with small requirements such as one to two bites and progressively increase requirements once the child is successful. Set requirements that are easy to follow. Make eating enjoyable and provide a lot of verbal praise for consuming the required bites. Volume is a matter of time and can be increased once the child learns that there are requirements to eating. It is critical that all medical issues are resolved before any requirements are placed on the child for eating because you could be pairing more negativity with eating.

HEALTHFUL EATING IS A FAMILY AFFAIR: A Recipe from the Bordwell Family Kitchen

When Lynne Bordwell’s son was an infant, eating was one of the family’s greatest challenges. Brady, who has a genetic condition, would eat only a few bites of baby food at a time and often fall asleep while eating. Brady’s low weight and poor intake made meals a “frustrating experience”, Lynne recalls.

When Lynne sought the help of a nutritionist, she received a wealth of valuable information on how to increase calorie intake, yet she would often wonder about what to cook. She then embarked on a mission to create nutritious, high calorie and delicious meals. With the help of the special foods Lynne prepared, Brady’s weight slowly increased. Brady, now a teenager, loves to help his mom prepare family meals. In fact, he hopes to one day be a chef.

Some of Lynne’s recipes can be found on her website, www.kidsrecipeboosters.com. Lynne was inspired to create the site because, “I saw others going through the same things we did, and I thought I could share ideas that worked for us.”

VEGGIE PINWHEELS

Submitted by Lynne Bordwell, mother to Lauren (DCM), Brennen and Brady (DCM)

Ingredients:
1 cup finely chopped fresh vegetables (try spinach with stems removed, shredded carrots, cucumbers, peppers, or celery)
1 (8 ounce) package cream cheese, softened
1/2 cup mayonnaise
1/2 cup sour cream
1/4 cup chopped bacon
2 green onions, minced
1/2 cup shredded cheddar cheese
1 package (8 count) of 10-inch whole-wheat wrap

Preparation:
Combine cream cheese, sour cream and mayonnaise. Add green onion, cheese, bacon pieces and vegetables. Mix thoroughly.

Spread mixture onto tortillas, leaving a 1/2" space around edge. Roll up each tortilla tightly, and wrap each in plastic wrap. Chill for several hours or overnight.

To serve, slice into 1/2" slices. Salsa or ranch dressing is suggested for dipping.
Heart Failure Society of America Offer Guidelines for GENETIC EVALUATION OF CM

In the March 2009 issue of Journal of Cardiac Failure, medical researchers from the Heart Failure Society of America proposed guidelines for the genetic evaluation of hypertrophic cardiomyopathy (HCM), dilated cardiomyopathy (DCM), restrictive cardiomyopathy (RCM), arrhythmogenic right ventricular cardiomyopathy (ARVC) and left ventricular noncompaction (LVNC). While the recommendations for genetic testing and screening vary for the different forms of cardiomyopathies, there are some universal guidelines recommended by the researchers.

- Genetic and family counseling is recommended for the affected person and family members. Even though there is no family history of cardiomyopathy, there may still be an underlying genetic basis for the cardiomyopathy. All at-risk relatives should also be notified for cardiac follow-up.
- Since genetic counseling and genetic testing of cardiomyopathy patients are complex endeavors, families should consider going to centers that have expertise in genetic evaluation and family-based management.
- Doctors or geneticists should conduct a careful review of family history going back three or more generations.

- Clinical screenings should be done on asymptomatic members of the immediate family with follow-up screenings at regular intervals based on the screening results.
- If the results of genetic testing or clinical screening are negative, repeated screening is recommended.
  - The interval between screenings can be as short as one year during puberty for children at risk for hypertrophic cardiomyopathy and can extend to three to five years based on the age of the child and form of cardiomyopathy.
- If the genetic testing results are positive (e.g. a mutation is identified), the screening interval is generally annually for children with all cardiomyopathies except ARVD.
  - The interval will again depend on the age of the child and type of cardiomyopathy.
  - Those with an abnormal clinical screening should be rescreened in one year.
- Clinical screenings should consist of a medical history review, physical exam, electrocardiogram, echocardiogram, CK-MM (initial exam only), holter monitoring (HCM, ARVD), exercise treadmill testing (HCM), magnetic resonance imaging (ARVC) and signal-averaged electrocardiogram (ARVC).
- HCM and ARVC, although rare, have the strongest evidence to support genetic testing. Testing for DCM remains difficult due to the large number of genes involved and the low frequency of mutations in any one gene responsible for DCM. With both RCM and DCM, it has been a challenge testing the larger proportion of sporadic non-familial cases.
- Cardiomyopathies particularly those presenting in the first year of life, should be evaluated to determine if the underlying cause is metabolic derangement or mitochondrial dysfunction, which are autosomal recessive inherited traits and could pose risk of disease outside the heart and for which specific treatment may be available.
- Young children with cardiomyopathy should also be evaluated for genetic syndrome and muscle disorders associated with cardiomyopathy by an experienced geneticist. A complete evaluation will involve several blood and urine tests.
- Genetic testing and the discovery of a specific cardiomyopathy causing mutation usually does not guide therapy and treatment plans except in the case of metabolic diseases and genetic syndromes. The primary value of genetic testing is to more accurately predict the risk of a family member developing cardiomyopathy who has little or no clinical evidence of cardiovascular disease. Genetic testing is also used for family planning in determining the risk of having other children with cardiomyopathy and in considering genetic methods to prevent having additional affected children.

Update on CCF’s MEMBER FORUM

The CCF Member Forum, one of CCF’s most popular resource, allows registered members the opportunity to share information and provide support to one another through group e-mail exchange. Listed below are “cyber-guests” scheduled to answer questions submitted by forum members.

Helping Your Child Cope with Medical Tests or Hospitalization
Toni Millar, Director of Child Life & Alison Heffer, Child Life Specialist
Children’s Hospital of New York Presbyterian
January 25 - February 1, 2010

Updates on New Research
Seema Mital, M.D., Pediatric Cardiologist
Toronto Hospital for Sick Children
February 15 - 22, 2010

Feeding Issues
Suzanne Evans Morris, Ph.D., Speech-Language Pathologist
New Visions
March 8 - 15, 2010

Parents and healthcare 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.
Local Support Group Updates

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. CCF currently has nine support groups meeting at hospitals throughout the year. Contact Kella Boyer, 866-808-CURE, ext. 905, to learn more about our existing groups or to see if a group is forming near you.

**CALIFORNIA**
- Children’s Hospital Oakland
  Oakland, Calif.
  Outpatient Center Basement, Conference Room A
  Sept. 26: 10:00 a.m. - Noon
- Ronald Reagan UCLA Medical Center
  Los Angeles, Calif., Next meeting date TBD

**MASSACHUSETTS**
- Boston Children's Hospital
  Boston, Mass.
  Pavilion 1 Meeting Room
  Oct. 27, Dec. 8: 6:00 p.m. - 8:00 p.m.

**MICHIGAN**
- C.S. Mott Children’s Hospital
  Ann Arbor, Mich.
  Pediatric Cardiology Library
  Oct. 24: 1:00 p.m. - 3:00 p.m.

**NEW YORK**
- Golisano Children’s Hospital at Strong
  Rochester, N.Y.
  Children’s Heart Center, Room ACF-D
  Sept. 12, Dec. 12: 11:00 a.m. - Noon

**NORTH CAROLINA**
- Duke University Medical Center
  Durham, N.C.
  McGovern-Davidson Health Center, Room 4902
  Sept. 24, Oct. 22, Feb. 25, March 25,
  Apr. 22, May 27: 6:30 p.m. - 8:00 p.m.

**OHIO**
- Cincinnati Children’s Hospital
  Cincinnati, Ohio
  Room ED A1.603
  Sept. 26, Jan. 16: 11:00 a.m. - 1:00 p.m.
- Nationwide Children’s Hospital
  Columbus, Ohio
  Room TBD
  March 11, June 15: 6:00 p.m. - 7:30 p.m.

**PENNSYLVANIA**
- Children’s Hospital of Philadelphia
  Philadelphia, Penn.
  1st Floor Northwest, Room 21
  Oct. 10, Jan. 23: 11:00 a.m. - 12:30 p.m.

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- Minimized Variants of Unknown significance (VOUS):
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