CCF Announces its 2013 Research Grant Recipients

The Children’s Cardiomyopathy Foundation (CCF) has committed $75,000 to the National Heart, Lung, and Blood Institute (NHLBI) Pediatric Cardiomyopathy Registry (PCMR) to assist with patient recruitment related to the study, “Genotype-Phenotype Associations in Pediatric Cardiomyopathy.” The multi-center study aims to identify genetic mutations associated with pediatric cardiomyopathy and develop better and more targeted treatment for diagnosed children.

Pinpointing Disease Severity and Age of Onset
Human iPS cells and ECT in the Study of Hypertrophic Cardiomyopathy
John Carter Ralphe, M.D.
University of Wisconsin – Madison, School of Medicine and Public Health

Dr. Ralphe was awarded $50,000 to study the effects of a specific HCM causing mutation in cardiac myosin binding protein C (cMyBP-C), a protein that regulates heart

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CCF Contributes $75,000 to PEDIATRIC CARDIOMYOPATHY REGISTRY
Genetic Study

Principal Investigator and CCF Medical Advisor Steve Lipshultz, M.D. and James Wilkinson, M.D., M.P.H., professor of pediatrics and epidemiology at University of Miami will manage the PCMR study. Lipshultz and Wilkinson will work with a team of cardiomyopathy experts from 11 pediatric cardiology centers in the U.S. and Canada to genetically profile 600 pediatric cardiomyopathy patients.

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A Cause for Today… A Cure for Tomorrow
From Lisa Yue,
CCF Founder & President

Dear CCF Friends & Families,

As CCF begins its second decade, we are excited by the progress we have made as well as cognizant of the challenges ahead. With automatic budget cuts, the future of government funding for rare diseases is uncertain at best. What is certain, however, is our ongoing commitment to our cardiomyopathy families and to raising awareness of pediatric cardiomyopathy.

In this issue, you will find stories about CCF members making a difference and updates on CCF’s work in research, education and advocacy. We hope you enjoy the article on Scott Newport, a longtime CCF member who leads a dads’ support group and is an inspiration to other cardiomyopathy families. We also announce our 2013 research grant awards and the reintroduction of the Cardiomyopathy HEARTS bill. Our family fundraiser section highlights how families are helping to further CCF’s cause in their communities. We are so grateful for their support and enthusiasm.

We look forward to the next decade with you as we work towards a brighter future for children with cardiomyopathy and their families.

Lisa Yue

SPRING APPEAL
2013

Watch your mail for a moving letter from CCF family assistance recipient Linsey Rippy on how CCF helped her family during difficult financial times.

All funds raised from our Spring Appeal will help cardiomyopathy families in need like the Rippys. Please make an online donation in support of CCF’s Family Assistance Program. You can do so by going to CCF’s website and clicking the “Make a Donation” button at the top right page.
muscle contraction. It is unclear how different mutations in the DNA that produces cMyBP-C lead to severe cardiomyopathy in early childhood.

The study will take advantage of two powerful techniques to examine how the HCM-causing mutation found in humans, E258K, causes such a serious form of the disease. The first technology involves generating heart cells from fibroblasts (connective tissue cells) isolated from human skin biopsies. This technique reprograms skin cells to generate artificial stem cells, or induced pluripotent stem (iPS) cells, which can then be differentiated into beating heart cells that are genetically identical to the person from whom the skin biopsy was obtained.

The second technology that involves producing human engineered cardiac tissue (hECT) was developed with previous CCF funding and found to be a more cost-effective and efficient method than traditional animal models for replicating human disease. In this study, iPS-derived heart cells will be formed into a three-dimensional strip of heart muscle to measure and evaluate its contractile properties.

The E258K mutation will be introduced into the 3D engineered cardiac tissue model made from human iPS-derived heart cells. Dr. Ralph plans to isolate and grow the heart cells at a much younger age than typically studied, which would serve as a more comparable model for pediatric HCM. This model would allow Dr. Ralph to examine disease development and pinpoint how mutations in the same protein lead to a range of disease severity.

This is the second round of CCF funding for Dr. Ralph, whose CCF-funded 2010 pilot study on HCM treatments received subsequent support from the National Institutes of Health. “I am thrilled to receive my second grant from CCF,” said Dr. Ralph. “They understand the importance of identifying how environmental factors may affect the progression of HCM and how this understanding will help lead to new therapies.”

Isolating Causes of Aggressive Form of HCM

Pediatric Hypertrophic Cardiomyopathy Caused by Myosin Mutations

Leslie A. Leinwand, Ph.D.
University of Colorado – Boulder, Biofrontiers Institute

Dr. Leinwand received a $45,837 grant to study mutations in the MyHC gene that encode beta-myosin heavy chain proteins and cause severe HCM in children. The study also will evaluate a small molecule drug shown to be effective in adults with heart failure.

Beta-myosin heavy chain is a molecular motor protein responsible for making the heart muscle contract. More than 300 beta-myosin mutations have been identified to cause HCM in adults, but recently new mutations have been found in children. The myosin mutations that appear in young children cause a very aggressive form of HCM that can lead to transplantation and sudden cardiac arrest.

Dr. Leinwand will look at the functional impact of five pediatric HCM mutations in the human beta-myosin motor proteins using an expression system developed precisely for the purpose of studying the mechanism underlying HCM. Her study also will test the effects of a small molecule myosin activator to determine if it is an effective therapy for children in heart failure. The drug has proven successful in adults, and Dr. Leinwand hopes that the younger segment will also respond favorably.

“We would like to get beyond just treating the symptoms, and I believe we have the potential to treat the root cause of this disease,” said Leinwand. “CCF understands that young people with HCM have a much worse prognosis than adults and that up to 40 percent could die or require a heart transplant. Research is critical to saving these young lives.”

CCF’s grant program has been in existence since 2002. Funded entirely by donations, the program has supported 41 studies to date, which has resulted in more than 102 articles on pediatric cardiomyopathy being published in leading scientific and medical journals.
CCF Sponsors Inaugural PEDIATRIC HEART FAILURE MEETING

The Children’s Cardiomyopathy Foundation sponsored the Pediatric Heart Failure Group’s inaugural meeting on November 5, 2012 in Los Angeles, Calif. The evening reception and meeting, held during the American Heart Association (AHA) Scientific Sessions, attracted a diverse group of medical professionals to focus on pediatric heart failure research and patient care.

Led by Yuk Ming Law, M.D., director of cardiac transplant and heart failure at Seattle Children’s Hospital, the meeting was critical in bringing together physicians, scientists and nurses in the fields of pediatric cardiology and intensive care to address areas of growing concern to the pediatric heart failure population.

The focus of the meeting was to assess group objectives, discuss key issues in pediatric heart failure, determine research and clinical care priorities, and update members on current activities and future projects. Several collaborative projects were discussed, including updating the pediatric heart failure guidelines with the International Society of Heart & Lung Transplantation (ISHLT), developing a clinic survey to collect practice data from various pediatric heart failure programs, establishing a communication forum for members, and forming research consortiums for a registry and multi-center study.

“The meeting proved that there is enormous interest in advancing the field of pediatric heart failure,” said Dr. Law. “This is becoming very clear as we have support from important organizations such as CCF, AHA and the ISHLT.”

The Pediatric Heart Failure Group is a professional interest group focused on improving the exchange of ideas, education, quality of care and research related to heart failure in children. The group is comprised of medical and health professionals involved in the care of children with all stages of heart failure, and members interact within the framework of the ISHLT’s Pediatric Council Heart Failure Workforce.

This is the second CCF-supported pediatric heart failure conference. In 2008, CCF co-sponsored with the American Heart Association and National Heart, Lung, and Blood Institute a conference on the scientific basis of heart failure in children. “We plan to continue sponsoring these medical conferences to provide researchers and clinicians a forum for exchanging information and sharing ideas,” said Lisa Yue, CCF founding executive director.

CCF Contributes $75,000 to Pediatric Cardiomyopathy Registry Genetic Study

and their families to identify the genetic variations that cause or worsen their disease.

By studying such a large group, Dr. Lipshultz and others hope to identify the genetic factors that determine the development and progression of cardiomyopathy and therefore improve their ability to identify children who may develop the disorder suddenly and deteriorate rapidly. “Some patients live a full life expectancy after symptomatic presentation; others do well with medical management, and still others progress to transplantation right away. But they frequently look the same,” Lipshultz said. “So what is the difference? Do the affected children with bad outcomes have clusters of gene mutations? These are some of the questions we hope to answer.”

CCF’s contribution will supplement NHLBI funding and be used specifically for increasing research personnel at participating centers to expedite patient enrollment and follow up. “Our goal is to get the study completed as quickly as possible so that physicians can benefit from published findings and guidelines,” says CCF Founding Executive Director Lisa Yue. “We realize that without the dedicated resource to recruit the necessary number of children and their families, this study will not proceed efficiently.”
**CCF Welcomes NEW NHLBI DIRECTOR**

As a member of the National Coalition for Heart and Stroke Research, CCF joined 27 other sponsoring organizations in welcoming the newly appointed director of the National, Heart, Lung, and Blood Institute (NHLBI) Gary H. Gibbons, M.D.

CCF was a member of the working group committee for Dr. Gibbons’ reception held December 12, 2012. More than 150 guests attended, and remarks were given by Louis W. Sullivan, M.D., former secretary of the U.S. Department of Health and Human Services; Francis S. Collins, M.D., Ph.D., director of the National Institutes of Health (NIH); and Vice Admiral Regina M. Benjamin, M.D., MBA, U.S. Surgeon General. Senator Mike Crapo and Representative Lois Capps, both co-chairs of the Congressional Heart and Stroke Coalition, also extended their well wishes.

Dr. Gibbons will oversee the third largest institute at the NIH with an annual budget of more than $3 billion. Dr. Gibbons’ last position was as the founder and director of the Cardiovascular Research Institute at the Morehouse School of Medicine in Atlanta.

**Coalition to Petition for Increased AEDs**

CCF worked alongside 46 organizations of the Sudden Cardiac Arrest Coalition as a steering committee member to obtain more than 10,000 petition signatures to raise awareness of sudden cardiac arrest.

The petition, urging for an increase of automatic external defibrillators (AEDs) in schools and public places, was sent to U.S. Secretary of Education, Arne Duncan; U.S. Secretary of Health and Human Services, Kathleen Sebelius; and Mary Wakefield, Ph.D., R.N., administrator, Health Resources and Services Administration.

**CCF Family Assistance Program Awards $14,000 to Families**

CCF’s Family Assistance Program (FAP) has awarded more than $14,000 in assistance funds to families in 2012. During the year, six families from five different states (Calif., Minn., N.Y., Penn. and Ohio) were awarded funding.

Established in December 2011, CCF’s program assists low-income families with cardiomyopathy-related medical and non-medical needs when insurance and other financial resources have been exhausted. Covered expenses include treatment-related fees not covered by insurance, displacement fees incurred during evaluation and treatment, living costs during in-hospital treatment, select genetic testing, and health insurance premiums, deductibles or co-pays.

For more information on CCF’s Family Assistance Program, please contact Chris Colón at colon@childrenscrardiomypathy.org.

**Cardiomyopathy HEARTS Bill Reintroduced**

In February, U.S. Senator Robert Menendez (NJ) and Representative Frank Pallone (D-NJ6) reintroduced the Cardiomyopathy Health Education, Awareness, Risk Assessment and Training in the Schools (HEARTS) Act (H.R. 565/S. 254) to increase awareness of pediatric cardiomyopathy and the risk of sudden cardiac arrest among parents, schools and health professionals.

“We are grateful Sen. Menendez and Rep. Pallone have reintroduced this important legislation, which provides so many with lifesaving benefits,” said Lisa Yue, CCF founding executive director. “The Cardiomyopathy HEARTS Act will not only encourage preparedness for a cardiac emergency but it also will prompt families to evaluate their cardiac history, check for cardiomyopathy symptoms and seek medical screening if necessary.”

The Act would require the Secretary of Health and Human Services to coordinate with the Centers for Disease Control (CDC) and national patient advocacy and health professional organizations to develop educational materials and resources on cardiomyopathy for public awareness — covering symptoms, risk assessment, training in lifesaving procedures and planning for a cardiac emergency — and disseminate them to schools and families as well as post them on the CDC website.

Sen. Menendez said meeting CCF pushed him to introduce the Cardiomyopathy HEARTS Act to Congress. “When I first met with CCF, I was shocked to learn about the lack of federal efforts in educating parents and school administrators about this devastating disease,” said Menendez. He believes the Cardiomyopathy HEARTS act could solve the problem.

CCF continues to work in partnership with Congressman Pallone and Senator Menendez to move this legislation forward. CCF is in the process of getting legislative cosponsors and other organizations to sign on in support of the bill. Last year’s grassroots initiative resulted in more than 874 letters to lawmakers in 37 states and garnered the support of 19 cosponsors and 36 organizations.

To support this bill and send a personalized email to your representatives, go to CCF’s website and click the “Take Action Today” link at the bottom of the home page.
It was Las Vegas in New York City once again for CCF’s Fifth Annual All-In For a Cure No-Limit Texas Hold ‘Em Tournament. Held at Crimson on February 6, more than 260 individuals and 42 corporate sponsors attended to raise more than $210,000 for CCF’s research and education initiatives.

The evening began with a lively cocktail hour before the start of the much-anticipated Texas Hold ‘Em Tournament. Competition was intense but friendly, with seasoned players battling lucky newcomers to stay in the game. Rebuys were popular; as many players tried to stay in the game to make it to the final table. The highly coveted grand prize, a $10,000 entry to the 2013 World Series of Poker Main Event in Las Vegas, ultimately went to Jason Colabella of Macquarie Capital. Second prize, an all-inclusive trip for two to Las Vegas, went to Richard Zentko of Taconic Capital, and third prize, a weekend getaway to Atlantic City’s Borgata Hotel and Spa, was won by Aaron Ries of Jefferies & Co., John Maher of Brigade Capital Management won fourth prize, golf and lunch for four at Hudson National Golf Club. Taylor Leahy of Citibank was the fifth prizewinner receiving four tickets to a New York Giants Game. Gift cards to popular New York City restaurants were awarded to Marc Schwartz, Eric Needleman, Aaron Jackson, Noah Heller and Kevin Heller for sixth through tenth prizes.

Event photos and video are online under “News & Events/Poker.”

2013 Event Sponsors: Todd Arden; Bank of America Merrill Lynch; Andrew Brenner; Michael Brennan; Brigade Capital Management; Cantor Fitzgerald/Robert Barrett; Benji Cheung/Rob Franz/Jed Kelly; Colbeck Capital; Credit Suisse/Cathy Duffy; Christopher Delong; Deutsche Bank; David Fisch; James Fitzpatrick; Eric & Monica Friel; Rob Gallivan/Eddie Yu; Goldman Sachs; Guevara Family; Sandor Hau; Hunton & Williams; ICAP High Yield; Imperial Capital; Jefferies & Company/Jeffrey Manton; Katten Muchin Rosenman; Clint Kollar; Kramer Levin Naftalis & Frankel; Daniel & Lauren Krueger; Matt Lambert; Robert Lentin; Doug Logigian/Darren Richman; Jim & Laura Malley; Michael Miller; Eric Needleman; Genevieve Nestor; Gene Pagnozzi; Richards Kibbe & Orbe; Riva Ridge Capital Management; Royal Bank of Scotland; Edgar Sabounghi; Ian Sandler; Shearman & Sterling; Andy Stock; Andrew Susser

11th Annual Golf Classic 2013

SAVE THE DATE!

Montclair Golf Club
West Orange, New Jersey

Monday, July 22, 2013

Join CCF for this popular and fun-filled event!

Visit our event web page under “News & Events/Golf” for more information.
HEARTS OF HOPE BENEFIT FOR PEDIATRIC CARDIOMYOPATHY

On Sunday, October 14, the West Caldwell Women’s Club in New Jersey was transformed into a festive party for the Hearts of Hope Benefit for Pediatric Cardiomyopathy. Danielle Torok planned the occasion in honor of her 10-year old daughter Anna, who was diagnosed with dilated cardiomyopathy (DCM) at six months old.

Although the Torok family had organized a past CCF fundraiser, Anna initiated this year’s event hoping to increase awareness of cardiomyopathy and give back to CCF. Attended by dozens of friends, neighbors, coworkers, as well as CCF members Greg and Cindy Ryan from Cranford, N.J., the event raised more than $12,000 for pediatric cardiomyopathy research.

A Spooktacular Party Benefiting CCF

When Phillips Academy in Andover, Mass., was looking for a worthy organization to support for their Halloween dance, student James Heaney, 14, recommended CCF to the planning committee. He wanted to contribute to CCF’s cause in honor of his sister, Katherine, age 15, who has HCM. More than $1,000 in net proceeds was donated to CCF.

Zumba Fitness Party for Cardiomyopathy

Dawn Cresser of Valley Stream, N.Y. hosted a night of high energy zumba dancing and raffles on January 12. Dawn, recently diagnosed with left ventricular non-compaction cardiomyopathy, organized the event in honor of her daughter, Amber who has HCM and in memory of her father who also had cardiomyopathy.

Food, Fun and Shopping for a Good Cause

Kristin Guthrie held a Handbags for HCM event on November 1 in honor of her 19-year-old daughter, Gabriella Beckstrom-Bonnefil, who has HCM. The evening, which featured stylish handbags and accessories by Beijo, raised $2,625.

FAMILY FUNDRAISERS

MORE FAMILY FUNDRAISERS...

Let’s All Cheer for CCF
On October 27, the Sixth Annual Cheer for a Cause Cheer Off took place at Lake-Lehman Junior and Senior High School in Penn. This year’s event was held in memory of Eleanor “Ellie” Ayers, who had hypertrophic cardiomyopathy (HCM) and passed away at 8 months old. Ellie’s mom Jennifer, who is a Lake-Lehman graduate, said, “Even though Ellie isn’t here anymore, she can still do great things and has inspired so many people.” The event raised $5,000 for CCF.

Amber Cresser
Heart Month Happenings

Cardiomyopathy Day at School
CCF parent, Allison Bell, held a Valentine’s Day awareness event at her son, Fulton’s, 5th grade class at Greensboro Day School in Greensboro, N.C. She spoke about cardiomyopathy and how it affects the lives of children with the disease, the warning signs, and what to do in an emergency. The event was in honor of Garland, Allison’s daughter, who has hypertrophic cardiomyopathy. She gave the students materials on cardiomyopathy and red lollipops tied to CCF heart pens.

Awareness with Self Defense Product Sales
In memory of her daughter Kenzie, who at 4 years old passed away shortly after her cardiomyopathy diagnosis, Nicole Flores donated her sales commissions from Damsel in Defense products sold throughout the month of February.

Will Your Heart Be Mine? Event
Lisa Winship of Houlton, Maine, organized a Will Your Heart Be Mine? awareness event on Valentine’s Day at the Greater Houlton Christian Academy. The day was in honor of her daughter Hannah, 14, who has dilated cardiomyopathy. The school event included a presentation to children, parents and teachers on pediatric cardiomyopathy, handing out educational materials, and selling homemade valentine treats, cards and CCF curebands.

If you would like to host an awareness event in your community, please contact Joanne Bloomstein at jbloomstein@childrenscardiomyopathy.org.

CCF’s 2012 ANNUAL REPORT
Now online under “About CCF/Financials.”
A heartfelt thank you to all our 2012 sponsors and donors!

A carpenter by trade, CCF dad Scott Newport says he has always been a fixer, but the one thing he could not fix was his son’s weak heart. Scott’s son, Evan, was born with a severe form of Noonan syndrome and hypertrophic cardiomyopathy (HCM). Evan spent the first eleven months of his life in the hospital with doctors believing he would not live more than a year.

Rather than give up hope, Scott built Evan a mini-intensive care unit in their home so he could experience life outside the hospital. He and his wife Penni and their older son Noah, learned to manage his complex care with his ventilator tubes, multiple monitors, medications, and round-the-clock nurses and therapists. Against all odds, Evan lived for six more years.

From Evan’s diagnosis until his death in 2009, Scott has traveled a difficult journey to self-discovery, learning how to cope with the many challenges of caring for a seriously ill child and now sharing what he has learned to help others.

First an informal mentor to families and hospital staff at C.S. Mott Children’s Hospital in Michigan, Scott was then asked to contribute to a series of hospital training videos on palliative care and to be an advisor to families dealing with surgeries. Then in 2012 hospital staff approached Scott to lead a dads’ group. Scott was more than willing to help and had some creative ideas on the meetings, “Dads won’t come if it’s just a typical support group, but they will come build something for their kids and then get to talking,” says Scott. We want
them to meet other parents so they don't feel alone.”

Over the years Scott has noticed that families cope with serious illness in different ways. “Some make light of everything with laughs and jokes, while others obsess over numbers and test results,” says Scott. Recognizing that fathers often feel left out and alone in the process, Scott decided to plan group activities and creative projects to get Dads to feel more at ease talking. “I try to help Dads find healthy ways to cope.”

Scott mentions that it is not uncommon for Dads to feel angry. Anger is a normal reaction to having a chronically ill child, but anger can be channeled in healthy ways. “Accept anger,” Scott advises. “This is not the life you expected.” For Scott, writing was what helped him cope and process charged emotions. He strongly advises other fathers to write regularly, even if they are initially uncomfortable with the concept. Aside from this creative outlet, Scott has many other words of advice for fathers – advice that was passed onto to him and helped him tremendously.

• Accept that not everything can be fixed

A dad’s first reaction to any situation is often “how do I fix that?” When the situation is unfixable and not in their control, dads can become frustrated, unhappy, and feel even more alone. “As a father; when we can’t fix something, we feel like a failure,” Scott explains. “I had to figure out how to lead my family when I felt like a failure and not being able to fix my son.” Scott suggests, “Find other fathers in similar situations. Go hunting together or to a game. Build something with your hands. Make a connection and take it from there.”

• Learn how to relinquish control

Dads often try to resolve things on their own as it is generally thought that accepting help is a sign of weakness. However, Scott sees it differently now. It actually takes strength and courage to ask for help and accept it from others. “Dads must learn to rely on other people, letting them step up to the plate,” he adds. For example, it was Evan’s therapist who taught Evan how to ride a bike and to bowl, two of his greatest joys. At the time, it was hard for Scott to accept that he was not the one to teach his son these skills. Eventually Scott realized how beneficial it was to have Evan learn from his therapist.

• Don’t forget other family members

Scott encourages fathers to reach out to unaffected family members, as they are affected in other ways. “Some siblings feel pushed aside when a family is taking care of a sick child,” Scott explains. Scott and Penni tried to get out into the community as much as possible, and they encouraged Evan’s older brother Noah to play soccer and attend social events. This helped ease the family’s feelings of isolation. Scott also encouraged Noah to be involved with Evan’s care. Noah helped with Evan’s tube feedings and suctioning before school, which made him feel needed and appreciated. It also helped him to accept Evan’s multiple challenges and to better understand his death.

Evan died the day after Thanksgiving — normally a happy time for families. “Even though we knew it would happen one day, we still weren’t prepared,” remembers Scott. “I don’t want Evan to be forgotten so every year I light a candle for him; it’s my way of saying I’m proud of him and I miss him.”

Scott’s path has led him to discover how to live again in spite of his grief, and his journey continues by helping others find their own inner peace. “If you have a really sick kid, you’re going to have a lot of issues, and you have to figure out how to cope,” says Scott. “You have to bring the best you can to each day. You have to find a way to find the joy.”

If you’re a dad and are interested in finding out more about positive ways to cope with your child’s diagnosis, please email Scott at scottandpenni@hotmail.com.
**NUTRITIONAL GUIDELINES**

for Children with CARDIOMYOPATHY

For children with cardiomyopathy, proper nutrition is very important because the heart is not working at its optimal level, and the body requires more energy or calories to function properly. According to Tracie Miller, M.D., associate chair of pediatrics for clinical research at the University of Miami, “growth failure is one of the most significant clinical problems of children with cardiomyopathy with nearly one-third of children with this disorder manifesting some degree of growth failure during the course of their illness.”

Children with growth problems often have poor appetite; they may only like a few foods or get tired easily while eating. It can be a challenge for parents to increase the amount of calories their child eats in a healthy and positive way. Ensuring adequate nutrition often requires both dietary and behavioral modifications. The National Food Service Management Institute’s Handbook for Children with Special Food and Nutrition Needs states, “it is usually not effective to increase the calories for these children with large or double portions. The key is to increase calories by adding fats, oils, sugars or thickeners such as cereal or commercial supplements to the food without increasing the serving size.” In addition, slow introductions to foods generally help children feel less overwhelmed and more relaxed about trying something new.

**Oral Feedings**

Establish a regular meal and snack routine for your child; plan for three meals and two to three snacks, spaced 1 to 2 hours apart. Do not offer anything to eat or drink between set meal and snack times except for water.

For children who take food in by mouth, calories can be increased in a variety of ways. Your child’s physician and/or nutritionist will recommend what is best for your child.

**Babies and Formula Drinkers**

- Use concentrated infant formulas to increase caloric density
- Add iron-fortified baby cereal to the formula
- Mix corn oil into milk for older babies

**Higher Calorie Foods**

The following high calorie foods can be added to the child’s usual diet to maximize calorie intake:

- All fruits – serve with cream on top or dip into yogurt, chocolate or nut butters
- All vegetables – serve with butter, margarine or cheese on top
- Butter or margarine – add to meats, hot cereal, vegetables or bread products
- Cheese – add to creamy foods
- Commercial nutrition supplements or high caloric milk drinks – serve as beverage more often
- Eggs – add to baked goods, meat loaf and puddings
- Fats and oils – use in sautéing or frying, add to soups, casseroles, vegetables, gravies or oatmeal, and incorporate oil, mayonnaise and salad dressing to other dishes
- High protein foods – increase portions of beef, pork, chicken, turkey, fish, eggs, nuts and nut butters, and dried beans and peas
- Starchy foods – increase intake of breads, pasta and rice, along with certain types of fruits and vegetables
- High fat dairy products – increase use of whole milk or flavored milk, cream, half-and-half, cream cheese, whole milk yogurt, pudding, powdered dry milk, cheese, sour cream and ice cream
- Evaporated milk – add to beverages, soups, cereals and puddings
- Instant breakfast packets – mix into milk or other foods
- Powdered milk – add to soups, mashed potatoes, cream sauces and puddings
- Peanut butter and nut butters – spread on crackers or bread
- Rice cereal – add to pureed foods such as fruit, vegetables or soups
- Sauces and condiments – add or use chocolate syrup or caramel sauce, barbecue, tartar, sweet-and-sour sauce, ketchup, maple syrup, cheese spread, honey (for children older than 1 year), hummus or jams

**Vitamins and Supplements**

Vitamins, minerals and supplements can also help support healthy growth. Some vitamins and minerals can be harmful if taken incorrectly, so it is important to talk with your child’s health care team about which supplements and doses are right for your child. High calorie liquid supplements designed for children, such as Pediasure, Boost and Ensure, can be offered in place of usual beverages. Powdered nutritional supplements such as Carnation Instant Breakfast, Duocale and Scandishake can also be added to drinks or food.
Feeding Tubes

If a child is failing to thrive and not meeting their weight gain goals through their daily diet, their healthcare team may recommend a feeding tube for short- or long-term use. There are different types of feeding tubes such as nasogastric (inserted through the nostril), gastric (inserted through a small incision in the abdomen), or jejunostomy (inserted through the abdomen into the small intestine). Percutaneous endoscopic gastrostomy tubes are minimally invasive and a safe method to treat weight problems with low risk after surgery. Below are two useful resources for families using feeding tubes:

• Gastrostomy Tube (G-Tube) Home Care
  http://www.cincinnatichildrens.org/health/g/g-tube-care/

• Kids with Tubes: Support for parents and caregivers of tube-fed children
  http://www.kidswithtubes.org

References


Help CCF Win a Top Nonprofit Award

Thanks to your reviews, CCF was named a top-rated health organization for the second consecutive year by America’s leading charity evaluators Great Nonprofits, Charity Navigator, GuideStar and Global Giving.

We need your help to get top-rated for 2013. Simply write a review about CCF at www.greatnonprofits.org (select Children’s Cardiomyopathy Foundation) so that we can be considered again this year.
MEMBER SUPPORT SERVICES

CCF offers a variety of ways for members to share information on pediatric cardiomyopathy and provide support to one another.

CCF offers a member email forum, a private Facebook group and online support chats. For more information about these services or the below scheduled events, please contact Chris Colón at ccolon@childrenscardiomyopathy.org.

CFF Connect Forum Guest Q&A Sessions

- Left Ventricular Non-Compaction (LVNC)
  Stephanie Ware, M.D., Ph.D.
  Cincinnati Children’s Hospital
  April 15 – 22

To join, you must be a member of CCF’s listserv. You can register at CCF’s website by clicking “Become a Member.”

CCF Google Chats

- Wednesday, April 17
  9:00 p.m. EST

- Monday, May 6
  8:00 p.m. EST

- Thursday, June 13
  8:30 p.m. EST

To join, you must have a Gmail account, which can be created for free. For more information, visit: http://support.google.com/chat.

Now Available:

CCF 2012 CYBERGUEST COMPILATION

In case you missed any of the recent cyberguest sessions, the 2012 compilation Answers from the Experts: CCF Cyberguests is now available.

Topics include psychological concerns, medications, nutrition and several others. Compilations from 2006-2007, 2008-2009 and 2010-2011 also are available.

If you would like a copy, please email ccolon@childrenscardiomyopathy.org.