

... SAVE THE DATE ...

The annual CF Family Education Day will be held on Saturday, November 10, 2012 in Madison. Details to follow as they become available.

American Family Children's Hospital
Cystic Fibrosis Center
600 Highland Ave. K4/938
Madison, WI 53792-9988

www.uwcfcenter.org



HAPPY NEW YEAR

From the desk of Danelle O'Neill

Executive Director, Cystic Fibrosis Foundation – Wisconsin Chapter

A new year is upon us and here at the Cystic Fibrosis Foundation – Wisconsin office, we are gearing up for another successful year. 2011 was a tremendous year for the CF Foundation and we are truly thankful for all of the individuals who have helped to support our mission. We could not be making the type of strides in CF research without our dedicated volunteers, event participants, donors, sponsors and friends. Each individual contribution adds up to the success of this organization.

News of VX-770 and other treatments in the pipeline, has each one of us excited and motivated to continue our work in raising the money to buy the science to find the cure. The Cystic Fibrosis Foundation has given or committed \$315 million to companies for drug research. For our part, the Wisconsin Chapter has committed to raising \$1.7 million in 2012.

We cannot do this without your help. We have a busy event schedule planned in 2012, with 25+ events planned throughout the state. We will accomplish our goal through the efforts of our five staff members and the hundreds of volunteers who help make it happen.

To our 2011 volunteers, sponsors, donors, and to everyone who organized friends and families to raise money via our events, helped the day of the event, licked stamps, stuffed envelopes, made calls, and set up walk routes we say *THANK YOU!*

Now more than ever, we need volunteers to step forward and help us reach our goal of finding a cure for CF! Please consider becoming part of the 2012 volunteer crew and contact us today to discuss your involvement. We need all types of volunteers, and we are flexible and willing to work with busy schedules and time restrictions. The more people we have involved, the more we can accomplish.

GEARING UP FOR 2012 GREAT STRIDES

Great Strides is the CF Foundation's largest and most successful national fundraising event. Recruit friends and family and form a team to support the Cystic Fibrosis Foundation's mission. Dollars raised support crucial cystic fibrosis (CF) research, education and care programs. We have walks located all over the state, and our staff has exciting tools and incentives to help you reach your fundraising goals. Registration is easy, just visit: www.cff.org/greatstrides, and please contact us with any questions on how to get involved! Step forward and help us improve the lives of those with CF.

2012 WISCONSIN CHAPTER EVENTS

Please mark your calendars for these upcoming events. To learn more, or sign up for events visit our website at <http://www.cff.org/Chapters/madison/> or call us at (608) 298-9902 for more information.

Saturday, January 28, 2012 – Community Event Zach's 2nd Annual Euchre Tournament: Let's Trump CF

Location: The Northern Edge Restaurant and Bar, Lodi, WI.
Contact Andy Dettinger at 608-577-4900, or Brittany Koenig at brkoenig06@gmail.com to sign up or for more information.

Saturday, February 18, 2012 – Community Event Zach's Buddies Bowl For Breath

Location: Prairie Lanes in Sun Prairie, WI. Please contact Andy Dettinger at 608-577-4900 or ddettinger@msn.com to sign up or for more information.

February 24, 2012 Milwaukee Wine Opener

Location: Hilton City Center, Milwaukee
Staff Contact: Kelly Salentine (ksalentine@cff.org)

The Milwaukee Wine Opener has developed into Milwaukee's premier wine-tasting event featuring wines from around the world and food from Milwaukee's finest restaurants. Now in its sixth year, the Milwaukee Wine Opener appeals to wine novices, wine connoisseurs and anyone looking to sample Milwaukee's restaurant offerings with friends and co-workers. The event also includes exciting raffles, a fabulous silent auction and live music!

April 19, 2012 – NEW CHAPTER EVENT!

Milwaukee's Finest, Coast, Milwaukee

Staff Contact: Julie Brzostowicz (jbrzostowicz@cff.org)

The Cystic Fibrosis Foundation will be honoring Milwaukee's Finest Young Professionals, who show exemplary leadership, are active in their community, and have excelled in their profession or business. The honorees will receive many benefits including the personal satisfaction of helping to save the lives of children and adults with cystic fibrosis. The CFF Milwaukee's Finest Campaign begins with an honoree kick-off reception where the 2012 honorees and their respective nominators will be introduced. Honorees will also receive a fundraising packet, and will be assigned a CF Ambassador and a fundraising Mentor. Throughout the 13 week campaign one-on-one meetings, conference calls and networking events will take place. The campaign culminates with a ceremony where honorees are recognized and celebrated!

GREAT STRIDES

Pledge-based walks featuring scenic routes, snacks, entertainment and prizes. Teams include families, friends, schools, companies and more. Be a team leader and earn fabulous prizes while raising research dollars!

Great Strides walk on Saturday, April 28, 2012 at:

- Pierce Park (Pavilion), Appleton
Staff contact: Lola Budzinski (lbudzinski@cff.org)

Great Strides walk on Saturday, May 5, 2012 at:

- Fond du Lac Yacht Club, Fond du Lac
Staff contact: Julie Brzostowicz (jbrzostowicz@cff.org)
- Wisconsin Dells Ducks, Wisconsin Dells
Staff contact: Kathleen Ruby (kruby@cff.org)

Great Strides walks on Saturday, May 19, 2012 at:

- Carson Park, Eau Claire
Staff contact: Kathleen Ruby (kruby@cff.org)
- Colburn Park, Green Bay
Staff contact: Lola Budzinski (lbudzinski@cff.org)
- Myrick Park, La Crosse
Staff contact: Kathleen Ruby (kruby@cff.org)
- Elver Park, Madison
Staff contact: Alyssa Harvey (aharvey@cff.org)
- Wildwood Park, Marshfield
Staff contact: Alyssa Harvey (aharvey@cff.org)
- Twining Park, Monroe
Staff contact: Alyssa Harvey (aharvey@cff.org)
- St. Luke United Methodist Church, Sheboygan
Staff contact: Julie Brzostowicz (jbrzostowicz@cff.org)

Great Strides walks on Sunday, May 20, 2012 at:

- Milwaukee Lakefront at O'Donnell Park Milwaukee
Staff contact: Kelly Salentine (ksalentine@cff.org)
- Pfiffner Park, Stevens Point
Staff contact: Kathleen Ruby (kruby@cff.org)

May 13, 2012

Mother's Day Tea: Letter Writing Campaign

Staff contact: Julie Brzostowicz (jbrzostowicz@cff.org)

June 2012

Keg & Cork, Location TBD, Madison

Staff contact: Kathleen Ruby (kruby@cff.org)

Description: Join us for a casual beer, wine and food tasting event benefiting CFF. Madison vendors participate in this "after work happy hour" event. Live music sets a fun atmosphere for people to mingle as they walk around the venue, sampling the food and drinks. Keg and Cork features auctions, raffles and more!

July 16, 2012

65 Roses Golf Tournament, La Crosse Country Club, Onalaska

Staff contact: Alyssa Harvey (aharvey@cff.org)

Description: Presented by Multistack, the fifth annual event is held at a private country club and includes 18 holes of golf with on-course contests. The evening program includes cocktails, dinner, live and silent auctions, and featured speaker.

July 23, 2012

Four-Ball Golf Challenge, Hidden Glen Golf Club, Cedarburg

Staff contact: Lola Budzinski (lbudzinski@cff.org)

Description: Four-ball is a twist on the average golf outing offering a real tournament to challenge both scratch and avid golfers! In addition to 27 holes on this beautiful course, the day includes breakfast, lunch, cocktails, on-course contests, raffles... and a post-golf reception featuring a wonderful dinner, evening cocktails, exciting auctions and awards presentation! Along with terrific prizes and friendly volunteers, this event is truly great golf for a great cause.

August 2012

SKINS Golf Tournament, Madison

Staff contact: Kathleen Ruby (kruby@cff.org)

Description: Experience one of Madison's most exclusive golf courses while enjoying challenging on-course contests, a wonderful lunch, great cocktails and an entertaining post-golf reception. We also offer terrific prizes, friendly volunteers and, of course, great golf for a great cause.

Link Between Good Nutritional Status in Early Childhood and Improved Survival Rates in Cystic Fibrosis

During the recent North American Cystic Fibrosis Conference, an interesting study was presented about the effect of nutritional status early in life on height growth, lung function, survival, and CF related complications through 18 years of age. Not surprisingly, children with a better weight had better outcomes. Having a weight for age greater than the 10th percentile at age 4 years resulted in better lung function from 6 to 18 years. In boys and girls with a weight for age greater than the 25th percentile and 10th percentile, respectively, height growth improved. Those with a weight for age greater than the 50th percentile at age 4 years resulted in a reduced number of pulmonary exacerbations, fewer days spent in the hospital, and a reduced incidence of impaired glucose intolerance and/or CF related diabetes by age 18 years.

Although improvements in height growth, lung function, survival, and CF related complications can still occur with good nutrition after age 4 years, the take home message is that the earlier children achieve optimal nutrition status, the better. Additionally, even small improvements in weight (for example, going from under the 5th percentile on the weight for age growth charts to the 10th percentile) can produce benefits.

We must also not forget the previous studies which revealed that lung function improved with a body mass index (or weight compared to height) greater than or equal to the 50th percentile resulted in improved lung function. This is one of the reasons why we place so much emphasis on gaining weight at each and every visit to the CF clinic. This can become very tiresome, frustrating, and confusing, especially when you are receiving mixed messages from friends, other health care professionals, and the media.

A BMI goal of greater than or equal to the 50th percentile is aggressive and often requires infants, children, and teens to gain weight above and beyond what is considered to be a normal rate for age. Not all people in the healthcare community who do not routinely work with CF are of these guidelines. Genetics does come into play and some people do have great lung function despite having a lower body mass index. As noted above and in the previous article, there is a valid reason behind the goals we set. However, we are always willing to work with each of you individually to create your own personal goals.

CHECK OUT THIS NEW WEBSITE! Are you looking for high calorie recipes to help with gain weight? Go to www.chef4cf.com and check out some of the tasty meals and snacks. We got to sample the recipe listed below at the North American CF Conference in November. These bars are delicious, healthy, and a great treat to have for breakfast or snacks.

No Bake Peanut Butter Bars

Ingredients

- 3 cups old-fashioned oats
- 1 ½ cups honey
- 2 (16 ounce) jars of natural peanut butter (or any nut/seed butter such as soy, almond, sunflower seed)
- 1 cup dried fruit (raisins, cranberries, etc)
- 1 cup crushed nuts or seeds (almonds, cashews, sunflower, etc)
- 1 tablespoon salt

Directions

1. Combine honey and nut butter in a large mixing bowl.
2. Combine oats, dried fruit and nuts/seeds in another large mixing bowl.
3. Combine dry ingredients with the wet ingredients, one cup at a time, until thoroughly mixed.
4. Press into a 9x9 pan or dish of some kind. Eat right away or refrigerate overnight to let it set.

Serving Size

- Serving Size: 16 servings
- 570 calories per serving
- Fat: 32 g
- Sodium: 650 mg
- Protein: 16 g

September 9, 2012

Tent Event, Palmer's Steakhouse, Hartland
Staff contact: Julie Brzostowicz (jbrzostowicz@cff.org)
Volunteer contact: Jerry Arenas

We shut the street down for this fun tent event that takes place outside of Palmer's Steakhouse. The Tent Event offers delicious food, raffles and exciting auctions throughout the day. Bring the whole family!

September 2012

Milwaukee Bucks Golf Tournament, Ozaukee Country Club, Mequon
Staff contact: Lola Budzinski (lbudzinski@cff.org)

Description: Join us for one of Milwaukee's premiere golf events filled with Milwaukee Bucks players, coaches and other local sports and media celebrities! The day, which includes an 18-hole scramble golf format, begins with a noon shotgun start with evening festivities beginning at 5:30 and a post-golf dinner reception followed by a short question and answer with the Coach and GM. As always, we'll have incredible sports memorabilia, trips and other unique items in our auctions.

September 2012

Brew Madness, Location TBD, Milwaukee
Staff contact: Kelly Salentine (ksalentine@cff.org)

Description: From brew novices to advanced brew enthusiasts, Brew Madness is a casual and fun evening for all experience levels! Enjoy a night of sampling barley and hopes – along with great foods presented at festive tasting stations, where area chefs prepare their specialties just for you. Along with delicious food and beer pairings, guests will be treated to lively auctions and a live band.

September 8, 2012

Cycle for Life, Middleton
Staff contact: Alyssa Harvey (aharvey@cff.org)

Description: Our 2nd annual Cycle for Life will offer two bike tour options. Cycling is done at your own pace. Each ride will begin and end at the same location. Cycle for Life is fully supported with well-stocked rest stops, bike mechanics, ride marshals, breakfast and so much more! Don't miss out on the fun!

October 20, 2012

Breath of Life Gala, Harley-Davidson Museum, Milwaukee
Staff contact: Kelly Salentine (ksalentine@cff.org)

Description: The Breath of Life Gala is the Milwaukee area's premier event. This exciting black-tie-optional gala is unlike any other! Throughout the evening, guests will enjoy a cocktail reception, sit-down dinner, participate in a silent auction and enjoy other entertainment and surprises.

November 9, 2012

Wish Upon A Cure, Location TBD
Staff contact: Kathleen Ruby (kruby@cff.org)

Description: Wish Upon A Cure, Madison's premiere gala event, is a chic gathering with all the makings of an intimate dinner party. Guests will be treated to a red carpet experience, unique auctions, a sit-down dinner and terrific entertainment.

November 15, 2012

Climbing For a Cure, US Bank Building, Milwaukee
Staff contact: Julie Brzostowicz (jbrzostowicz@cff.org)

Description: Climbing for a Cure is a pledge-based event in which approximately 500 people meet at the US Bank Building, the tallest building in Milwaukee, to face the footrace of a lifetime: 47 floors, 94 flights, 1,034 steps – straight up! Once participants reach the top, they have the opportunity to enjoy amazing panoramic views of Downtown Milwaukee before heading down to the post-climb celebration complete with food, drinks, entertainment and awards! Participants include, but are not limited to, corporate teams, local fire and police departments and fitness fanatics.

Influenza

The following is reproduced from the Cystic Fibrosis Foundation Fact Sheet on Influenza:

Before and during the flu season, it is important to learn about influenza and how to keep yourself and your family as healthy as possible.

WHAT IS INFLUENZA (THE FLU)?

Influenza is an illness that is caused by a virus that can make you feel very sick. Every year in the United States, influenza epidemics occur during the winter months. Influenza (the flu) is a viral infection that is very contagious. It can spread from person-to-person in droplets created by coughing and sneezing. It can also be spread when people cough or sneeze onto their hands, and then touch things. Anyone can get the flu. However, some people can get much sicker. The young, the elderly, and people with chronic lung or heart conditions can get very sick from the flu.

WHAT ARE THE SYMPTOMS OF THE FLU?

Symptoms include fever, cough, sore throat, headache, chills, muscle aches, and fatigue. In people with CF, influenza can lead to severe pneumonia. If you have the flu, you will have many of the symptoms listed above. Most likely you will feel worse than you do with your usual lung infection or pulmonary exacerbation. It is very important to let your CF care center team know if you have flu-like symptoms, as soon as possible.

WHAT CAN WE DO TO PREVENT INFLUENZA?

Experts in CF and immunization have developed the following guidelines to help prevent influenza:

Get vaccinated — Each year in October or November, the influenza vaccination, or the ‘flu shot’, is given to people with CF, their family members, and their healthcare providers. This helps to prevent the flu by increasing immunity to the current types of the virus. The close contacts of people with CF should also receive the flu vaccine. This will help to protect people with CF from being exposed to the virus. October or November is the best time to get vaccinated, but getting vaccinated in December or January is still helpful as flu season can last until spring.

Flu vaccine spray — You may have heard about the “flu vaccine spray.” This vaccine is sprayed into the nose. It is only approved for healthy people 2 to 49 years of age. People with any kind of lung disease, like CF or asthma, cannot receive this type of flu vaccine. However, family members without CF or other health conditions can receive the “flu vaccine spray.”

Practice good health habits — Infection control measures can reduce the spread of flu in healthcare settings such as the CF clinic and in community settings such as at school and work. These habits include:

Clean your hands — Clean your hands often with soap and water or with alcohol-based hand gel (especially after coughing or sneezing). This will help protect you and others around you.

Stop the spread — Cover your mouth and nose with a tissue when coughing or sneezing. Discard the tissue into a waste basket or covered container. Make sure you clean your hands afterward to prevent spreading germs and the flu to others.

Don't touch — Avoid touching your eyes, nose or mouth. Germs are often spread when a person touches something that has germs and then touches their eyes, nose, or mouth.

Stay home — If you are sick, just stay home. You will help prevent others from becoming sick.

Keep your distance — Avoid close contact with people who are sick (stay at least 3 feet or an arm's length away). When you are sick, keep your distance from others to protect them from getting sick.

Practice other good health habits — Get plenty of sleep, drink plenty of fluids, eat nutritious food, be physically active and manage your stress.

Medications — Anti-viral medications are available to treat people when they get the flu. They are most effective if taken

within 24 hours of the start of symptoms, so it is important to contact your CF care center or doctor as soon as you feel flu-like symptoms. These drugs may help to lessen your symptoms or how long you are ill. They do not prevent you from getting the flu.

ARE THERE ANY SIDE EFFECTS FROM THE “FLU SHOT”?

The flu shot does not give you the flu, because the viruses in the flu shot are killed (inactivated). The risk of the flu shot causing serious harm is extremely small. However like any vaccine, you could have mild side effects such as soreness, redness or swelling where the shot was given, a low grade fever, or some mild aches. If these problems happen, they will begin shortly after the shot and usually

last 1-2 days. If you are allergic to eggs, talk with your doctor about other ways to get the flu vaccine.

WHAT IS AN INFLUENZA PANDEMIC?

A pandemic is a disease outbreak that occurs around the world. A flu pandemic occurs if a new flu strain emerges for which people have little or no immunity and for which there is no available vaccine. Thus, a flu pandemic could spread easily person-to-person and cause serious illness in many people in many countries in a very short time.

MORE INFORMATION

To learn more about germs and infection control, you can watch the CF Education Day Web cast “Infection Control & Germs.” (http://www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/#Infection_Control_Germs) and read the pamphlet: “Respiratory: What You Should Know About Germs” available from your care center or the CF Foundation’s Web site (<http://www.cff.org/UploadedFiles/LivingWithCF/StayingHealthy/Germs/WhatYouShouldKnow/Germs-What-you-Shouldknow.pdf>). Should you have specific questions, please contact your care center or contact the CF Foundation at 800-FIGHT CF or info@cff.org. For more information on flu, visit the Center for Disease Control and Prevention’s (CDC) Web site (www.cdc.gov/flu) or the World Health Organization’s Web site (www.who.org) or the Department of Health and Human Services’ Web site (www.flu.gov).

WHAT IS KALYDECO™ (IVACAFTOR)?

The Spring 2011 issue of Center Focus had an article about the Vertex Pharmaceuticals drug VX-770. This is a small molecule drug that improves the function of the chloride channel in patients with CF who have the G551D mutation. Further exciting news about this drug was discussed at the North American Cystic Fibrosis Conference in early November 2011 and an article of the final results of the phase III trial were published in the November 3, 2011 issue of the New England Journal of Medicine (<http://www.nejm.org/doi/full/10.1056/NEJMoa1105185>). In summary, the patients who received VX-770, compared to placebo:

- Were 55% less likely to have a pulmonary exacerbation
- Had a weight gain of 2.7 kg (almost 6 pounds)

- Had an increase in FEV1 by 10.5%
- Felt better (as measured by a validated Cystic Fibrosis Questionnaire)
- Sweat chloride values decreased by approximately 48 mmol/L

In answer to the question headlining this article: Kalydeco™ is the brand name of VX-770 and Ivacaftor is the generic name.

Although this drug does not help patients with the F508 mutation (the most common mutation), the CF Foundation and its drug discovery partners are actively working on other medications that would be helpful to the vast majority of patients.

Vertex Pharmaceuticals is applying to the Food and Drug Administration for approval of Ivacaftor. It is hoped that this drug will be available for CF patients with the G551D mutation in the second half of 2012. This is truly one of the most exciting developments in the history of medical treatment for CF... a drug that actually results in improvement of the faulty functioning of the chloride channel.

MYCHART

UW Health MyChart is a secure online service that offers users the privacy and convenience of accessing portions of their UW Health medical records.

MyChart allows you to:

- Receive test results online
- View and print selected health issues, medications, allergies and immunizations
- Schedule, cancel and view appointments
- Send secure electronic messages to your health care team
- Access billing information
- Access the above information for your children or others you care for (authorization required/age restrictions apply)

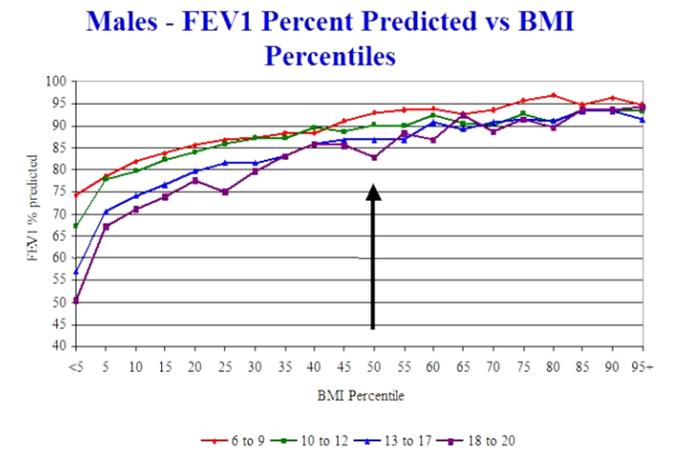
If you are a patient at a UW Health clinic, we encourage you to visit uwhealthmychart.org and follow the instructions to “Request an Account.” An activation code will be mailed to your home in 7 to 10 business days.

NUTRITION AND TUBE FEEDING

Although your CF care provider focuses on lung diseases, we are always paying close attention to nutrition. Here are a series of Frequently Asked Questions about nutrition and tube feeding:

OK, so I am thin. Why is that an issue in CF?

Approximately 7-8 years ago, the CF Foundation performed an analysis of data in the Patient Registry in which FEV1 percent predicted was graphed as it related to the patients’ body mass index:



This data shows that the pulmonary function improves steadily up to a BMI of the 50th percentile. Above a BMI of the 50th percentile, the pulmonary function is stable and in the normal range of over 90% predicted for FEV1. Therefore, the goal for patients up to 20 years of age is a BMI of at least the 50th percentile. For patients above 20 years of age, the goal BMI is 23 kg/m² for males and 22 kg/m² for females.

Is tube feeding a “last resort”?

Although often a number of months elapse while there are enzyme adjustments and the use of appetite stimulants and oral nutritional supplements, tube feeding should NOT be considered a “last resort”. Nearly all CF patients who try tube feeding get on track quickly and experience the benefits of improved nutrition.

What are the options for tube feeding?

Tube feeding can be accomplished by a nasogastric (NG) tube or by a gastrostomy tube. A nasogastric tube is a tube that is advanced through the nose into the esophagus and stomach. There are some patients who are taught how to do this and they place their own NG tube at night, every night. The other option is a gastrostomy tube. This is a tube that is surgically placed by a gastroenterologist or surgeon. Initially, there is a tube that is taped to the surface of the skin on the abdomen. After the surgical tract has healed (approximately 8 weeks), the tube can be changed to a “button”.

How and when do you give tube feedings?

The most common method of tube feeding is a continuous drip overnight. This utilizes a bag of formula and a pump to deliver the tube feeding at a specific rate. Using this technique, one can receive 1000-2000 calories at night. Another option are bolus feedings during the day. This method is often used for young children who do not eat enough calories during the day.

How are enzymes given for continuous drip feedings overnight?

For continuous overnight feedings, we ask that patients take enzymes orally before starting the tube feeding. Also, the CF care provider and nutritionist will often make recommendations to crush a certain number of the contents of enzyme capsules and mix that with the formula.