February 2013

The CF Breeze

"Wisdom & inspiration for CF families"

Tax Time!

Claiming all your Tax Deductions

Did you know that you may be able to claim a tax deduction for the food purchased to feed your child with CF? Federal tax allows people to deduct medical expenses that are not otherwise covered by insurance if the total expense is greater than 7.5% of the family's gross income. This includes the cost of food needed to meet the high nutritional requirements for Cystic Fibrosis. According to the Cystic Fibrosis Foundation handout titled "Tax Tips for Food Expense and Deductions", you should do the following things:

1. Consult with the nutritionist and/or CF Care Provider and request documentation of your child's nutritional needs.

2. Establish a system for recording the cost of food used by your child with CF.

3. Include information on the nutritional needs for individuals of the same age and sex as your child with CF.

4. Only claim a medical deduction for the amount of food that exceeds the cost for a person without CF.

5. Keep relevant paperwork to support the claimed medical expense deduction.

If you have any questions about this deduction, please consult with an attorney, a licensed tax accountant, or an IRS consultant about Section 213(a) of the Internal Revenue Code of 1986.

Upcoming Events

February 25 - CF Parent Support Meeting
Children's Minneapolis

March 2-3- Checking for CF Hockey
Tournament - National Sports Center in Blaine

March 25- CF Parent Support Meeting
Children's Minneapolis

April 22 – CF Parent Support Meeting
Children's Minneapolis

May 4 – Great Strides Walks
Minneapolis, Rochester, Winona, Fargo

May 11– Great Strides Walk
St. Peter, MN

May 18– Great Strides Walk
St. Cloud, MN; Rapids City, SD

May 19– Great Strides Walk
St. Paul, MN

For more information, visit:
www.cff.org/Chapters/minnesota

www.childrensmn.org/services/cystic-fibrosis/cf-community-parent-support-group

The CF Breeze will be distributed electronically for patients and families of Children's Hospital and CRCCS.

To be added to the distribution list or to update your e-mail address, please complete a listserv form available in the lobby of CRCCS or by contacting Mary Sachs or Sandy Landvik.

Your 2013 Appointments

Changes you can expect to see….

The CF Foundation is a leader in the efforts to advance and promote specialized care that improves and extends the lives of people with CF. The Foundation provides its accredited care centers with up-to-date care guidelines.

In an effort to improve our compliance with the CF Foundation Guidelines, which will improve the outcomes of children with Cystic Fibrosis, we will be making the following changes to your 2013 appointments:

1. Highly encourage annual labs to be scheduled during the first appointment of the year and the annual team visits on the second appointment. This will help reduce the previous day long appointment.

2. Eliminate chest x-rays as a standard with annual appointments. After evaluating the cost vs. benefit of chest x-rays and the mild risk of radiation exposure over time, chest x-rays will only be scheduled on an as needed basis.

In addition, CF Clinic team members have created a “passport” for families to carry with them on their annual team visit. Once you have visited the departments and team members, you will receive a sticker to place on the passport. Each child will receive a prize once they have completed their entire schedule for the appointment. We hope this will improve the efficiency and create a fun activity to do during your visit.

Research Corner

It is Children’s CF Research Program’s mission to improve the quality of care we provide and to improve the overall quality of life for the patients we serve. Thank you to all the CF families who have donated their time and energy participating in clinical trials. You are the key to finding a cure. Without your help, research cannot move forward. We need your continued participation to move promising therapies from the testing phase to the people who need it most.

Studies Open for Enrollment:
- Evaluation of Sleep in Children and Adolescents with Cystic Fibrosis
- Early MRSA therapy in CF – culture based vs. observant therapy (treat or observe) (STAR-too – STaph Aureus Resistance – treat or observe)
- Baby Observational and Nutritional Study (BONUS-IP-11)
- A Long-Term Prospective Observational Safety Study of the Incidence of and Risk Factors for Fibrosing Colonopathy in US Patients with Cystic Fibrosis Treated with Pancreatic Enzyme Replacement Therapy: A Harmonized Protocol Across Sponsors

Research Contacts
To learn more about the Cystic Fibrosis Research contact:
- Mahrya Johnson: Office 612-813-6384; Email: mahrya.johnson@childrensmn.org
- Andrea Gruber: Office 612-813-6661; Email: andrea.gruber@childrensmn.org

If you would like to learn more about the CF Foundation research activities, please visit their website at http://www.cff.org/research/

Featured Recipe

BMI Booster Cake

Best Chocolate Sheet Cake Ever

Ingredients

Cake:

2 cups flour
2 cups sugar
1/4 t salt
4 T cocoa
2 Sticks butter
1 cup boiling water
1/2 cup buttermilk
2 whole eggs (beaten)
1 t baking soda
1 t vanilla

Frosting:

1/2 cup chopped pecans (optional)
1 3/4 stick butter
4 T cocoa
6 T milk
1 t vanilla
1 lb (minus 1/2 cup) powdered sugar (equals about 3 1/2 cups)

Preparation Instructions

- *In mixing bowl combine flour, sugar, and salt.*
- *In a saucepan, melt butter. Add cocoa and stir together.*
- *Add boiling water, allow mixture to boil for 30 seconds, then turn off the heat. Pour over the flour mixture and stir lightly to cool.*
- *Mix together buttermilk, beaten eggs, baking soda, and vanilla. Stir buttermilk mixture into butter/chocolate mixture.*
- *Pour into sheet cake pan and bake at 350 degrees for about 20 minutes.*
- *While cake is baking, make the frosting. Melt the 1 3/4 stick butter in saucepan. Add cocoa, stir to combine, then turn off heat. Add the milk, vanilla, and powdered sugar. Stir together and add pecans. Pour over warm cake.*
- *Cut into squares, eat and enjoy.*

**Note: I use an 18x13 jelly roll pan and spray it with cooking spray*

Probiotics – *the good bacteria*

What are they and what is their benefit?

Probiotics are bacteria that help to maintain the natural balance of organisms (or flora) in our intestines. There are about 400 types of probiotic bacteria in our digestive tract and they have a role in promoting a healthy digestive system. These organisms also help in reducing the growth of harmful bacteria.

Changes can occur in our intestinal flora during an acute bacterial or viral infection or by being treated with frequent antibiotics (either preventively or for acute illnesses). Antibiotic treatments often lead to diarrhea and the loss of “good” bacteria. Taking probiotics may help replace these lost “good” bacteria and prevent further diarrheal loss.

The largest group of probiotic bacteria in the intestine is lactic acid bacteria of which lactobacillus acidophilus (found in yogurt with live cultures) is the best known. The following foods may contain probiotics:

- Yogurt
- Cottage cheese
- Buttermilk
- Kefir
- Soy sauce
- Miso
- Tempeh
- Fresh sauerkraut

This probiotic type, as well as others, are available as dietary supplements and may be purchased in a pill form or as a powder which can be sprinkled on food. Most probiotics taken as supplements are similar to what is already in our normal digestive flora, so side effects are rare.

As always however, if you are considering taking any supplements talk to your CF provider.

CF Family Council is Seeking New Parent Members

The CF Family Council (CFFC) at Children's Hospital and Clinics of Minnesota exists to foster partnerships between children with Cystic Fibrosis, their families, their care team and the CF Foundation to enhance both the patient and family experience with all facets of care, as well as, improve health outcomes of the children through empowerment, communication and education.

The CF family council has partnered to develop things such as a quarterly newsletter, travel brochure, and travel medication form. We are currently working on "What to expect at visits for your child during the first year after diagnosis."

The team meets on the 2nd Monday of every month from 6-8 pm in the CSC building on the Children's Minneapolis Campus. You will receive free parking, as well as receive reimbursement for your mileage to and from the meeting, and applicable child care expenses.

All new members need to complete an application for the Families as Partners Program and attend a ½ day training prior to joining the council. Training will be provided through the Families as Partners Program at Children's Hospitals and Clinics.

If you are interested in joining this fun and energizing team, please contact Sandy Landvik at 612-813-3304.