November 2014

The CF Breeze

"CF wisdom & inspiration for CF families"

Cystic Fibrosis Related Diabetes

Cystic fibrosis related diabetes (CFRD) is a unique form of diabetes that often occurs in people with cystic fibrosis. It shares features of both type 1 diabetes (insufficient insulin) and type 2 diabetes (insulin resistance). The likelihood of developing CFRD is:

- 2-10% at 5-9 years of age,
- 15-25% at 10-19 years of age,
- 25-35% at 20-30 years of age,
- 35-55% at 30-39 years of age.

It is important to screen for CFRD, which is done through an oral glucose tolerance test. We treat CFRD in order to prevent weight loss and a decline in lung function.

In women with CF, treatment of CFRD has been shown to improve life span. Therefore, Children's Respiratory and Critical Care Specialists (CRCCS) begins glucose tolerance testing of CF patients at the age of 8 and then continue to be performed annually.

Insulin therapy is the only form of treatment for CFRD. Some people with CFRD with very high blood sugars need intensive insulin therapy with multiple doses of insulin each day, similar to a person with Type 1 diabetes. **But many people who are diagnosed with CFRD based on an oral glucose tolerance test have an early stage of CFRD and may only need one dose of long acting insulin each day, with only intermittent blood sugar monitoring (once a week). Insulin therapy is then adjusted as needed.**

If your child is found to have an oral glucose tolerance test suggestive of CFRD, you will be scheduled for an appointment in the Endocrine clinic. They will review the results of the test with you and discuss what further testing or therapy is needed. If insulin is recommended, we will have you meet with our diabetes educator so that we can make the initiation of insulin as smooth as possible. Given the proven benefits of insulin, we do not want to postpone therapy if indicated.

My daughter Mia (age 11) was diagnosed with CFRD in August. It was devastating news. Was her disease progressing? How could we put our daughter through one more thing? We've known lots of people with diabetes. Seen them struggle with managing the disease. Then we met with Dr. Gandrud and she immediately reduced our anxiety. CFRD is different than "normal" diabetes. The treatment plan is different. Mia takes one dose of insulin once a day before bed and we only monitor her blood sugar once a week. Her diet remains the same as pre-CFRD. The insulin has made a big difference in maintaining her blood sugar which we know will help improve her long term health.

Upcoming Events

The CF Community Parent Support Group is a place for parents of children with cystic fibrosis to come to for support and information. This group meets the fourth Monday of each month from 7 p.m. to 9 p.m.

November 22
Mortenson Construction Breath of Life Gala
Hyatt Regency, Minneapolis

November 24
CF Parent Support Meeting
Children's Minneapolis

January 26
CF Parent Support Meeting
Children's Minneapolis

For other CF Foundation activities, please visit: www.cff.org/Chapters/minnesota

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.

Alternative Airway Clearance Options

Flutter Valve and the Acapella

The Flutter Valve and the Acapella are two versions of handheld devices that can keep your lungs clear of mucus so you can breathe easy. It combines the benefits of positive expiratory pressure (PEP therapy) with airway vibrations.

These devices create resistance in the bronchial airways by exhaling through the device. The resistance causes positive pressure to build up in the lungs – helping to hold the airways open. The pressure gets behind the mucus, helping push it out of the smaller airways. At the same time, the pulses (or oscillations) create vibrations within the airways helping to thin and shake loose mucus that may be too thick or sticky for the pressure alone to move. The combination of oscillations and pressure aids in moving mucus into the central airways, where it can be coughed out.

The PEP devices are to be used as a supplement, or in addition to vest therapy. Unlike the vest, **the effectiveness of PEP therapy depends entirely on the effort given by the user.** Therefore, the Children's Respiratory Therapists only recommend using these devices as supplements or back-up when needed; they can be helpful for travel, camps, etc.

Medical Research Updates

Studies Open for Enrollment:

1. 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.

2. Clinical Outcomes in Pediatric Patients with CFTR-Related Metabolic Syndrome (CRMS) for patients with CF or CRMS and were diagnosed by newborn screening between 2006-2015. The Cystic Fibrosis Foundation has developed Practice Guidelines for managing patients with CRMS, but we would like to improve our understanding of CRMS. Long-term data on outcomes for patients with CRMS is needed to help patients and their families understand what to expect and for appropriate medical management.

New Studies Opportunities Coming in 2014-2015

To learn more about the Cystic Fibrosis Research Program contact:
Mahrya Johnson at 612-813-6384 or via email at mahrya.johnson@childrensmn.org

Back to School Nutrition Trivia

Directions: Fill in the blanks using the "Word Bank" below. Then search up, down, forward, backward and on the diagonal to find the words hidden in the word search puzzle below! Let the fun begin.

1. Skim chocolate milk is a great substitution for _____ milk.
2. Enzymes should be taken _____ lunch and snacks.
3. Take this when you take your enzymes to help with absorption. _____
4. Check with this person about the administration of enzymes for meals and snacks at school. _____
5. Eating foods that come from _____ is a great way to increase protein and calories in your diet!
6. Person who assists with nutritional status. _____
7. Enzymes are good for _____ hour.
8. Good nutrition status has been linked to better _____ function.
9. After school ____ are a great way to add calories to your child's diet.
10. Kids with cystic fibrosis lose a lot of this in their sweat. _____

K	N	K	C	G	N	B	I	C	D	T	N	W	W	N
V	Q	Y	R	O	G	R	X	I	V	L	U	J	I	X
R	T	H	H	N	E	T	E	V	E	A	T	M	L	W
L	D	Y	W	R	Q	T	V	E	U	S	A	O	F	L
U	S	P	O	A	I	U	Q	K	H	T	C	O	I	I
N	N	F	U	T	I	V	E	X	I	Y	D	U	N	A
G	E	F	I	E	V	Y	I	V	S	N	A	C	K	S
B	D	A	S	Z	C	J	N	L	A	V	U	B	E	U
W	N	R	D	H	Q	Z	Y	K	W	Y	H	A	O	J

Word Bank

- ❑ Animals
- ❑ Before
- ❑ Dietitian
- ❑ Lung
- ❑ Nurse
- ❑ One
- ❑ Salt
- ❑ Snacks
- ❑ Vitamin
- ❑ Whole