Back To School- CF and the Classroom

It’s that time again—Back To School! And if your child is just beginning elementary school, here are a few suggestions to make the transition more easily. Most schools welcome a chance to sit down with you and discuss your child’s needs. An IEP and 504 plans are available but most schools will ask for a written list of your requests first. If they agree to all your requests, an IEP or 504 plans may not be necessary. A good first thing to do is to email the Principal, nurse, and all teachers (homeroom, PE, technology, music, etc) who would have contact with your child. Explain what CF is and what special considerations your child may need. Some considerations could be:

- Extra bathroom privileges—being able to go at anytime
- Being able to leave class 5 minutes before eating to get enzymes in nurses office
- Always being able to carry own water bottle
- Setting own pace in gym class
- Having extra high fat/high protein snacks and drinks available in nurse’s office/classroom.
- Carrying own enzymes on themselves in school and/or on field trips.
- Not being within 3 feet of another student with CF

Communication with the school staff is key to a successful partnership. Letting the staff know when your child will be gone for a CF appointment, telling them of upcoming hospitalizations, explaining any medical assistance your child may need at school all are ways to facilitate open communication with your school. By letting the school staff know of your child’s impending hospitalization—they can organize books and homework for them. Your child’s teacher could also be asked to have classmates make cards and posters for your child’s room! Don’t be afraid to ask. Most teachers want to help you and your child in any way possible.

Depending on your child’s personality, they may want to explain what CF is to their class or bring a book about CF to read. A good book to take to school is: Taking Cystic Fibrosis to School by Cynthia S. Henry. Solvay Pharmaceuticals. Let your child guide you on who they feel comfortable with telling about their disease after the initial staff has been told. Our Child Life Specialist, Amy Kaufhold also makes school visits to educate staff if needed. Meet the Teacher Night is not ideally the time to go over everything with the teacher but it is a good time to give them a resource about CF and a written list of special needs your child may have if you have not been able to communicate previously. Ask for your teacher’s email if they have any questions or concerns for you.

Here are some great resources you can give to teachers.

- **Cystic Fibrosis in the Classroom by CFRI (Available in Clinic)**
- **Cystic Fibrosis: A Handbook for Teachers and Day Care Providers by Solvay (Available at our CFIT day in April)**
- **A Teacher’s Guide to Cystic Fibrosis** is available on [www.cff.org](http://www.cff.org)
Backpacks, Books, and Bedtimes...it’s that time again! Making good nutrition a priority can be a challenge with the demands of starting back to school. However, a well-balanced, high-calorie diet with enzymes is the key to being able to study hard, stay healthy, and be strong with CF. Check out the tips below to help you start the school year out right!

**Breakfast Before The Bell:** Breakfast can be tough to squeeze in on top of early morning practices, last minute homework assignments, and breathing treatments. Try these quick breakfast ideas to give you energy... in a hurry!

- Prepackaged muffins (such as Otis Spunkmeyer®)
- Microwavable breakfast sandwiches (made with bagels, biscuits, or croissants)
- Breakfast quesadillas, tacos or burritos
- Microwavable pancakes, French toast sticks or waffles. Add butter, syrup, & fruit for an extra boost!
- Single serve oatmeal mixed with whole milk, butter, nuts, dried fruit, & brown sugar for added energy!
- Fruit smoothies or milkshakes made with whole milk and full fat yogurt
- Yogurt parfait with granola and sliced fruit
- Add a side of microwavable bacon or sausage links
- Mix up a bottle of carnation instant breakfast or Scandishake® the night before. Then, grab and go!

*Remember: Cold cereal is typically a better snack than a meal!*

**Lunch With A Punch:** Buying or packing a lunch can be a great opportunity for your child to learn how choosing the right foods can give them energy during school and for after-school activities.

Give your Brown bag a boost

- Think outside sliced bread – try making sandwiches with higher calorie breads such as bagels, foccacia or hoagie rolls, biscuits, or flour tortillas.
- Choose higher calorie meats such as salami, ham, pepperoni, or bologna to make sandwiches, wraps, and rolls. Avoid low-fat or fat free deli meats!
- Energize a sandwich with an extra slice of cheese, avocado or crispy bacon
- Dunk veggies or fruits in yummy dips (some of my favorites: celery & peanut butter, broccoli & ranch dressing, cucumber & hummus, tomatoes & Caesar dressing, apples & Nutella®)
- Send a Thermos® of hot soup on chilly autumn days. Cream based soups such as bisques or chowders provide the most energy. Add grated cheese, croutons, or cornbread for an extra boost!
- Don’t forget last night’s leftovers. Last night’s spaghetti & meatballs can be today’s meatball sub!
The Cook’s Corner: Recipe for Success

Celebrate the Season with this mouthwatering recipe...

Pumpkin Bread

Yield: 2 loaf pans

Ingredients:
- 3 1/2 cups unsifted all purpose flour
- 2 1/2 cups sugar
- 1 1/2 tsp salt
- 1 tsp cinnamon
- 1 tsp nutmeg
- 1 tsp allspice
- 1/2 tsp cloves
- 2 cups canned pumpkin (1-16 ounce can)
- 1 cup canola oil
- 2/3 cups water
- 4 eggs
- 1 cup chopped walnuts
- 2 tsp baking soda

Directions:
Preheat oven 350 degrees. Grease & flour loaf. In one large bowl, stir together sugar, soda, salt, cinnamon, nutmeg, allspice, cloves, and flour. In separate bowl, add pumpkin, corn oil, and water. Add eggs one at a time to pumpkin mixture. Beat well after each addition. Make a well in the center of flour mixture. Add pumpkin mixture. Mix & stir until moist. Add walnuts and mix well. Pour into baking pans. Bake 1 hour or until inserted toothpick becomes clean. Cool 10 minutes before serving.

Nutritional information (per slice): 360 calories, 5.5g protein, 20g fat, 1g fiber

Savvy Snacking

Some people with CF need to eat a mid-morning and/or a mid-afternoon snack to help them meet their increased energy needs. Here are some snack ideas to get you started!

- Trail mix with nuts, dried fruit, and chocolate chips
- Yogurt covered nuts or chocolate covered dried fruit
- Banana chips
- Yogurt parfait (full-fat) with granola and sliced fruit
- Milkshakes or fruit smoothies. Remember to always use whole milk!
- Granola bars ...Snickers® and Paydays are great too
- Pita chips and hummus
- Tortilla chips and queso
- Slim Jim
- Ice cream sundae
- Salted edamame
- Graham crackers with peanut butter or Nutella
- Dip veggies and fruits in yummy spreads and sauces

Get more Bang for your buck

- Look over the school menu together. Help your child learn how to make well-balanced, high calorie choices.
- Pack a lunch 2-3 days per week to help ensure your child is getting the extra energy he/she needs if you are worried they are not making the best choices,
- Work with your school district to arrange for larger lunch portions.

Treat your sweet to homemade baked goods – add dried fruit, nuts, or frosting for extra energy.

Send a thermos with whole milk since most school cafeterias only serve low-fat milk (1% or skim)

Just for fun - cut sandwiches into shapes or smaller pieces – it’s easier for little hands to hold and it’s more fun to eat!
Forced Expiratory Volume (FEV1) is one of the percentage results from your breathing test.
- It is the amount of air you can forcibly exhale from your lungs in the first second of exhalation.
- It is the best indicator for degree of obstruction.

How does the computer come up with that number?
The respiratory therapist puts information into the computer including age, height, weight, ethnicity and sex. The computer then comes up with your predicted values from that information.

What is a normal number?
- A percentage of 80% or higher is normal.
- It is important to know your number before you leave the clinic.
Fruits and vegetables are an important part of a balanced diet...yes, even a high calorie diet! They contain essential vitamins and minerals as well as fiber that are key to being healthy and staying healthy. So, with the days getting shorter and the nights getting cooler, take the challenge this autumn to fall in love with fruits and vegetables. Just remember to add calories by sautéing’ them in butter, baking them in a pie crust, sprinkling them with cheese, simmering them in cream, or dipping them in caramel.

Curious about what’s in season...check out some fall favorites as well as a few of their health benefits.

| Vitamin A | Helps keep eyes, skin, bones, and teeth healthy. Also works in the lining of your lungs to fight infection. | Seasonal sources: Avocados, beans, Bok Choy, Brussels sprouts, cabbage, carrots, collard greens, kumquat, pumpkin, rutabaga, spinach, winter squash, sweet potatoes |
| Vitamin C | Helps your body fight infection and enhances absorption of iron in your diet. | Seasonal sources: Avocados, Bok Choy, broccoli, Brussels sprouts, cabbage, cauliflower, Clementine, collard greens, cranberries, grapefruit, kale, kiwi, orange, persimmons, pumpkin, red grapes, rutabaga, winter squash, sweet potatoes, tangerine, turnips |
| Vitamin E | Works in the lining of the lungs to fight infection and helps keep your intestines healthy. | Seasonal sources: avocados, green leafy vegetables |
| Vitamin K | Helps your blood clot and works to keep your bones healthy. | Seasonal sources: broccoli, collard greens, kale, spinach, turnip greens |
| Calcium | Helps build strong bones and teeth. Keeps your nerves and muscles working correctly. | Seasonal sources: acorn squash, beans, broccoli, spinach |
| Iron | Carries oxygen in the blood from the lungs to the cells. | Seasonal sources: collard greens, kidney beans, pomegranates, spinach |
| Fiber | Helps to regulate stools and prevent constipation and distal intestinal obstruction syndrome (DIOS) | Seasonal sources: apple, banana, beans, broccoli, cauliflower, carrots, Clementine, cranberries, grapefruit, kiwi, orange, pears, sweet potatoes, tangerine, winter squash |

Voluntary Recall on Children’s and Infants’ Tylenol®

The CF Foundation stated that certain lots of Children’s and Infants’ Tylenol® has been recalled due to the discovery of B. Cepacia in a portion of the raw material used. McNeil Consumer Healthcare initiated a voluntary recall on the lots manufactured between April 2008 and June 2008. They do note that “No bacteria has been detected in the finished product and the finished product has met all specifications.” For more information on the full story, please visit www.cff.org. To view which products and lot numbers were affected, please visit the Tylenol® website at www.tylenol.com
The CF Foundation is closely monitoring the seasonal and H1N1 (swine) flu situation.

The Foundation recommends that all individuals with cystic fibrosis and those living with them follow the recommendations of the Centers for Disease Control and Prevention (CDC) on both seasonal and H1N1 flu prevention and vaccination.

Based on the CDC’s recommendations, the Foundation urges everyone with CF and those who live in the same household to:

1. Get the seasonal flu vaccination as soon as possible
2. Get the H1N1 vaccination when it becomes available in October
3. Watch for symptoms of the flu if they appear, call your doctor. Symptoms include:
   - Body aches and headaches
   - Fatigue
   - Fever and chills
   - Increased cough
   - Sore throat
4. Minimize the spread of germs by:
   - Washing your hands often with soap and water or alcohol-based gel sanitizer
   - Use a tissue when coughing or sneezing, then washing your hands
   - Avoid touching your eyes, nose and mouth since germs are spread that way
   - Staying away from others who are ill

The seasonal flu vaccination is an important step in protecting against seasonal flu. Vaccination is especially important for people at high risk of serious flu complications, such as people with CF.

The seasonal flu vaccine will not protect you against the H1N1 flu.

Vaccinations for people with CF are available at your CF center. Please talk to your CF doctor about vaccinations should any questions arise.
Transitions...

Transitioning from the Children’s Hospital to Adult Care

The CF adults are being transitioned to appropriate adult care at hospitals that specialize in care for adults. The adult CF doctors will still hold the CF Clinic at the Pulmonary Department at Cook Children’s Hospital; however, hospitalization will occur at other hospitals. I must say getting adult CF care was a long time coming for me, at age 51!

Those of us who have received great care at Cook Children’s for much of our lives are now going elsewhere and hoping for that same great experience! Well, I can tell you Harris Methodist Hospital is not the same as Cook’s, but they are really putting forth effort to provide great care. I have been hospitalized at Harris occasionally over the years and on my recent CF stay I noticed vast improvement in their CF care! The hospital and staff are adapting to having CF patients, just as we are adapting to a different hospital for our care.

CF patients are redefining what patients typically do in the hospital. We might wear clothing instead of gowns in our room. We might leave the room and go down stairs and walk for a while, or even work out. Hospital staff will get used to our ways, but we must let them know what we are doing. I leave my cell number so that if I am needed in my room I can be called. I would not want to miss a breathing treatment or a doctor visit while I was getting my exercise in!

Patients should be aware there is a charge for parking at Harris, the daily fees can really add up on a long hospital stay. You can make other arrangements (such as being dropped off) or buy discounted stickers. The stickers are five for $10 and are given to the parking attendant with your time-stamped parking ticket. The stickers reduce your daily parking cost to $2 per day. Discounted stickers can be purchased at the desk on the ground floor of the Harris Professional Center. (There is a parking garage next to the Professional Center). The parking is not free for patients or families because the parking garages are independent of the hospital.

Talk to your health care providers, ask questions and kindly explain your needs. They are there to help you and they appreciate it if you are kind and patient with them. Together with our caregivers we can have appropriate adult CF care.

Written by: Carol Shepherd, Adult CF patient

Save the Date!

2009 North American CF Conference (NACFC) Update

Our staff of CF experts will be presenting information from the 2009 North American CF Conference held in Minneapolis, Minnesota. Our staff will provide CF patients and families with the latest and greatest updates on CF research and care.

Tuesday, November 10, 2009
Cook Children’s Hospital,
Hochberger Auditorium
7:00-8:30 pm
The CF Center at Cook Children’s has added some new faces! Dr. John Saito joined us in August and is busy building his practice. He is originally from the Philadelphia area and obtained his undergraduate Medical degrees from Temple University. Dr. Saito then headed south to Orlando for his residency and UNC at Chapel Hill for his fellowship. He finally made it to Texas when he joined Scott & White and Texas A&M University in Temple in 2005. Dr. Saito has been very involved in making Newborn Screening a reality in Texas. He is a member of the task force responsible for implementing newborn screening. Dr. Saito is also an accomplished artist and is an advocate for art therapy in children with CF. Dr. Saito will team up with Liz Musser, RN who has worked in the Pulmonary department previously to fill in for absences.