

COOK CHILDREN'S CYSTIC FIBROSIS CENTER NEWS

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FALL 2009

The Cystic Fibrosis Center at Cook Children's Medical Center is one of more than 115 accredited CF centers throughout the nation. These centers are accredited by the Cystic Fibrosis Foundation, a non-profit organization founded in 1955 dedicated to funding research to find a cure for CF and improving the quality of life for people with the disease.

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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

Nutrition 101: Back to School

**TELL
US!**

We want to hear from you!

If you've discovered a quick and easy, high energy breakfast or lunch idea that is working for you, please let us know so we can share it with others.

Questions? For questions about this or any other nutrition issue, please speak with your CF dietitian: **Staci Brummett at 682-885-7496**

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, foccaccia 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 corn-bread for an extra boost!
- Don't forget last night's leftovers. Last night's spaghetti & meatballs can be today's meatball sub!

- 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!

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.

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

The Cook’s Corner: Recipe for Success

Celebrate the Season with this mouthwatering recipe...

Pumpkin Bread

Yield: 2 loaf pans

Ingredients:

- 3 ½ cups unsifted all purpose flour
- 2 ½ cups sugar
- 1 ½ tsp salt
- 1 tsp cinnamon
- 1 tsp nutmeg
- 1 tsp allspice

- ½ 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

ORDER OF NEBULIZERS MAXIMIZES VALUE

Our center staff recommend the following sequence for inhaled medications:

WHAT ORDER SHOULD I TAKE MY NEBULIZER MEDICATIONS?

1. Bronchodilators:

(Albuterol, Combivent® Xopenex®) to open the airways

2. Hypertonic Saline (7%):

To mobilize mucus and induce airway clearance

3. Airway Clearance Technique:

Vest, Flutter® chest PT, IPPV, etc.

4. Pulmozyme® (DNAse)

To thin mucus (Note: studies find no significant differences for order of inhaling DNAse, hence patient preference can govern timing)

5. Antibiotics:

(TOBI®, Colistin) the previous therapies open and clear the airways of mucus, thereby improving the distribution and therapeutic impact of these medications

6. Steroids:

(Flovent®, Pulmicort® QVAR®)

If you start coughing blood, stop Pulmozyme®, saline, airway clearance technique, and inhaled antibiotics. Call your CF doctor or nurse for further advice.

Just Take A Breath!

Q & A With The Respiratory Therapist

With a respiratory illness or change in symptoms:

- Begin or increase airway clearance techniques.
- Use breathing treatments as ordered; you can use bronchodilators every three to four hours, and often additional vest and/or hypertonic saline treatments are useful.
- Contact your CF doctor or nurse to see if antibiotics or additional intervention is needed.

What is a FEV1?

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.

Questions?

For questions about this or any other respiratory issue, please speak with your CF respiratory therapist.

FALL in love with fruits & veggies

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

www.fruitsandveggiesmatter.gov
www.foodfit.com

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

CF Foundation Guidance on Seasonal and H1N1 Influenza

People at greatest risk for the H1N1 flu— especially those with CF, should receive the H1N1 vaccination as soon as it is available.

Additional resources on Seasonal and H1N1 flu:

- www.cff.org
- www.flu.gov
- www.cdc.gov/h1n1flu

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

CookChildren's

Cook Children's Medical Center Cystic Fibrosis Center

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"Making CF stand for "Cure Found"

Pediatric CF Center Staff:

Center Physicians: **James Cunningham, MD**– Center Director (Nurse: Stacy), **Nancy Dambro, MD**– Center Director (Nurse: Dennise and Karen), **Maynard Dyson, MD** (Nurse: Stacy), **Sami Hadeed, MD** (Nurse: Sharon), **James Pfaff, MD** (Nurse: Chrystal), **John Saito, MD** (Nurse: Liz), **Karen Schultz, MD** (Nurse: Paulette)

Adult CF Center Staff:

Center Physicians: **John Burk, MD**– Adult Center Director, **Steve Davis, MD, Stuart McDonald, MD**

CF Coordinators:

Janet Garbarz, Carrie Stradley 682-885-6299 (#6)

Dietitian:

Staci Brummett 682-885-7496

Respiratory Therapists:

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Ruthie Oney, Crystal Thompson 682-885-4189

Child Life Specialist:

Amy Kaufhold 682-885-4892

Social Services

Lauren Morrow 682-885-2863

After hours and on weekends/holidays, call 682-885-4000

Please welcome... John Saito, MD

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.

