

CF Connection

Winter 2007/2008

University of Florida Pediatric Pulmonary Center



Condiments Count!

Looking for a way to increase calories without trying to fit in another snack? Try adding high-calorie condiments to meals and snacks you are already eating! Here are some ideas:

Sour cream (2 Tbsp = 50 calories) – Put on baked potatoes, burritos, and tacos; stir into cream soups.

Hummus (2 Tbsp = 50 calories) – Spread on pita bread or crackers; use as a dip for raw veggies.

Wheat germ (2 Tbsp = 50 calories) – Sprinkle on yogurt, pudding, oatmeal, and ice cream; mix into milkshakes.

Large black or green olives (5 olives = 50 calories) – Add to salads, tacos, nachos, and pasta.

Shredded coconut (3 Tbsp = 55 calories) – Add to trail mix, cereal, oatmeal, ice cream, yogurt.

Cheese dip (2 Tbsp = 60 calories) – Melt over cooked veggies; use as dip for raw fruits and veggies.

Heavy cream (2 Tbsp = 100 calories) – Add to mashed potatoes, macaroni and cheese, cream soups, oatmeal, eggs; mix with whole milk.

Mayonnaise (1 Tbsp = 60 calories) – Spread on sandwiches and burgers; add to fruit and veggie salads.

Guacamole (2 Tbsp = 60 calories) – Add to tacos and burritos; use as veggie dip.

Cream cheese (2 Tbsp = 100 calories) – Spread on bagels; use flavored cream cheese as a fruit dip.

Honey (1 Tbsp = 60 calories) – Serve on bagels, toast, warm rolls, and cornbread; add to cereal and oatmeal; mix with peanut butter; use as a fruit dip.
**Not for children under one year old.

Nut butters (1 Tbsp = 100 calories) – Spread on breads, crackers, apples, bananas, and celery. Try Sunflower seed butter, almond butter, or pecan butter.

Butter (1 Tbsp = 100 calories) – Add to vegetables, breads, muffins, pastas, casseroles, hot cereals, eggs.

Nuts, seeds, ground flax seeds (2 Tbsps = 100 calories) – Add to trail mix, salads, cereal, ice cream, yogurt; mix into muffins, cookies, and quick breads.

Vegetable oil (1 Tbsp = 120 calories) – Drizzle over noodles and vegetables; use in salad dressings; use as a dip for breads and rolls.

Salad dressing (2 Tbsps = 145 calories) – Serve with salads; use as a vegetable dip; spread on sandwiches.

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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 6 or e-mail them to hillajb@peds.ufl.edu.

Thank you to Solvay Pharmaceuticals for funding the printing of this newsletter.

New CF Drugs in Development

At the North American CF Conference this year, we heard exciting news about over 30 new drugs that are in the process of development right now! As you read this, there are drugs in the works that will treat problems in both the airways and the digestive system. There are other drugs that are designed to fix the gene-related problems of CF. Current areas of study include:

- Gene therapy – adding normal copies of the gene that causes CF may help correct these cells and ultimately cure CF
- Protein repair – fixing the way the faulty CFTR protein works so chloride and sodium can move properly in the cells
- Salt transport – hydrating the thick mucus in the lungs by correcting the amount of salt along the cell surface
- Mucus management – thinning and clearing the thick mucus from the airways
- Anti-inflammatory – reducing lung inflammation
- Anti-infective – fighting lung infections
- Transplant – helping to improve the chances of successful transplants
- Nutrition – improving nutrition for those with CF

The process of drug development has to start in the laboratory (called the “bench”) before it can be tried under very controlled conditions in patients. There are three phases of clinical trials (tests) in people before a new drug can be approved for use in everyone with CF. The trials are used to see if a drug works and if it is safe. The results of these trials have to meet the standards of the U.S. Food and Drug Administration before a new product is approved. The CF Foundation calls this whole process a “pipeline.”

Participants in clinical trials are the key to helping find new treatments and a cure, and more volunteers are needed. Clinical research would

come to a halt if there were not enough participants! Why should you (or your child) volunteer? Consider these benefits:

- ✓ You may get access to investigational drugs before they are available to the public.
- ✓ You can take a more active role in your own health care.
- ✓ You will have the chance to help people who are newly diagnosed with CF.
- ✓ You can help researchers get closer to a cure for CF.
- ✓ You can help researchers find new therapies to improve quality of life for people with CF.

To learn more about clinical research and how you can participate, visit <http://www.cff.org/research/ClinicalResearch> or call the CF Foundation's toll-free clinical research hotline, 877-8CF-JOIN (877-823-5646). You can also go to ClinicalTrials.gov and search Cystic Fibrosis. When our center is participating in those trials, we may ask if you want to participate!



Hypertonic Saline News: No More Mixing!

The FDA has approved a premixed, unit dose 7% hypertonic saline preparation called PARI Hypersal™. It will probably take a while for all the pharmacies to gain familiarity with this product. The manufacturer assures us that all the major pharmacies have access through their suppliers. It will also take a while to convince third party payers to pay for it. This preparation will make it SO much easier to use hypertonic saline therapy!

Co-Pays Making You Poor? Got CMS?

Children's Medical Services (CMS) provides care for children with special health care needs and their families. Like Medicaid, they do have income guidelines that determine who qualifies for services. HOWEVER, they have a process called "spend down" that subtracts out-of-pocket healthcare expenses from family income. This helps more families to qualify. If you've been over income for CMS in the past, you may want to reapply if your out-of-pocket expenses have increased. CMS may help pay for clinic visits, hospital stays, lab work, nutrition supplements, radiology and pharmacy services. Call 1-866-695-1480 to apply. The process can sometimes be frustrating and time consuming, but the benefits make it worthwhile!

If you go through the call-in process and hit a wall, call us. We may be able to find someone in your local office who can help.

CF Newborn Screening

The Cystic Fibrosis Foundation and the Centers for Disease Control and Prevention (CDC) recommend screening for cystic fibrosis (CF) in all newborns. More than 10 million Americans are carriers of the defective gene that causes CF and most are not aware of a family history of the disease.

Research studies conducted over the past two decades have shown that early nutritional intervention helps to improve height, weight and cognitive function for people with CF. Early care also may impact respiratory function and life expectancy, and reduce hospitalizations.



Does a positive newborn screen mean that a baby has CF?

No, not necessarily. A newborn screening test is not a diagnostic test. In fact, only a fraction of babies with an initial positive CF newborn screening test ultimately are diagnosed with the disease. If an initial screen is positive, a sweat test is done to rule out or confirm a CF diagnosis.

Schedule Changes

In the coming weeks you may notice a change in the way you are scheduled for return visits in CF clinic. To provide better care to all of our CF population, and to follow CF Foundation recommendations, we will be grouping patients based on the "bugs" found in sputum cultures. Based on these results, you/your child will be rescheduled to a specific clinic day/time (CF clinic will still be on Tuesdays). You will be in clinic with other people with CF who have similar "bugs." Please keep this new policy in mind when you call to reschedule appointments.

We hope that this change will help prevent the spread of bacteria among our patients and keep everyone healthier!! Thank you for your patience as we make this gradual change.

Adult CF Center Patient & Family Retreat

The Adult CF Center is planning the 2nd Annual Patient & Family Education Retreat this Spring. If you have CF and you are 16 years or older, you and your family are invited to join us. We are in the planning stages and would like to talk about concerns you may have about transitioning to the Adult CF Center. If you're interested in attending and/or have ideas for the retreat, please contact Wanda Nichols, Adult CF Coordinator at 352-846-0750 or cfcenter@medicine.ufl.edu.

University of Florida Pediatric Pulmonary Center

Family Corner

Family Advisory Boards – an important part of the healthcare partnership.

Families of children with special healthcare needs have their hands full coping with the demands of giving their children a 'normal' life as well as dealing with the complications that a chronic illness brings to the family. While we all acknowledge that we want to do all we can to improve the healthcare system that tends to our children, it is often difficult to see how we can play an active role while juggling all the other demands made on us.

The Pediatric Pulmonary Center at the University of Florida has been working with patients and their families to improve the service they provide. Why do your healthcare professionals want to involve you? There are a number of reasons:

- ✓ Sharing information leads to a better healthcare plan.
- ✓ Patients who feel part of the decision making process are more likely to follow the treatment plan.
- ✓ Studies show that collaborating with patients and families results in improved patient safety and fewer medical errors.
- ✓ It makes good economic sense – a satisfied customer will come back again.
- ✓ Most importantly, it is the respectful thing to do.

At the PPC, the Family Advisory Board has been active in providing feedback to the Division on the service they provide. FAB members also help educate medical students. 'Telling your story' is recognized as a compelling educational tool.

If you would be interested in being on a panel of caregivers interested in sharing your family's story with small groups of students and healthcare professionals, please consider contacting us. We would also love to hear from you about any aspect of yours or your child's care that would benefit other patients. Please send us an email or call us at the office (contact info at right).

Thanks,
Robin and Angela

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