

CF Connection

Fall 2013

University of Florida Pediatric Pulmonary Center

Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (PPACA) will make some changes to health insurance that can benefit you and your child(ren).

If you have private insurance, your child now can stay on your policy until age 26, even if he/she is not living at home and is not in school. Your child cannot be refused health insurance due to a pre-existing condition.

Starting in January 2014, adults will have more health insurance options. Adults will be able to get insurance even if they are unemployed or if their employer doesn't offer insurance. Adults will be able to get insurance through their employers or through an insurance exchange.

The health insurance exchange is like a car insurance broker—you get several insurance options, and you pick the one you like best. Someone who needs insurance can go to the exchange website www.healthcare.gov to see their options.

All health insurance policies through the exchange must cover: doctor's visits and outpatient care, emergency care, hospitalizations, maternity and newborn care, mental health and substance abuse services, behavioral health treatment, prescription drugs, rehabilitative services and devices, laboratory services, preventive and wellness services, chronic disease management, pediatric services, and oral and vision care. Many forms of preventive care,

such as vaccines, will be free.

The insurance exchange will offer several plans. Some plans will have lower premiums each month, but higher copays and deductibles. Some plans will have higher premiums, but lower copays and deductibles. Other plans will have mid-price premiums, copays, and deductibles.

Anyone under age 30 or people who are not required to buy health insurance can buy a catastrophic plan. This costs less, but it also covers less (and has high deductibles). It is most helpful in the case of an accident that requires hospitalization or some other need that is very expensive.

Under the PPACA, everyone must get health insurance (there are some exceptions such as religious reasons). People who don't get health insurance must pay a penalty unless they have an extremely low income. Middle and lower income families will receive tax credits to help pay for their insurance.

The PPACA places limits on how much a person with a low income pays in premiums. An individual earning \$17,000 a year will pay a maximum of \$510 (3%) a year in premiums. There are also limits on how much individuals and families will pay in copays or deductibles each year. For a family of four, the limit is \$12,000. Starting in 2015, insurance

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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 4 or e-mail them to hillajb@peds.ufl.edu.

PPACA (cont. from page 1)

companies can no longer put a limit on the amount they will pay over the course of an person's lifetime.

Starting this month, people can sign up for health insurance at www.healthcare.gov. If you have questions or need any help, please feel free to contact Susan Horky at (352) 273-8380 or Chauncey@ufl.edu.

Bugs in the Breath—A Research Study

Dr. Hegde has been conducting a research on a new diagnostic method (a lab test). In this test, Dr Hegde will collect breath samples, hoping to detect infection in the lungs. If Dr Hegde's hypothesis turns out to be true, we will be able to develop a breath based test instead of bronchoscopy in future. As part of the pilot study, Dr. Hegde is recruiting subjects who are known to have had Pseudomonas in their lungs. Breath test results will be compared with that of sputum, throat swab and lung washings obtained from bronchoscopy. If your child is between 5 and 18 years of age, he or she may be eligible to participate in this study. If you are an adult patient with Cystic Fibrosis and under the age of 21 years, you may be eligible to participate. If you are interested, please contact Dr. Hegde on 352-273-8380 (8 AM to 5 PM, Monday to Friday).

Pseudomonas is a bad bug that causes lung damage in patients with CF. If you are not sure if you or your child has had Pseudomonas infection, your CF care team should be able to help you.

You may also visit the following website for further details: <http://pulmonary.pediatrics.med.ufl.edu/research/>

Infection Control—Changes are Happening

The CF Foundation recently made new recommendations for infection control for the first time since 2003. We will learn about these guidelines this week at the North American CF Conference. Then we will be making changes in clinic and hospital to better protect our patients with CF. We have already started with the use of gown and gloves for all health care staff in the clinic. People with CF will still be asked to wear masks when not in a patient room and to use hand disinfectant every time they enter and leave a room. Other changes will be shared with you as they are rolled out. We will greatly appreciate your help in this process!

Cindy Capen, MSN, RN



GET YOUR FLU SHOT!!!

Back to School with High-Calorie Lunches

As parents of a child with CF, you know it's important to give your child high-calorie meals. More calories help your child to grow and be strong. During a busy week of work and school, it can be hard to find ways to prepare easy and appealing lunches. Work with your child to choose lunch ideas from below that will mesh with your taste buds and schedules!

1. Lunchtime Fiesta

It is easy to pack in calories and nutrition with a Mexican-themed lunch. Use 2 tortillas (190 calories per tortilla) to double wrap a burrito with foil, then fill with any or all of the following:

- ½ cup rice (95 calories) To save time, buy “pre-cooked” Ready Rice packs.
- ½ cup black beans (105 calories)
- 2 Tbsp guacamole (50 calories)
- ¼ cup shredded cheese (110 calories)
- 2 Tbsp sour cream. (50 calories)

Tips: If your burrito gets soggy by lunch hour, consider making it a “burrito bowl” in a container instead of using tortillas. Add extra rice for more calories. Or pack all the ingredients separately and put it together at lunchtime.

2. The Super Bagel

While 2 slices of sandwich bread usually supply no more than about 150 calories, a plain bagel packs in about 260! Make your child's favorite sandwich on a bagel, or try some of these filling ideas:

- 2 Tbsp peanut butter (190 calories) + 1 small sliced banana (90 calories) and 1 Tbsp honey (65 calories) or 2 Tbsp Jam (100 calories) = 540-550 total
- 2 Tbsp cream cheese (100 calories) + 3 slices turkey (65 calories) + 2 slices American cheese (90) = 515 total
- 2 Tbsp hummus (70 calories) + 2 slices muenster cheese (200 calories) + 2 slices tomato + sliced cucumber + ½ avocado, sliced (115 calories) = 385 calories.

Tip: Ask your local bakery if they sell day-old bagels for a reduced price. You can stock up for the week, and bakery bagels are usually higher in calories than pre-packaged brands. Bagels freeze well, so take advantage of Buy One, Get One deals at the grocery store.

3. Try a “salad”

Choose from the ideas below to boost calories in chicken, tuna, or egg salad. Serve on a bagel, croissant, pita bread, or with crackers. The more mayo you add, the better! If serving on a sandwich, add a slice or 2 of cheese, and spread mayo on both sides of the bread.

Egg salad: 2 eggs (160 calories) + 2 Tbsp mayonnaise (180 calories)

Chicken salad: ½ cup chicken (120 calories) OR 3 oz (1/2 of can) albacore tuna (110 calories) + 2 Tbsp mayonnaise (180 calories) + ¼ cup chopped dry roasted pecans (200 calories) + ¼ cup cranberries (130 calories)

Tip: To save time, try using canned chicken. You can also try canned salmon. Salmon is similar to tuna in calories, and high in heart-healthy omega 3 fatty acids.

4. On the side...

Round out your child's school lunch with some of these snack ideas. Or on busy mornings, fill your child's lunch box with these grab-and-go for an easy, high-calorie meal.

8 oz full-fat yogurt (170 calories)

Full-fat Greek yogurt has more protein (about 14 grams protein per 6 oz), but can be more expensive. If your child likes Greek yogurt, stock up when they are on sale!

Pre-packaged cheese sticks (90 calories)

Peanut butter “to-go” cups (250 calories) with apple slices (90 calories) or pretzels (110 calories)

Pre-packaged mixed nut and dried fruit packets (200 calories)

Chocolate milk boxes (150 calories)

Large banana (120 calories)

Cheese and Peanut Butter Sandwich cracker packs—or any variety (200 calories)

Morgan Denhard, Nutrition Trainee



University of Florida Pediatric Pulmonary Center

G-Tubes: Not so Spooky After All

As Halloween approaches, you may want to keep an eye out for witches and ghosts, but G-tubes are nothing to fear! Families know that increased body weight is related to better lung function, but sometimes it can be hard (or impossible) to meet the calorie needs of a kid with CF. If your CF Care Team is concerned about your child's growth, they may recommend a gastrostomy tube (G-tube).

A G-tube is a tube inserted through the abdomen that delivers nutrition right into the stomach. Many families have questions and concerns about what it will be like to have a G-tube. As a nutrition trainee at the clinic, I had a lot of questions, too! I talked to a 12-year-old boy with CF who recently got a G-tube, and I asked him and his family about their experiences.

When getting his G-tube placed, Ben* spent 3 days in the hospital before going back to his normal activities, such as sports and wrestling around with his siblings. He was afraid that the surgery might hurt, but it really only bothered him a little bit in the hospital. Now, he doesn't feel it at all.

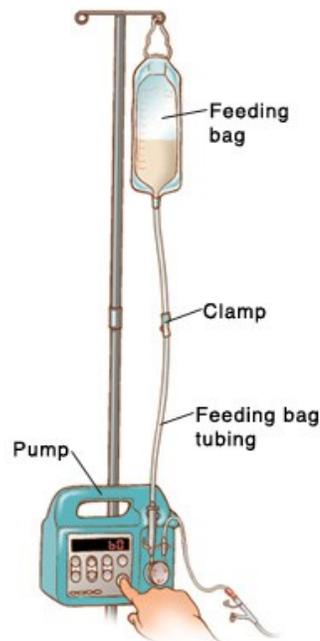
In the hospital, Ben learned how to do nighttime feedings all by himself. He just fills his bag up with formula, takes his enzymes, primes his pump, then pops it into his tube. Ben's mom was worried about infections or nighttime leaks, but they haven't experienced any of these problems.

"We would have done this years ago if we had known it would be like this," said Ben's mom. She said that before the tube placement, she and Ben's dad constantly pushed Ben to eat more food and drink more nutrition supplements. This caused tension in the house. Now, meal times are more peaceful because Ben gets five cans of formula through his tube every night.

Some families may worry that getting so many calories overnight can cause a decreased appetite during the day. Ben is usually not hungry for breakfast, but has an excellent appetite the rest of the day. His weight has improved, and his mom notes a visible change in his appearance, just within a couple of months!

Do you have questions about life with a G-tube? Ask the dietitian during your next visit!

Morgan Denhard, Nutrition Trainee



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