

CF Connection

Winter/Spring 2006-2007

University of Florida Pediatric Pulmonary Center

About Hypertonic Saline

In 2004 we learned the results of an Australian study funded by the CF Foundation to find out if inhaling a mist of "hypertonic" saline would help people with CF. Since CF lungs have too little salt and water, the researchers thought breathing in a salt water mist might help clear the thick mucus in the lungs.

These researchers got the idea from surfers with CF who said they were better after they had been out in the ocean. The study group who used 7% saline twice a day for a year had better lung functions and fewer lung infections than the comparison group who just did normal saline (.09%) treatments. "Normal saline" is the same concentration of salt and water that naturally occurs in our bodies.



So, should everyone with CF use hypertonic saline? We just don't know. In the study, 83 people over the age of 6 and with pretty good lung functions got the

hypertonic therapy. Some of these people complained of increased cough, sore throat, and chest tightness. Sixteen withdrew from the hypertonic treatment either because of time issues or side effects. Two were taken out because of a drop in lung function.

Hypertonic saline can irritate airways, so we recommend that the first treatment be done in the pulmonary lab with PFT's before and after to make sure the airways don't react badly. For the most part, we are willing to try it for people who are interested, willing to add a twice daily nebulizer treatment to their daily care routine, and can find a way to pay for it.

As medicines go, it's pretty cheap (about a dollar per treatment), but not everyone can manage that cost. Because it isn't really a "medicine," it isn't covered by insurance companies. It can only be obtained in two ways. The easiest and cheapest way is to get it from a pharmacy that can "compound" (mix medicines). They

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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 email to hillajb@peds.ufl.edu.

About Hypertonic Saline

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can combine available mixtures of saline to make a 7% solution and package it in sterile single dose containers. You can also order 3% and 10% bottles that are already made by drug companies and then learn to mix your own. This actually costs more because it requires the use of syringes, and some saline is wasted because the bottles have more saline than is needed for a treatment. They do not have preservatives, so the extra has to be thrown out. But sometimes insurance will pay for the saline this way.

A Pari LC Plus nebulizer was used for the study and is, therefore, recommended. A bronchodilator, like albuterol (Ventolin®, Proventil®) should be

used before the saline. The saline should be used before airway clearance. As with all nebulizer treatments, the nebulizer should be rinsed after every treatment and then disinfected every day.

Hypertonic saline treatment for CF will get more study. Also, beginning in 2006, the CF Foundation has asked centers to report the use of hypertonic saline. Since they can compare that information with lung functions on everyone in the US CF Registry (about 20,000 people), that data will help us better understand how hypertonic saline affects CF lung health. If you have questions about hypertonic saline, please give us a call or ask us at your next clinic visit.

Cindy Capen, MSN, RN

Axcan Calendar Contest

Congratulations to Katie Croft from Live Oak, whose drawing is on the cover of the 2007 Axcan Pharma™ CF Calendar! Her beautiful fish drawing was selected from over 90 entries from artists with CF.



Axcan Pharma™ will be accepting original works of art from people with CF for the 2008 calendar. All people who submit entries will receive an award. For more information, go to

http://www.axcan.com/ultrase_contest.php?lang=1

Get Your Flu Shot!

It's important for people with CF and their family members to get the flu shot. It's not too late! Flu season can last until the Spring.

People with CF can develop severe pneumonia from the flu, which can be hard to distinguish from a CF exacerbation or from another respiratory viral illness. It is very important to let your CF care team know about flu-like symptoms.

When to Call — Part One: Lung Changes

Many people aren't sure when to call the CF Center and when to wait and see. Here are some tips for determining when to call. Let's start with lungs in this issue and we'll move on to digestive system changes in the next issue.



An "exacerbation" or worsening of lung disease in CF is sometimes an all-of-a-sudden event, but more often is just a sneaky increase in cough over days or weeks along with a decrease in energy or appetite. Either one can be confusing. A cough that is suddenly worse can usually be watched for a couple of days. If it continues, please call us to discuss antibiotics.

Noticing the sneaky cough means getting a clear picture of what "best" looks like in your case and then checking the daily or nightly cough against that best. For example, when does the cough usually happen? Lots of people notice more cough first thing in the morning, with airway clearance or exercise. Some people cough off and on all day but not usually at night. Notice your/your child's cough right after a course of antibiotics when the cough is as good as it gets and then measure against that standard. If you notice more cough than usual for a few days, call us.

Whether it comes on fast or slow...it's important to treat an increased cough so it doesn't get worse. Remember that in CF, the lung's ability to clear

secretions is not good and the worse an infection gets, the longer it takes to get back to "best."

Another lung symptom to be aware of is change in the color of the sputum (mucus) that usually happens with the increased cough. This may be from clear to yellow or green. We also want to know if there is blood in the sputum. If you see blood, it may just be streaks in the mucus or it may look like it's all blood. This is a sign that inflammation has damaged the walls of little blood vessels in the lungs. Don't panic because it's not unusual in CF, but please call us.

We also want to hear from you if you/your child have pain that is sudden, bad, or gets worse with a deep breath or cough. Pain is most often due to sore muscles from coughing a lot, but it could be something else. If you call, we can help you decide what is causing it.

To sum up, lung things to call about include increase in cough and mucus, changes in color of mucus, pain, and of course, difficulty breathing. If you are concerned, call. We don't want you to worry. Don't feel like you are bothering us—we are here to help!

Cindy Capen, MSN, RN

In the next issue, we'll talk about digestive system changes that you should call us about.

But What Does an Inpatient Social Worker *DO*?

In the last newsletter, we learned what our social worker Susan Horky can do for you. But we also have a social worker who works with patients and families in the hospital. Read on to learn what Judah Cordovano can do for you!

Inpatient social workers at Shands AGH do three main things. We provide counseling, concrete services, and connect patients and families with resources.

Part of the counseling we do is to help patients and families adjust to being in the hospital. Counseling can also focus on adjusting to a new diagnosis, grief and loss, or counseling about personal issues that impact the patient's medical care. Inpatient social workers also conduct psychosocial assessments, including child abuse/neglect assessments.

The concrete services we provide can range from giving food to needy families to helping families find a place to stay while their child is in the hospi-

tal. While our funds are limited, we can help needy families pay for discharge medications or coordinate transportation at discharge.

We also help families access resources in the hospital and in the community that can enhance their lives. These resources range from a Child Life referral in the hospital to a referral to enroll in Children's Medical Services to a referral to a chaplain for spiritual guidance. We can give families instructions on how to apply for Social Security, Abilities, and other government programs.

Judah Cordovano, MSW
Social Worker
Shands Children's Hospital at AGH

If you or your child would like to speak with a social worker during your next hospital admission, you may contact Judah Cordovano at extension 3612 or ask your nurse to page social work.

Happy Holidays!

...from your CF care team

Introducing Christina Adams, PhD

Dr. Adams is a pediatric psychologist who works with children and adolescents who have cystic fibrosis or asthma. She began her career in this area over 12 years ago, working at the University of Florida for a couple of years before moving with her family. Dr. Adams just recently returned to Gainesville from Children's Mercy Hospital and Clinics in Kansas City.

What can a psychologist do to help you and your child in clinic? Dr. Adams can talk with you about troubles coping with CF or adjusting to its effect on your child's daily life, difficulty in following a treatment regimen, problems with family relationships, and general behavioral or emotional concerns.

In addition to seeing people with CF in clinic and in the hospital, Dr. Adams also supervises graduate students in a clinical psychology doctoral program and pre-doctoral interns at the University of Florida. You may see some of her students at your next clinic appointment, shadowing members of the medical team, providing families with psychological consultation, or asking families if they would like to take part in a research study.

If you have any questions for Dr. Adams, feel free to call the clinic or ask to speak with Dr. Adams or one of her students at your next clinic visit. She looks forward to meeting you!

Sour Cream Bacon Chicken

This easy crockpot recipe is high in calories and low in prep time!

470 calories and 60 grams protein per serving

Ingredients

8 bacon slices

8 boneless, skinless chicken breasts

2 (10 oz) cans roasted garlic cream of mushroom soup

1 cup sour cream

½ cup flour

Preparation

Wrap one slice of bacon around each boneless chicken breast and place in a 3-4 quart crockpot. In medium bowl, combine condensed soups, sour cream, and flour and mix with wire whisk to blend. Pour over chicken. Cover crockpot and cook on low for 6-8 hours until chicken and bacon are thoroughly cooked. Serve with rice and mixed veggies covered with extra sauce! Makes 8 servings.

Source: Linda Larsen from about.com. For more great recipes and cooking tips, visit <http://busycooks.about.com/od/kitchenreference/a/toppicks.htm>.

University of Florida Pediatric Pulmonary Center

Family Corner

Dear Families,

I thought I would take a few minutes to jot down some things that have affected us over the years in hopes that it may help keep some of our children healthier thru the holidays.



First, since it is the "change of the season," there are things that we should be aware of in our daily lives and living environments. The weather is getting nice and we want to be outdoors, but we need to remember some key things that will keep our kids healthier. Yard work, including raking leaves, can be a serious problem for people with CF or asthma. Not only is the dust from raking leaves a problem, but the leaves carry a mold that is not good for our kids to be around. If your kids are raking leaves, have them wear a mask. Or better yet, pick a different chore like washing the car or bathing the dog.

Also look UP in your home or wher-ever your child is spending a lot of time. Look for brown or yellowing on the ceilings and walls; this could be mold and it also makes our kids sick. I know this from experience, so be an investigator when it comes to the places that kids hang out or play.

Robin's 18-year-old son was diagnosed with CF in 1988. Contact Robin at jojo424@verizon.net or 352-613-2441.

One last thing that I am sure many of you already know—make sure you have a HEPA filter on your heating and cooling system. It seems to me that a lot of sinus stuff can start because of dry air from the heater. One thing that has helped us in the past is simply putting a small bowl of water in the bedroom at night so there is some moisture in the air. You will be surprised how it helps!

Have a safe and HEALTHY Holiday Season! If you have a child going in for a tune-up, call me and I will drop off some coupons for free Block Buster videos or games, Pizza Hut, and Sonny's BBQ!

Robin Muetzel, Family Resource Partner

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